



Telling pain: a study of the linguistic encoding of the experiences of chronic pain and illness through the lexicogrammar of Italian

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Telling pain: a study of the linguistic encoding of the
experiences of chronic pain and illness through the
lexicogrammar of Italian

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Linguistics,
University of London

2012

Declaration

I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

Signed:.....

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Thesis Abstract

Since the publication of Halliday (1988) a number of studies on the linguistic encoding of pain have appeared. These include Lascaratou (2003; 2007) on Greek, Hori (2006) on Japanese, Overlach (2008) on German. Using *Systemic Functional Grammar (SFG)*, this thesis adds another language to the existing body of work on how physical pain gets encoded cross-linguistically. The empirical work undertaken comprises the analysis of an original corpus of interviews with seven Italian speakers living with one of three chronic conditions: *Systemic Lupus Erythematosus (SLE)*, *Rheumatoid Arthritis (RA)*, and *Spinal Disc Herniation (SDH)*.

This thesis shows the multiple ways in which the lexicogrammar of Italian encodes bodily pain as THING, (nominally), HAPPENING (through verbs), and as QUALITY of something (adjectivally). The analysis shows that speakers in the corpus favour the first type of encoding and suggests why this might be the case.

From pain itself, the scope of the analysis broadens to include the lived experience of physical pain related to chronic illness by looking at the informants' use of evaluative language. This is analysed by means of *Appraisal Theory* (Martin and Rose, 2003; Martin, 2005; Martin and White, 2005), which identifies three *attitudes* encoded through the system of *appraisal*. These are: *affect* (the speaker's feelings and emotive responses), *appreciation* (the evaluation of things and events), and *judgement* (evaluations of people's behaviour). The analysis shows the most frequently encoded attitude is *affect*, with a tendency to favour indirect over direct encodings. It is suggested that this is because of a desire to avoid coming across as over emotional and therefore unreliable, a sentiment rooted in the informants' experiences of having their symptoms and conditions doubted in the past, even in medical encounters.

A broad narrative analysis approach is then used to explore the types of identities that are constructed and presented by the informants. The notion of *agency* is used to critique the commonly-held view of chronic illness and pain as completely disempowering. The analysis shows that – within the same individual – feelings of powerlessness coexist, in a fluid state, with notions of heightened agency. My informants work towards preserving a pre-illness identity where contradictions and paradoxes are harmonised through language.

Acknowledgements

This thesis has been a long time in the making. It all began during the spring of 2001. At the time, I was nearing the completion of a an Master of Studies in *General Linguistics and Comparative Philology*, already thinking of undertaking further research for a doctorate on some topic in the field of Italian dialectology or sociolinguistics.

All that would change following a casual chat with a friend and fellow student. Only a few moments after skimming through the introductory pages of a book she had just borrowed (Elaine Scarry's *The Body in Pain: The Making and Unmaking of the World*), all my projects and my academic life up to the present were to change quite drastically. For me, it was the beginning of an intellectual preoccupation, and a lasting academic interest. Therefore, it seems appropriate to mention that friend first, since she was the one who set the ball rolling, so to speak. Over the past ten years or so, Lesley Pattinson (now *Dr* Pattinson) has been providing invaluable intellectual stimulation, much needed food, for both body and soul, laughter, and – most of all – unwavering friendship.

Secondly, I would like to thank my thesis supervisor at Queen Mary, Professor Jenny Cheshire. Over the years, she has been most supportive in several ways. By offering constant advice and assistance, often beyond the purely academic level, she has made it possible for this thesis to become a reality. It was through reading her early work as an undergraduate, at Cardiff, that I made the decision to turn my attention to the field of sociolinguistics. For this inspiration, I am most grateful. I am sure that this thesis would be of much higher quality, had I followed all of her advice.

As all those who have worked towards a PhD can testify, although the finished product only bears one name, many people have contributed to it, in more or less obvious ways. Mine is no exception and I would like to mention, and thank, some of them by name in what follows.

My late maternal grandparents, Luigi and Maria Rimoldi, were a source of material and moral support, as well as an inspiration. They always believed in me, nurtured me, and encouraged me whilst keeping me grounded. I shall never forget my late grandfather's comment when, towards the end of secondary school, I told him that my interest was in languages. Without a hint of irony, he said: "But that's great, so when you finally graduate you can find a good job announcing trains in many languages at Milano's Central Station." I wonder what he'd have said if he had known that for two years, I did exactly that, albeit for London Underground. To my mother Ivana, I am grateful for the gift of language.

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I would like to express my gratitude to the people who accepted to be interviewed for this project. They all taught me a great deal not only about language but, more importantly, about courage, strength, and resilience in the face of hardship. Little did I know that, years after we met, some of their concerns would become mine too. I am convinced that meeting them and being allowed to collect their stories left me better prepared for the challenge.

Finally, I would like to express my love and gratitude to a rather recent arrival on the scene: my partner, Peter John Simcock. His love, generosity, and support are invaluable to me. Should I ever be foolish enough to write another thesis, this time on the language of happiness, it would be because of him.

From 2002 to 2005 I was in receipt of a bursary from Queen Mary, University of London, for which I am most thankful.

Introduction

1 Origins of the present work

1985 saw the publication, by the American literary scholar Elaine Scarry, of 'The Body in Pain: the Making and Unmaking of the World'. The work has been very influential and has generated considerable debate.

Essentially, it is a meditation on the vulnerability of the human body. Central to this vulnerability is the nature of bodily pain, its place among human experiences, its characteristics, and its effects on the individual experiencing it and, arguably, on society at large.

Scarry argues that the power of bodily pain lies in the difficulty of encoding it linguistically. The difficult relationship between pain and language has a number of consequences, both personal (i.e. relevant to the individual) and political (i.e. relevant to society).

Although it certainly was not the first scholarly work to deal with the topic of pain and its relationship to language¹, it can be confidently stated that it was instrumental in bringing the topic once again to the fore, as attested by the plethora of articles, monographs, and conferences discussing bodily pain that have since followed. Among this scholarly output, it is rare not to find references to Scarry's work. Some critique it; others support it. All acknowledge the importance and topicality of the issues it raises.

¹ See chapter one for other works dealing with the topic of pain, both preceding and following Scarry.

This thesis can be situated among the works inspired by the publication of *The Body in Pain* and is without a doubt intellectually indebted to it. Specifically, it has its genesis in reflections prompted by one of the central themes of the book, regarding the already-mentioned relationship between bodily pain and human language.

For the American scholar, at the heart of this relationship lies — fundamentally — an impossibility. Her view is that bodily pain is antagonistic to language. Not only does the former resist the latter; it has the power to effectively annihilate it. Scarry's position on the language-pain relationship is that language is rather ill-suited to capture the complexities of pain:

Physical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sound and cries a human being makes before language is learned (p. 4).

My initial assumption, after reading Scarry's position on the matter (of which, as mentioned, the quotation above is perhaps the strongest statement), was that although bodily pain did present particular challenges for language, it did not lie beyond its grasp.

On this matter, I found myself in agreement with Natoli (2000). In his book on the experience of pain in western culture², after discussing the manifold difficulties that sufferers encounter before they can give their experiences even some rudimentary linguistic form, he states: *eppure del dolor si parla* 'and yet one does talk about pain'.

² I shall discuss Natoli's position in more detail in chapter one.

In truth, as the discussion in chapter one will show, there is a certain ambiguity (not always picked up by her critics) in Scarry's reasoning. A careful reading of her text (1985: pp. 3-23) reveals that – at least implicitly – she acknowledges the ability of language to re-emerge from the abyss where, in her view, pain has banished it. In many cases sufferers manage, somehow, to voice their pain, breaking the silence and going beyond the groans and grunts or, in the most severe cases, the screams that at times appear to be the only audible encodings of such experience:

Physical pain has no voice; but *when it at last finds a voice, it begins to tell a story* (Scarry, 1985: 3; my emphasis).

Language then begins doing (again) what it is supposed to do: it construes and shapes experience; it objectifies and orders it; it expresses the self, builds rapports and sustains interactions. It partly overcomes pain by allowing the individual to affirm his or her existence and reify their experience.

Telling of one's pain and of the overall experience of illness helps the sufferer to regain coherence (Frank, 2002) and the act of finding the words orders what pain has rendered disordered. Language may not be a cure but it constitutes the first 'tidying up' exercise (Heshusius, 2009) from which healing (at least a partial one) may finally emerge.

Whether or not, once they have found a voice, sufferers also find a listening ear is quite another matter. As I will show, a recurrent theme in the interviews that I collected for this research is the frustration that sufferers often endure as a consequence of not being really listened to, let alone understood, especially, and sadly, in their encounters with the medical profession.

2 M.A.K Halliday's study of the linguistic encoding of pain: relation to the present research

Not long after the publication of Scarry's book, Halliday's (1988) wrote a brief, yet seminal paper on the linguistic encoding of the experience of bodily pain³. In it, he analysed the linguistic encoding of physical pain through the lexicogrammar of English using a small corpus of doctor-patient exchanges (English was the language of the analysed encounters). Halliday's paper is clearly situated within the theoretical framework of *Systemic Functional Grammar* (henceforth: SFG), which he developed. In spite of the significance of the study, one of its limitations (which I shall discuss in more details in chapters one and three) is the small size of the corpus he utilised and the fact that the conclusions he draws only relate to English.

3 The ALOMAR Plus corpus

This thesis came into existence partly in response to Halliday's invitation to further test his analytical paradigm with larger corpora and on languages other than English.

In order to do this, I collected an original corpus of interviews with a group of native Italian speakers (six women and one man), each affected by one of three chronic conditions: *Systemic lupus erythematosus (SLE)*, *Rheumatoid arthritis (RA)*, and *Spinal disc herniation (SDH)*. The ages of the participants when the interviews were collected ranged from the early thirties to the late

³ It has not been possible to establish whether Halliday had any knowledge of Scarry's book,

sixties. Building an original corpus of interviews in Italian has allowed me to explore how the experience of bodily pain is encoded in a language other than English using Halliday's theoretical framework (SFG). A more detailed discussion of Halliday's paper is found in chapter one.

Throughout this thesis, the corpus will be referred to as the "ALOMAR Plus corpus". The name indicates that six out of the seven participants interviewed belonged to a support and advocacy group for people with rheumatic (or autoimmune) diseases called ALOMAR, whereas one of them — the only male interviewed — was not a member of the group, since his condition (SDH) is not an autoimmune disease. More about the composition of the corpus will be said in chapter two, where individual biographical sketches for each participant are to be found. More information about each of the aforementioned conditions is also to be found in chapter three.

4 Specific research questions

This thesis aims to answer the following research questions:

1. How does the lexicogrammar of Italian encode the experience of bodily pain?
2. What kind of evaluative language do the participants whose interviews are collected in the ALOMAR Plus corpus use to present their experience of being chronically ill and in pain?
3. What kinds of 'selves' and/or identities (in this thesis, I use the terms more or less interchangeably) do the participants create and present

through the language they use to describe their experiences of chronic illness and bodily pain?

5 Organisation of the thesis

Chapter 1 contains a literature review; its purpose is to outline the general intellectual background against which this research has been conducted and to situate it among existing literature on the topics of language, pain and chronic illness. The chapter is divided into two sections. Section one discusses contributions from various disciplines on the subjects of pain and language, often in relation to each other. The works discussed in this section have been included because they provide a useful background to the discussion on language and pain. In section two of the chapter, I shall present works which are more directly relevant to the arguments made in this thesis; in most of them language is a central focus and this thesis is partly a response to them, partly a further development of arguments made in those works, and partly an attempt to fill perceived gaps in the debate.

Chapter 2 presents and justifies the methodology and theoretical orientations adopted in this thesis.

Chapter 3, which is the first analytical chapter, addresses question 1. In it, my findings are compared with those of Halliday (1988) and discussed. In addition, Halliday's paper is discussed in more detail. This chapter also presents relevant aspect of SFG, the theoretical tool adopted by Halliday and

extended to the analysis of the ALOMAR Plus corpus presented in chapter three.

Question 2 is discussed in chapter 4, where *Appraisal Theory* (Martin and White, 2005) is presented and used to analyse the ways in which the experiences of bodily pain and chronic illness are evaluated by my informants. Furthermore, the chapter also addresses what other elements are evaluated in the interviews of the ALOMAR Plus corpus and in what way. The encoding of the participants feelings (*affect*) in relation to their experiences of chronic illness and attendant bodily pain is also addressed.

Adopting a broad narrative analytical approach, and building on the findings of the previous chapters, chapter 5 addresses question 3 and looks at the identities that the speakers in the corpus construct and present.

Chapter 6 brings together the various strands of the discussion found in the preceding chapters and discuss them. It identifies the original contributions of the present research and suggests some practical applications (and implications) of the findings. This final chapter gives, based on the preceding analysis, an answer to the two questions: can one talk about pain? If so, how?

6 A note on the use of language in this thesis

A work on the experience of pain and illness (or any other topic, for that matter) that claims to be grounded in linguistics cannot ignore the fact that words *mean* in more than one way.

From early work on denotation and connotation to more recent studies in fields such as sociology (Bourdieu, 1992) linguistics (Irigaray, 2002), Critical Discourse Analysis (Fairclough, 1995) and performativity (Butler, 1999)⁴, research has shown that language is never neutral. Terminologies and taxonomies carry a number of overt and covert meanings; they offer (often impose) interpretative keys which can be biased in a number of ways.

In the case of this thesis, the problem became apparent shortly after the writing up process had begun. How, for example, ought the individuals who took part in the research, giving their consent to being interviewed, be referred to? In sociolinguistic studies, such individuals are variously referred to as 'subjects', 'informants', 'participants' or simply 'speakers'. These commonly-used labels offer advantages, such as the possibility of protecting people's identities. With their anodyne, supposedly neutral sound/tone, they also contribute to claims of objectivity, scientific precision and detachment, something that the social-sciences appear to envy of the so-called 'hard-sciences', such as biology, chemistry, and physics. As Halliday points out (in Webster, ed. 2003: 199), 'those who study language have often been

⁴ Obviously, this is not meant to be a full list of works on language as a tool for 'creating' reality, rather than merely 'reproducing' it. It should also be noted that not all the mentioned scholars agree with each other's views.

concerned with the status of linguistics as a science [...] us[ing] other, earlier developed sciences as a model.’

Such supposed detachment, however, comes at a cost: depersonalisation. One thing that became obvious during the research for this thesis was the intensely personal nature of the experiences collected. Pain may be invisible and intangible, but it is always experienced by an embodied individual: a woman or a man with a unique biological and psychological make-up, a unique history. Pain and illness are always embodied and, crucially, personal (Heshusius, 2009).

Other terms employed in the literature, especially discourse studies on medical language, or works from the medical humanities, include *sufferer*, and the obvious *patient*. They too are unsatisfactory. The former, *sufferer*, provides an interpretative key: the person as ‘victim’; the latter medicalises the individual, attributing a role that may be far from the truth, and this is true whether one concentrates on the etymological sense of the word or on the current meaning of ‘someone in the care of a medical institution or professional.’ Like the terms mentioned earlier, these too depersonalise the individual; in addition, they can be patronising and can perpetuate stereotypes often seen as demeaning and disempowering.

The fact that words applied to certain groups of people or employed by certain communities of practice are at least problematic has been noted by linguists but the point has been made particularly forcefully by authors involved in social work (Thompson, 2001) and in disability advocacy (Morris, 1991). As Thompson (ibid p. 31) writes, ‘what is needed is not a simple list of proscribed

words but, rather, an awareness of, and sensitivity to, the oppressive and discriminatory power of language.'

Therefore, in light of the above, choosing how to refer to the women and the one man who accepted to take part in my research has been challenging. I have opted for a mixed approach: in many cases, in what follows, I shall be referring to the individuals whose language is the topic of the present work by their first names (albeit changed, to protect anonymity). I shall also be using terms such as *patient*, *informant*, *subject*, *speaker*, and *sufferer* as more or less synonymous. This represents, in my view, a less than satisfactory choice and I am aware of the problems it entails.

Chapter 1: Cultural background to this thesis and literature review

Introduction

As mentioned in the previous chapter, one of the aims of this thesis is to fill a gap in the existing studies on the linguistic encoding of the experience of bodily pain. This absence, as noted, has been particularly visible in the field of linguistics.

Although the situation began to change with Halliday (1988), as late as 2007 Lascaratou (2007: 9) was still able to point out, correctly, how peculiar it was that, despite the central role of language in human pain behaviour, 'pain has not been the object of comprehensive study within and across languages.' Since then, more attention has been devoted to this area and more scholars have been working on these topics, albeit from different perspectives. More linguists are responding to Halliday's invitation to investigate the language of pain with larger corpora and cross-linguistically.

The debate initiated by Scarry (1985) on the pain-language nexus has resulted in increased interest from a number of academic quarters. Such works are not immediately relevant for this thesis, its scope, structure, and theoretical orientation. Nonetheless, it is felt that, to varying degrees, they deserve mentioning. Beginning with *The Body in Pain*, this large body of work forms the cultural and intellectual background upon which the present research rests and with which, in a way, it has entered into a dialogue. A selection of this 'background literature' will occupy section 1 of this chapter.

The works included have been chosen to illustrate the variety of scholarly approaches they represent. Furthermore, many of the topics they address, such as the life-altering nature of illness and pain, illustrate and shed light upon points made by my own informants and that I address in chapters 3-5. Attention to these points will be made where necessary, in section 1 of this chapter.

A further reason for presenting and discussing a selection of this vast body of literature is to highlight that no research originates in a vacuum. As well as being the latest instalment in a dialogue within a particular discipline — be it sociolinguistics, DA, or any other — it responds and is intellectually indebted to a much wider discussion.

Section 2 will be devoted to presenting and assessing studies that deal with the topic and that are immediately relevant for the present research, with reasons given for their selection. The same section will also introduce and justify the choice of analytical frameworks to be employed as analytical tools in the present research.

Unlike for bodily pain, the role of language in medicine has been the focus of considerable attention. The medical encounter, for example, has proven a fertile area of investigation for discourse analysis (DA) and critical discourse analysis (CDA). The so-called ‘narrative turn’ (Riessman, 2008) in the social sciences has been fruitfully applied to the investigation of various aspects of the illness-experience and the relatively recent burgeoning of what are now collectively known as (auto)pathographies. Studies in this area can be considered to be part a developing field of research: ‘health communication’.

Harvey and Adolphs (2001⁵) provide a broad definition of what health communication studies include. The present study would sit comfortably within this field:

Health communication, by definition, refers to all aspects and modes of communication that take place within medical contexts or broadly relate to the subject of health and illness. Accordingly health communication is an all-embracing term that takes into account a huge and diverse range of communicative activities touching on health and healthcare, ranging from personal accounts of health and illness and encounters with medical professional, through to health policy documentation and side effects information presented on drug packaging.

Because pain is mainly experienced and investigated as part of the wider experience of illness (and the present study is no exception), a number of such studies will also be presented and discussed in section 2 of this chapter, especially for their relevance to the latter portion of the thesis.

1.1 The cultural background: the broader tradition of reflections on pain and language in non-linguistic literature

a) Philosophical reflections on pain and its experience

‘[T]he useless, unjust, incomprehensible, inept abomination that is physical pain.’ These are the words of the French writer Huysmans (1959: 2). The

⁵ I have been kindly allowed to see the typescript in pre-publication form; I am therefore unable to provide an exact page reference.

same sentence, however, might have been spoken or written by nearly anyone who has ever had to personally endure physical pain, or watch someone they love endure it. Since time immemorial, human beings have been reflecting on the nature of pain, as well as on wondering about the reasons for its very existence. Often, like Huysman, they have concluded that it has no reasons and ultimately remains a puzzle.

It is perhaps because of its enigmatic nature that pain, in its various permutations, has been the object of much philosophical interest over the centuries. A full discussion of what philosophy has had to say about it is beyond the scope of this thesis. However, there is one aspect of the pain experience that philosophers have investigated and which is immediately relevant to the present study: the communicability of pain.

As pointed out in the previous section, the impetus for the present research arose out of being confronted with precisely one such claim, namely, Scarry's (1985) argument about pain's essential unsharability, which — she argues — is ensured through pain's 'resistance to language' (p. 4).

Scarry partly bases this assertion on a view derived from our everyday life, namely, the difficulty encountered by anyone experiencing pain of accurately describing it. This situation is directly relevant for health communication. In both patients and medical professionals, it is often the source of considerable frustration. For the patient, not being able to accurately encode the precise nature of a noxious stimulus (its intensity, the type(s) of sensation(s) it engenders, its exact location, and so on) is, from a pragmatics point of view, face threatening.

As many of the participants who were interviewed for this thesis testify (see chapters four and five), this difficulty often results in being considered a less than reliable witness of one's own experience. In the worst cases, patients can, in a more or less veiled manner, be accused of exaggerating symptoms, even of inventing them. On the other hand, patients' difficulty in articulating their own pain may mean that medical professionals are unable to quickly formulate a diagnosis and prescribe the appropriate treatment.

This difficulty in communicating pain is often the source of frustration outside, as well as inside, the consultation room. This is again attested by some of the Alomar Plus informants and again can be face threatening.

In the broad sense given by Harvey and Adolphs (2011), *health communication* can include all those encounters with non-medical professionals — such as spouses, other family members, and friends — where health (and pain) matters are discussed. Friends and relatives are obviously not expected to provide a diagnosis, yet their support can be crucial for the well-being of someone suffering because of their health. Solidarity is established linguistically and it is therefore extremely frustrating when an individual is not able to encode and communicate his or her experience.

Natoli (2002) offers a comprehensive overview of the meanings given to the experience of physical pain in western culture. His work reflects, among other things, on the challenges that pain inflicts upon language and the relationship between the former and the latter.

In common with other scholars (Good, 1994; Scarry, 1985; Morris, 1991, *inter alia*), Natoli argues that the experience of pain has a *transformative* power: when it does not destroy it, it alters and heightens perception. For the Italian philosopher, pain is not only a personal experience, but also a 'cosmic event' which potentially concerns everyone. It is precisely in this intertwining of the personal with the universal that, for Natoli, resides the possibility of the transformation of the experience of pain into language. Pain, Natoli goes on to say, belongs exclusively to the one who is suffering; and yet, witnessing any suffering abruptly brings onto the scene the possibility of your own suffering:

Hence the plot, the feeling that everyone is concerned [...]. The experienced pain becomes universal in the image of the possible pain' (p. 11)

This dialectic tension brings about the 'rebirth of language'. In spite of the difficulties, the one in pain 'breaks the wall of silence that separates him from the rest, looks for words, and perhaps even finds them' (p. 10). Whether spoken or unspoken, the experience of pain positions the one in pain within what I would term a 'community of sufferers'. Perhaps paradoxically, pain both isolates and brings together.

Natoli's argument that the 'cosmic nature of pain' is a force that leads to language-generation is certainly interesting and, in my view, it can be used to counterbalance Scarry's (1985) argument that pain is 'language-destroying', as discussed in the introduction. Pain does, however, impose particular constraints on the manner in which it is communicated.

It is this very same possibility of seeing one's own possible suffering in somebody else's pain (whether linguistically encoded or left unspoken) that can account for the difficulty of transforming one's pain into language. The one in pain is acutely aware of the fear, even horror, that his or her suffering can engender. Often, for people who suffer from an illness (chronic or acute) there is an absence of what Ramanathan (2010; 2011) calls 'languaging', the transformation of the experience into language, which results in invisibility. It is precisely this 'languaging' (in its various aspects) that, broadly speaking, this thesis is concerned with.

The perceived lack of language about pain, meaning not only the absence or paucity of lexical items (i.e. pain-descriptors) but also the scarcity of literary works on pain as opposed, for example, to romantic love, may be accounted for pragmatically.

From a politeness-theory point of view (Brown and Levinson, 1987), those in pain who do not or cannot communicate their pain might be seen as addressing their interlocutors' negative face, the desire not to be imposed upon. In addition, sufferers might have convinced themselves of the futility (from a therapeutic point of view, but not exclusively) of communicating their suffering to somebody who does not share in the experience.

It is common for human beings to refuse to even contemplate the idea of pain. There is, in other words, a 'cultural aversion' to pain; the mention of it, even as a mere object of study, is often enough to cause unease and discomfort. Pain, whether experienced or even simply studied can separate

and isolate. It is therefore unsurprising that, unlike romantic love, bodily pain is hard to find in literature (at least in the West). It is not that those in pain do not have the words to tell about their experiences; rather, they often do not see the point in talking about it. This may be for a number of reasons, loss of hope in a solution being only one of them.

It is true, however, that, as Bending (2000: 82) states, '[i]t has become a commonplace that pain defies language [...] that it is unique as a sensation and that [it] cannot be described or shared.' With reference to Woolf's (1926) often quoted passage on the failure of literature to offer 'the merest schoolgirl' words to 'describe a pain in [her] head to a doctor' (vol. iv, p. 318), Bending (*ibid* p. 84) opines, with reason, that it is usually misquoted (for example by Scarry, 1985). When the passage is read in context, it becomes clear that what Woolf actually means is that, considering the ubiquity of both pain and illness, it is surprising that "they have not become the subjects of literature, superseding love, battle, and jealousy as 'the prime subjects of literature'" (p. 84). Thus it is the aforementioned human fear of pain, its aversive nature, rather than a supposed inability of being encoded by linguistic means that explains such paucity. Bending sheds light on Woolf's position by pointing out that, for the English author, the main barriers to writing (and, I would add, *talking*) about pain involve elements such as 'taste, decorum, and fear' (p. 84). Especially in a culture like ours, with its relentless emphasis on youth, efficiency, and the body beautiful, talk of pain is considered, often by those in pain themselves, to be out of place. And for the healthy, hearing about pain is unpleasant because, as Natoli (2002) points out, hearing about someone else's pain reminds us of the possibility of our own possible suffering. It seems

therefore unsurprising that in literature, just like in everyday speech, pain should be the eminent absentee.

Pain is centripetal. It looks – and forces the sufferer – to look inwards. Love, joy, and physical pleasure (*jouissance*), are potentially just as hard to linguistically encode. However, they are ‘centrifugal’: they project outwardly, like a liquid from a container which is full to the brim. Herein resides the main difference between the experience of physical pain and that of other sensations. As Natoli (*ibid* pp. 9-10) argues: ‘Love, which is demonstrative, cannot be told, but it generates signs and words. Pain — on the other hand — in all the signs it gives off reproduces itself as the ultimate enigma.’

A crucial point in Bending’s argument, and one that I and other linguists (see below) share entirely and that I hope this thesis will contribute to support, is that the flaw in the argument of those who argue for the fundamental uncommunicability of the experience of pain is a failure to realise that ‘pain can enter into language and be accommodated by its structures – whether descriptive or metaphorical – in the face of a paucity of directly expressive words for painful sensations’ (Bending, 2000: 82). Pain is complex and so is the language that speakers employ to talk about it, as chapters 3-5 of this thesis will demonstrate. The number of directly descriptive words to refer to one’s pain are probably few, and this explains why the person in pain:

[F]aced with the absence of appropriate language, is compelled to move outwards from the direct description of pain itself into a metaphorical and explanatory realm in which pain is fitted into another and distinct framework of reference (Bending, 2002: 85).

Figurative language (similes and metaphors) is not, as Scarry (1985) appears to suggest, proof of the inability of language to encode the experience of pain, and thus of the latter's ineffability. On the contrary, as the data in the present study will help to demonstrate, figurative language is testimony to the resourcefulness of human linguistic systems.

In addition, as both section 2 of this chapter and chapter three will show (both following Halliday, 1988), the complexities of an experiential domain such as that of bodily pain are dealt with not only at the level of the lexicon but also, crucially, at the level of the grammar, through the system of 'transitivity'.

b) The view from history

A point that I shall make repeatedly throughout this thesis is that pain is both socially and historically situated. As such, it takes on meaning(s) from its socio-historical surroundings.

As Melzack and Wall (1996) show, the very perception of painful phenomena is to a large extent influenced by the cultural meanings assigned to them; in this respect, for example, religion is a particularly powerful interpretative tool.

A number of researchers have looked at pain from a historical perspective. Like philosophers, historians appear to have given the issue of pain more thought than have, until recently, linguists. Their findings, although not primarily preoccupied with the linguistic encoding of the experience of physical pain, have a bearing on any meaningful study of any aspect of the pain experience. It is beyond the scope of this review, and of this thesis, to provide

a full account of historical research on pain. However, the insights of historical research presented here have influenced, to varying degrees, the thinking behind this thesis and have helped to focus the questions asked.

Rey (1993) draws on different sources to present the universally shared experience of physical pain, from antiquity to the present. The French scholar stresses the importance of cultural and social factors in the experience of pain. She makes the important observation that the meanings attributed to pain influence the way it is perceived and lived. This point, as mentioned, has been made by other authors (e.g. Melzack and Wall, *op cit*), working from different perspectives.

Like others after her (see below), Rey argues that the often-made distinction between physical and psychological pain is often blurred, and perhaps ultimately meaningless. She then notes that often a distinction is made between *pain*, which is understood to be physical, and *suffering*, which is seen as moral. However, she points out that there is a further distinction that can be superimposed on the first:

[T]he word suffering seems more to refer to the subject while pain seems more to apply to the objectification of this suffering, which legal parlance translates perfectly when it evaluates the "*pretium doloris*" [the price of pain]. When a doctor questions a patient, he is more likely to ask, "Where does it hurt?" or "Are you suffering?" or even "What seems to be the trouble?" rather than to ask him directly what type of pain he feels; however, he transcribes in his patient's file "abdominal pain" or "lower back pain" (1993: 3).

This simple observation highlights the conceptual and terminological confusion surrounding the experience of pain. Rey also stresses that when pain is 'intense and persistent or simply chronic [as is the case for the speakers in the ALOMAR Plus corpus] *it always involves the entire being*. [... The person's] entire personality becomes doleful and his intellect becomes dulled' (p. 3; my emphasis). This complexity of the pain experience is bound to find linguistic realisation; for example through the grammar, a point which, as noted, has been made by Halliday (1988; Halliday and Matthiessen, 2004). Rey's study is broad in scope and deals with the scientific theories of pain as well as the various remedies for pain in history. Interestingly for the present study, however, it also addresses – to an extent – the relationship between pain and language. Obviously, the possibility of analysing transcripts of encounters such as medical consultations is only a recent development. By necessity, Rey relies on literary works, such as the Homeric texts (the *Iliad* and the *Odyssey*), the works of the tragedians, like Sophocles (*Philoctetes* [also discussed by Scarry, 1985] and *Trachiniae*). And although not a literary work, Rey comments on the linguistic encoding of pain in one of the most important medical works (or, to be precise, collection of works) in the entire western tradition: the *Corpus Hippocraticum*.

The aforementioned works offer relevant insights on the lexical encoding of pain, its perception and psychological aspects. For example, in Sophocles '[p]ain is perceived almost as an independent being which takes possession of the subject, invades it and takes over' (Rey, 1993: 15).

These construals of pain persist through time: pain as the *Other*, the "it" that invades and takes over has been observed in modern medical encounters

(see Cassel, below; I shall discuss the encoding of pain as an 'entity' that displays agency in chapter three). From a cognitive point of view, the diachronic and cross-cultural persistence of this way of linguistically reifying pain is a striking phenomenon, pointing, it appears, to a cognitive universal. As the present research will show, this is an understanding of pain that persists to this day.

c) Anthropological perspectives

The understanding of the experience of pain, and its construal through language, has provided anthropologists with fertile ground for research.

Jackson (2000: 144) states that 'pain is a concept, not a thing'. As such, it is culturally interpreted and historically situated. Culture and history both have personal and wider, societal dimensions. It is therefore unsurprising that pain (as well as, more generally, illness) should be interesting as objects of research for anthropologists of various theoretical persuasions and working within different sub-fields. Obviously, medical anthropologists figure prominently in research on pain, illness, and their relationship with language.

Morris (1991), not an anthropologist but, like Scarry, a literary scholar, argues that pain, in a way, is a cultural artefact. '[T]he experience of pain is decisively shaped or modified by individual human minds and by specific human cultures' (p. 1). Pain, he argues, is situated and constructed historically, culturally and psychosocially.

With references to (among other things) art, history, and literature, he convincingly argues for a multidisciplinary approach to the study of pain and one which makes use of different perspectives. If, as Morris puts it, ‘pain is always personal and always cultural’ (p. 25), then it is imperative that we approach its manifestations, such as the linguistic ones, from a variety of points of view. Any study of pain and its language is, perforce, a study in subjectivity if, as Morris opines:

[t]he pain we feel [...] always belongs to a particular place and time and person. It may be trivial or negligible (if we choose to interpret it so) but is never simply an impersonal code of neural impulses, like changeless, computer-generated messages sent over an internal telephone (p. 29).

Like Jackson, Morris (*ibid* pp. 9-12) argues against the sharp dichotomy physical pain – mental pain. He refers to it as ‘a myth’ (p. 9) which ‘like all myths – no doubt depends on the serviceable truth it brings into a murky world’ (p. 9). Indeed, one of Morris’s stated aims is ‘to begin to collapse the artificial division we create in accepting a belief that human pain is split by a chasm into uncommunicating categories called physical and mental’ (p. 9). Language is instrumental in perpetuating this myth but also crucial in ‘dismantling’ it.

As I shall argue in chapter four, attention to the language of evaluation can begin to show the mental and emotional dimensions of chronic pain. Morris’s argument against a sharp distinction, based in a Cartesian world-view, between mental and bodily pain is — as stated — shared by other scholars.

The present research too is intended to problematize such a view. However, as Davies (2010) cautions, it is important to acknowledge that although the commonalities and interfaces between so-called mental and bodily pain may be numerous, the fact that speakers so consistently differentiate between the two indicates that there are ways in which these two modes of suffering are essentially distinct.

Del Vecchio Good, Brodwin, Good, and Kleinman (1992) combined their efforts and points of view to produce a collection of papers on pain and illness from the perspective of anthropology (medical and 'general'). Their work is particularly important in highlighting the connections between pain, its understanding and interpretation, and culture. They note that pain is present across time and in every culture. As such, it is the focus of attention in various traditions of medical literature: Islam, India, China, and the West. Del Vecchio et al. (*ibid*) point out that the relationship between pain and culture is essential because the latter provides the one in pain different 'categories, idioms, and modes of experience' (p. 1) to experience, interpret, and – crucially for the present study – speak of the former. This is apparent, for example, in some of the metaphors that speakers in the ALOMAR Plus corpus employ, that will be addressed in chapter four.

For example, among the Sakhalin Ainu of Japan, one often hears complaints about 'bear headaches' that 'sound' like the heavy steps of a bear; or of 'deer headaches' that sound and feel like the considerably lighter steps of a deer, whilst a 'woodpecker headache' feels like a woodpecker pounding into a

trunk. Latinos in North America make a distinction between a *dolor de cabeza* (headache) and *dolor de cerebro* (brainache), presumably a deeper, more intense experience. Such cultural differences can at times be striking. Del Vecchio et al. (*ibid*) point out that Nigerians complain about a range of different types of pain using language that in North America “would be considered potential indicator [...] of psychoses [such as]: ‘it seems as if pepper were put into my head,’ ‘things like ants keep on creeping in various parts of my brain,’ or ‘by merely touching parts of my brain it hurts’” (p. 2).

Del Vecchio et al. (*ibid*) explain that the interest of chronic pain for anthropologists is tripartite. First, the anthropological study of chronic pain ‘exposes basic contradictions of medical ideology’ (p. 7). For example, ostensibly the medical profession has the reduction of suffering as one of its stated aims. However, anthropological research of the experience of pain highlights how a lack of understanding of the psychological and cultural aspects of the true significance of pain for a patient results in a number of negative outcomes: over or underprescription of drugs, and the inability of the patient to fully participate in the economic life of the community are just some of them.

Secondly, chronic pain translates into a number of social problems, like its socio-political effects. Patients often complain that medical professionals, even pain specialists, often appear to be insensitive to their suffering and needs. They concentrate on the biomedical side of pain at the expense of what might be termed the social and cultural model of it. Understandably, it is often the case that medical professionals only pay attention to a patient’s linguistic output in order to ascertain the intensity of pain and its source. This

is not wrong. However, the totality of the language used by a patient to describe her experience is revealing of the true effects of pain on the individual and those around him or her. Furthermore, attention to and an understanding of the cultural models used by patients and available to them could potentially help the practitioner to assist the patient in the fight against pain with means that complement drug therapy.

Thirdly, the study of chronic pain allows anthropologists to explore issues of embodied experience. Such study has both theoretical resonance and practical relevance for the study of pain, especially of the chronic type.

Anthropologists concerned with the anthropology of everyday experience and the embodiment of cultural categories of distress are drawn to pain in order to understand how the bodily experience itself is influenced by meanings, relationships, and institutions (Del Vecchio et al. 1992: 7).

The work of these authors has added very valuable insights to the study of the experience of pain. For the linguist looking at language and pain, one of their observations is particularly relevant:

[H]uman conditions such as pain are not adequately appreciated if the analysis begins and ends with the exploration of linguistic terms and cultural taxonomies (*ibid* p. 7).

In other words, pain and its manifestation, linguistic and otherwise, do not occur in a vacuum.

More recently, Jackson (1994, 2000, 2003, 2005) has written extensively about the experience of pain, in particular chronic pain, and the challenges of encoding and communicating it. Writing as an anthropologist, she is particularly interested in the relationship between culture and the experience of pain, especially in how it is communicated and 'translated' both inter and intra-culturally.

Like other researchers (see above), Jackson comments on the difficulty of communicating pain. Interestingly (and crucially), she also highlights the fact that part of the difficulty of communicating pain is caused by the ways in which such communication is received (or not received, by being ignored or underestimated, for example). Like all communication, pain-communication is (at least) a two-way process; it must be encoded but also *decoded* correctly. '[A] sufferer grappling with enormous amounts of pain will find that the more she communicates her pain, the greater the risk of its being seen as illegitimate' Jackson, 2003: 174). That sufferers often encounter disbelief regarding their experiences, and frequently see their pain 'delegitimised' in both medical and non-medical encounters, became apparent while collecting the interviews on which this thesis is based.

Across cultures, one of the most important interpretative constructs that humans have at their disposal to come to terms with various aspects of their

lived experiences is religion. As the present studies reveals, language that draws on specific religious traditions is often employed to communicate the emotional aspects of, among other things, the experience of pain.

Glucklich (2001), partly historical investigation and partly anthropological enquiry, is a study of the religious meanings attributed to physical pain. One of the common assumptions, when talking about physical pain, is that it is always evaluated negatively, especially by the person experiencing it. One might mention the complex phenomenon of masochism; however, this is considered, by the general public and by psychiatry (Hales and Yudofsky, 2003) as pathological, and often related to the sphere of sexuality. By exploring various religious narratives, Glucklich shows how the experience of pain can, and indeed is, evaluated positively in some situations. Pain, he argues, 'can make self-transcending realities accessible and vivid' (p. 207). Unsettling as this may be, it alerts us to the fact that it is not sufficient to look at the lexicon of pain. According to context, one can, and indeed does, encounter entirely contrasting *discourses* of pain, where by discourse I mean 'stretches of language as short as a conversational exchange or as long as the literature of an academic discipline [or a religious community]' (Barton, 2001: 169).

It would be interesting, in such cases, to see – for example – what metaphors are employed, what lexical choices are made. It would also be useful to systematically investigate (as I will do in chapter four of the present thesis, for the ALOMAR Plus corpus) how people and communities where pain has the kind of functions discussed by Glucklich use the resource of *appraisal*. As I

will discuss, although in the ALOMAR Plus corpus speakers conform to the expectation that pain will receive negative evaluations, even more so do the various therapies they are prescribed. And in some instances, the disease itself is evaluated positively, at least after its onset, for the possibility it allows the person to fashion a different, preferred self.

Cohen (2010) looks at depictions and descriptions of pain in the late Middle Ages. The body of texts she looks at is wide-ranging; it comprises martyrdom narratives, descriptions of torture, and of surgery. Like the works mentioned above, her research too looks at the ways pain was understood, through cultural references, by a historically situated society – the mediaeval - and the mediaeval mind. Like the other scholars mentioned here, Cohen contextualises pain. She points out that, if one looks carefully enough, even in temporally remote cultures one can find numerous example of language *of* and *about* pain. Importantly, Cohen observes that the language of and about pain (its discourses, lexicons, metaphors) are – to a large extent – culturally shaped, if not culturally *imposed*. The meanings attributed to physical pain are bound to be reflected in the language used to speak it (in the sense of giving voice to it) and the language to speak (or write, of course) *of* it.

For example, in the mediaeval period, self-inflicted pain as a form of penitence and to purify oneself from sin was not uncommon. As Cohen observes, '[i]t was deeply tied to the most basic narrative of Christianity: the Crucifixion' (p. 28). Although pain thus obtained would still provoke an aversive reaction (i.e. it could still be clearly identified as an unpleasant, noxious stimulus), its

interpretation, deriving from its redemptive function, could be, overall, evaluated positively.

The same is true of illness and the pain it causes. Cohen points out that '[p]ractically all late medieval religious texts dealing with pain counted it as a blessing, not a danger. [...] [O]ne could build one's hopes, fears, and understanding of life upon the irregular and abnormal that often become a regular part of life – illness and pain' (p. 32). St. Augustine, one of the most influential mediaeval thinkers, said about bodily pain that it is useful ('*utilis dolor est*') 'because it indicates life. It is better to have a painful wound than an insensitive gangrene, for the latter indicated the death of the affected organ' (p 32). As far as illness was concerned, it could indeed signify a punishment from God, but more often than not it was considered to be a sign of his favour.

Cohen (*ibid* pp. 147-167) makes the obvious but important observation that pain, which is not transmissible (through contagion, for example) and not visible (although *pain-behaviour* can be) relies on language to be noticed and observed. 'A stable vocabulary of pain was the principal requirement for any sort of functional discussion on pain' (p. 150). To describe pain, physicians borrowed lexical items from other sensory fields, for example smell and taste. To describe the quality of pain, descriptors could be described as *piercing*, a *knife*, or *throbbing*. 'Such semantic transitions had become so common that one had no need ever to think about the original usage of the terms' (p. 147). Indeed these terms are still in use today. Cohen also makes interesting observations about the relative stability of the vocabulary of pain (which, in her usage, also includes figurative language: metaphor and simile). She argues that 'the conservatism of pain vocabulary lies in its functions' (p. 150). Patient

and physician had to be fairly confident that the lexicon and figures of speech they used would be easily, accurately, and quickly understood. Within 'communities of practice', meanings had to remain stable to allow understanding and facilitate diagnosis and treatment. Cohen opines that '[w]hen it came to the description of symptoms, it made little sense for physicians to pioneer a new vocabulary or be creative with the literary forms of language' (p. 150). The paucity of the lexicon of pain, the recurrence of the same metaphors – as commented upon by, among others, Scarry (1985) – might therefore be a function of the imperative to guarantee prompt understanding. It might be, in other words, a point of strength, rather than a weakness.

To return to the general discussion, obviously our mindset and that of the speakers in the ALOMAR Plus corpus is far removed from that of the late mediaeval man or woman. However, it is interesting to note, as I do especially in chapter four, that even for the 21st century speakers of this corpus, the language used to talk about the overall experience of chronic illness and its attending pain (e.g. illness and pain as a limitation vs. illness and pain as an opportunity) is influenced, even shaped, by the interpretative frameworks they choose to adopt.

In recent times, studies of the linguistic expression of pain within specific linguistic communities have begun to appear. Koffman, Morgan, and Higginson (2008) interviewed Black Caribbean and White British patients

suffering from cancer-related pain. The research shows similarities but also interesting, culture-related differences. Pain is central in the experience of both ethnic groups and both groups characterise it as unpleasant, a challenge, and an enemy. However, more Black Caribbeans than white British consider their pain as either a test of their faith or a punishment from God. This, the researchers claim, reflects Black Caribbeans' strong faith. Neither group refuses analgesic treatment; however, in findings that echo Glucklich (2001), for the West Indian patients, pain provides redemptive qualities and offers the means of getting closer to God. Interestingly, 'instead of being perceived as maladaptive or negative, justified punishments were perceived by Black Caribbean patients as being a positive and an active response to their illness that strengthened character' (p. 356).

1.2 The language of Health Communication: Literature review of studies of direct relevance for this thesis

As previously stated, this thesis can be considered as a contribution to the study of health communication, as defined by Harvey and Adolphs (2011). In particular, it offers a contribution to one aspect of health communication, namely, communication about bodily pain within the experience of chronic illness.

The purpose of this section (2) is to present and critically evaluate the existing literature on those aspects of health communication that are the most relevant for the present research. Doing so will clarify how this research sits within this expanding field of enquiry and will point out what original contribution it makes.

Unlike the majority of works the works mentioned and discussed in section 1 of this chapter, the ones addressed here all specifically, and primarily, concern themselves with *linguistic aspects* of health communication (as opposed to historical, philosophical, and so on). However, it will be noticed that they originate not only from different sub-fields of linguistic enquiry but also from other disciplines, such as medicine. The reason for their inclusion, however, is simple: they have the linguistic datum at their centre, albeit different aspects of it.

1.2.1 The medical tradition

For understandable reasons, the medical profession has always been aware of the intimate relationship between language and the experiences of illness and pain; of the limitations of the former and the peculiar challenges of the latter.

For example, countless doctor-patient encounters contain the question: “What does your pain feel like?” or variations thereof. All such encounters are bound to alert both patient and practitioner to the difficulty of appropriately encoding this most common and yet most unique of human experiences. It is therefore unsurprising that some of the earliest studies on the dyad pain-language should have originated from within the medical field, and with very practical aims.

Melzack and Wall (1982; 1988; 1996) - the former a psychologist, the latter a physiologist – have paid considerable attention to ‘the puzzle of pain’ and to its complex relationship with language. In what is now considered a classic work, they comment on the difficulty of ‘expressing [the] pain experience⁶’ (p. 36). In common with lay views of language (i.e. from non-linguists), that mainly identify language with lexical items, they concentrate on single words that express, or fail to express, as the case may be, what patients might be feeling when they say they are in pain.

⁶ All quotations from Melzack and Wall are from Melzack and Wall, 1996.

The reason for [the] difficulty in expressing pain experience [...] is not because the words do not exist. There is an abundance of appropriate words, but they are not words which we use often. There is another reason: the words may seem absurd. We may use descriptors such as splitting, shooting, gnawing, wrenching or stinging, but there are no 'outside', objective references for these words (Melzack and Wall, *ibid.* p. 37).

It is clear from this quotation that Melzack and Wall are aware of the specific cognitive and philosophical problems that the encoding of the experience of physical pain entails. Like Scarry (1985) they identify the absence of an external referent for pain as one of the main obstacles to its linguistic encoding. Physical pain happens, quite literally, 'under the skin'. Even when it produces 'pain behaviour', it remains invisible and, as Scarry (1985) points out, its very existence can, and very often is, doubted.

This view is not without merit; pain does indeed reside within the body. In those instances where no damage to bodily tissue is visible to the onlooker and where no visible pain-causing agent can be discerned, to accurately communicate one's pain can indeed prove challenging. However, as pointed out by Bending (2000), amongst human experience bodily pain is not unique in lacking a visible external referent. So is sexual *jouissance*; and so is love, in its broadest sense, when the object of affection is, or has been, visible to no other than the lover. To this can be added, as previously mentioned, that as Bending (2000) has pointed out, rather than the lack of a visible, external referent, what makes pain-communication problematic is the difficulty ought to be discerned in existing cultural norms dictating what subject matters are more or less 'legitimate' and acceptable as topics of communication. Across

many cultures, there is a certain resistance to talking about one's pain. This in turn adds to the difficulty people have in verbalising the experience. Language acquisition is not only about mastering grammar, it is also about learning how to talk about specific topics. Crucially, it is also about learning about *what* can be talked about. However, in fairness to Melzack and Wall (1996) it must be said that, although they do not state it in such terms, they recognise that, in trying to communicate pain, what the sufferer is often faced with is what, echoing Hymes (2000), might be termed a deficit in 'communicative competence' when it comes to pain.

Melzack and Wall's research is relevant because many of their observations are derived from direct experience with patients and by careful analysis of pain-related talk. Careful attention to this material was instrumental in the development of the famous, and now widely-used, *McGill Pain Questionnaire*. The questionnaire, now available in many languages, contains a list of 'pain descriptors'. These are lexical items that are read to patients; the patients are then asked to 'choose only those words which describe [their] feelings and sensations at the moment' (Melzack and Wall, 1996: 39). The pain descriptors used were selected according to the frequency with which they appeared in previously collected interviews with a number of patients. They include: *flickering, throbbing, beating, pricking, tiring, pressing; hot, scalding, burning; tingling, itchy; dull, sore, sickening, suffocating, nagging* (for the full list, see Melzack and Wall, *ibid* p. 63)

It would be beyond the scope of this thesis to dwell on the details of the McGill Questionnaire. However, it is relevant for the present research (and of interest to linguists) to point out that, quite aside from its validity as an

evaluative/diagnostic tool, the questionnaire highlights the importance of language in encoding the experience of pain; and it also highlights the subjective nature of the pain experience. In fact, all the above pain-descriptors are subjective evaluations (e.g. situated in the patient's own and unique experience) of the pain sensation. In view of Halliday's study of the 'grammar of pain' (which will be discussed below), it is interesting to note the aforementioned pain-descriptors are adjectives. These refer to one particular lexicogrammatical encoding of it (as identified by Halliday): that of pain as a *quality of something*.

In discussing Melzack and Wall, I have referred to the subjectivity of the experience of pain. The strongest acknowledgement of the importance of the individual, with her own biography and psychological makeup, in the experience of pain is offered by McCaffery (1972: 8), a professor of paediatric nursing, who famously stated: "[P]ain is whatever the experiencing person says it is, existing whenever he says it does.' Discussing the importance of the patient's experience for the interpretation of the painful stimulus, she adds:

The body in which [the] sensation of pain occurs cannot be viewed as a machine, but rather as the patient's *personal, private possession*, invested with *the patient's particular emotions*. [...] with the conceptualization of pain as an affect, verification of the pain by others is meaningless. *Pain can be verified only by the person experiencing it* (*ibid.* p. 7; my emphasis).

These insights have caused controversy, and to an extent they still do. For example, Spence (2010) – a general practitioner – caused a stir when, in an article in the *British Journal of Medicine* (BMJ), he doubted figures estimating that the percentage of chronic pain sufferers in the UK is as high as 20%. For him, '[the] evidence is based on the unscientific [i.e. untrustworthy] definition that 'pain is whatever the patient says it is', *an assertion so simplistic that it cannot be true*' (p. 1144; my emphasis). The patient's voice is therefore, once again, doubted and her voice effectively silenced, an experience lived by most of my informants and reported by researchers such as Honkasalo (2000).

However, quite apart from its diagnostic and therapeutic value, insights such as MacCaffery's have inspired much of the thinking behind the present research. Attention to the patient's linguistic output is therefore paramount; more than other, technologically advanced diagnostic and imaging tools, language can reveal not only *where* pain occurs but also *what* it is for the person experiencing it and what it *means* for her or him.

Returning to Melzack and Wall, for the linguist, the importance of their work on the linguistic encoding of the experience of physical pain also lies in their methodology. As mentioned, these researchers compiled the list of pain descriptors by noting their frequency in preparatory work done with other sufferers. This implicitly acknowledges the role of repetition and of previously-occurred talk in learning to speak of one's pain. Speakers are not entirely 'creative' when trying to verbalise their experience. Words and expressions used to talk about pain are often 'recycled' from previously occurred exchanges and chosen from the culturally and socially available lexicons of 'pain talk'. Every utterance about pain thus becomes a 'text'. As mentioned,

one of the difficulties in talking about one's pain might lie precisely in the physical, psychological, and cultural constraints that inhibit the production of 'pain texts', thus greatly reducing the possibilities of dialogic and intertextual work.

Other interesting and insightful studies into pain and some of its linguistic dimensions are those of Fabrega and Tyma (1976a, 1976b). In their work, the two researchers address the cultural, cognitive, and linguistic aspects of pain. They identify three classes of terms used by sufferers in pain utterances: *primary pain terms*, *secondary pain terms*, and *tertiary pain terms*. *Primary pain terms* (in English) consist of a limited set of words: *pain*, *ache*, *hurt*, *sore*. These function as a base for the perceptual description of the experience of pain. *Secondary pain terms*, on the other hand, are lexemes that denote physical changes of state or damage and are used as 'qualifying pain metaphors' in pain description: they refer to what the experience feels like *burning*, *throbbing*, *splitting*. *Tertiary pain terms* are terms of qualification that sufferers employ to signal degrees of intensity, the duration of a painful sensation, and location: 'I have a *burning* pain in my stomach.'

Fabrega and Tyma's early study is valuable for its attention to the linguistic element. What they refer to as 'primary terms' are — interestingly — nouns (but note that, in English, *sore* can also be an adjective and *hurt* a verb); 'secondary' and 'tertiary' terms, on the other hand, are adjectives. Although Halliday's work will be presented and discussed later, it is important to note that — without embedding their insights into a grammatical theory (as Halliday

does) — they acknowledge that the complex, different perceptual characteristics of the pain experience are accommodated by different categories of words in the language. The ‘limited sets of words’ they identify as ‘primary terms’ encapsulate, for the most part, the ‘quantity’ dimension of the pain experience, i.e. its intensity. Secondary and tertiary terms, on the other hand, capture pain’s ‘quality’, i.e. its type. Fabrega and Tyma recognise that although, especially in the case of ‘primary’ terms, the number of words is limited, language resourcefully manages to deal with the complexity of the experience by combining words and drawing on other semantic fields. Thus, language responds creatively to the problem of having to encode a complex, highly subjective sensory experience such as pain by ‘combining’ various lexicogrammatical resources.

Studies like the one by Fabrega and Tyma’s are extremely important first of all because they drew attention to the issue of pain, within health communication, well before they were recognised as legitimate fields of enquiry. For the present research, they are particularly relevant for the attention devoted to the linguistic element. However, one element, or point of view, that is still lacking in their research, and that later works — including this thesis — address is the widening of the focus over and beyond single lexical items to include *context* and *co-text*.

1.2.2 Health communication and the language of medicine

As stated, the studies mentioned above do not originate from within the field of linguistic studies but from medicine and psychology.

Until relatively recently, and as a result of the 'linguistic turn' in the social sciences, linguists paid more attention to what might be grouped under the already-mentioned general heading of 'health communication', without specifically addressing pain which — as I will show below — began to become of specific interest to linguists only later.

The literature on the topic shows a wide difference of interests, methodologies, and theoretical orientations. As Ainsworth-Vaughn (2001) points out, the majority of studies on medical encounters (which she terms 'praxis literature') are atheoretical about language. In the *praxis literature*, language is 'assumed to be the transparent vehicle of meaning' (p. 453); utterances are assigned a single functional meaning, such as information-giving, information-requesting, affective display, direction. The other type of studies identified by Ainsworth-Vaughn (*ibid*) are referred to as 'discourse literature' and consist of analyses of talk that stem from contemporary theories about situated discourse: conversation analysis, sociolinguistics, ethnography of speaking, interactional sociolinguistics. In both the praxis literature and the discourse literature, 'research has had an explicit or implicit orientation toward the balance of power between patient and physician (Ainsworth-Vaughn, *ibid* p. 453).

Although such research is not immediately relevant for this thesis, it does address important questions that cannot be ignored in any study on the experience of pain and illness that does not concentrate exclusively on pain descriptors. This is because, as already stated, pain communication *is* health communication.

One such question is the aforementioned issue of the power relation between patient and physician and, more generally, of personal agency. An early consequence of becoming ill and experiencing pain is, for most people, loss of (or reduced) autonomy. The patient, as the interviews collected for this study show, makes the transition from a state where she has freedom to act to one where such possibility is seriously curtailed, both for physical and psychosocial reasons. From *actor* she becomes *acted upon*.

Focussing on questions in the doctor-patient encounter, some researchers (Frankel, 1979) concluded that the lower number of questions initiated by patients demonstrated a power imbalance in the doctor patient-consultation. However, as part of the present research will show, the situation might be more complex and, in evaluating concepts such as 'power' and 'agency' a wider context than the medical consultation ought to be taken into account. In the ALOMAR Plus corpus, for example, informants are seen clearly questioning, and even openly defying doctors' clinical judgments and instructions. As Ainsworth-Vaughn points out (p. 463), the generalisation of findings such those by Frankel has probably contributed to the stereotype of the patient as powerless.

Since the 1980s, a topic related to but wider than doctor-patient communication is the area of language and medicine. It comprises doctor-patient communication but extends to medical language, health communication among the public, and everyday discourse about health and illness. Of particular interest for the present research are those studies that look at the lexicon of medicine as well as at metaphors in medicine and discourse about illness, disease, and health.

Jason and Murray (1985) investigate the uses of euphemism in medical language. Euphemisms in medicine may have evolved to allow medical teaching with the patient present, in order not to upset her or him. Jason and Murray report that euphemisms are still used in many cultures whilst others (North American, for example) have abandoned them for the sake of clarity, honesty, and also to avoid possible litigation. There is also the possibility that the official, scientific name of a disease offers 'dignity' to it; it is the name that is repeated by the diagnosed in countless encounters that confirms and vindicates her status as 'officially ill'. As the interviews in the ALOMAR Plus corpus show, the moment when the person is given an official diagnosis, with an official, scientific name for it, is a time of momentous importance which often takes on quasi mythical status. Even if the diagnosis is serious and potentially life-threatening, the act of naming ratifies the person's status as 'ill', it explains and justifies behaviour and complaints that may have been hitherto unexplainable and disbelieved, even by clinicians.

However, medical language has been shown (McCullough, 1989; Mintz, 1992) to often 'erase' the patient, to highlight diseases, body parts, whilst obfuscating the patient's experience. Fleischman (2001) makes a comment

which is particularly relevant for this research, especially in view of its theoretical orientation (see introduction). She observes that this type of medical discourse:

tends to cast the sufferer in the role of passive substrate, or medium, on which the more interesting player in the game, the disease, operates. (p. 476).

Translating this into functional linguistics terms, we might say that the sufferer is assigned the “dative/experiencer” role and the disease the “agent” role; or, in terms of “grounding” relationships, that the disease is foregrounded and the sufferer backgrounded (p. 476).

1.2.3 Metaphor in health communication

With regards to metaphors in medical language, Lakoff and Johnson’s (1980) seminal work on the pervasive nature of metaphorical language has clearly been influential. Medical discourse is fertile ground for metaphorical language and even more so discourse about pain, as even a cursory look at the linguistic data gathered in the ALOMAR Plus corpus will show.

Talking about one’s own illness and suffering is challenging from an emotional and a conceptual point of view. Metaphorical language therefore becomes a very useful tool for the patient (but the same could also be stated of a patient’s loved ones) to grasp the enormity of his or her situation. The use of

metaphorical language, as the data in the following chapters clearly demonstrates, benefits all participants in health communication. The aforementioned cognitive and emotional benefits are in fact also important for the patient's interlocutors. It should be pointed out that the use of the term 'metaphor' made here includes not only regular, 'lexical' metaphor (Steen, 2009), but also simile which, as Steen (*ibid* p. 37) states, is:

typically characterized by direct language use, which sets up an opposition between two conceptual domains within the referential situation model which needs to be resolved in terms of the rhetorical purposes of the sender in the context model.

To include both types of metaphors, the term 'figurative language' will often be used in the present research.

Sontag (1978; 1988) and Scarry (1985) have been critical of the use of metaphors in talking about illness (Sontag) and pain. Gwyn (2001), on the other hand, has convincingly argued for their usefulness. Although this research does not have as its main concern, the use of figurative (metaphorical) language in pain and illness discourse it will, I believe, contribute to supporting Gwyn's view.

Figurative language is not, as Scarry (*op cit*) appears to argue, proof of the inability of language to encode the experience of pain and of the latter's ineffability. Metaphorical language, on the contrary, is testimony to the resourcefulness of language. As stated earlier, this type of language allows

the one in pain to *make sense* of pain by making it less alien; figurative language provides, to a degree, understanding.

Sontag (1978, 1988) is right in arguing that illness (and, it can be added, pain are not metaphors. She is also right when she claims that the metaphors used to talk about illness (and pain often is part and parcel of the illness experience) are often unhelpful, even 'lurid' (1978: 7). One need only think about current metaphors around cancer, where people affected by the disease are often spoken of as 'fighters' who can/will beat it. Here, the dangerous, although unstated, implication is that those who succumb to the disease were perhaps not brave enough or did not put up a good enough fight.

If this is the case, then one ought to think about how to substitute new metaphors for old ones, rather than doing away with them altogether. But in talking of illness and pain, metaphors are part of the solution, not of the problem. Their usefulness is demonstrated by their ubiquity. Gwyn (2001) cleverly critiques Sontag's position by quoting the following passage which, ironically, is the opening passage of her book:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born has dual citizenship, in the kingdom of the well and in the kingdom of the sick [and in pain]. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place (1978: 7).

It is precisely taking up residency, albeit temporarily, in this 'other kingdom' which forms the basis of that fear, referred to above, that makes speaking and hearing about pain so difficult.

Radley (1993) has looked at the role of metaphor in adjusting to chronic illness. This is particularly relevant for the present study, since all the informants have chronic conditions. Radley states that there exists an 'implied stigma' in illness which requires that sufferers employ a number of 'tactics' to either disguise or minimise the impact of their illnesses. Thus sufferers are able to be accepted as 'fully capable participants in social life' (1993: 109).

To fall short of such acceptance, either through the nature of the disease manifestations [...] or through being judged as failing to bear one's illness properly, is to risk being deemed 'less of a person'. The chronically ill are subject to cultural expectations that, in their evaluation of the personal and social status of the afflicted, can be said to be the expression of a public morality. (*ibid*)

Crucially for the present study, bodily pain which in most cases (for the individuals whose interviews are discussed in this thesis) is not accompanied — at least in the initial stages of the illness — by any visible manifestations, contributes more to placing the patient against the 'public morality' which Radley refers to. This is because pain disables but does so invisibly.

In talking about the use of metaphor in health communication, it should also be noted that as Nerlich and Koteyko (2009) have shown, contrary to what is often assumed, it is not only patients and the media that resort to figurative

language when discussing pathology. Scientific and medical discourses too often resort to it by, for example, talking of 'disease as invasion, the immune system as a defence system against foreign invaders, bacteria as good or bad, friendly or unfriendly and so on' (p. 157). In particular, Nerlich and Koteyko (*ibid*) point out the high frequency of war metaphors in medical and scientific papers about MRSA infection in UK hospitals (the so-called 'superbug'). Such finding has relevance for this research where, in the language used by the ALOMAR Plus informants war and — more generally — violence metaphors abound. Nerlich and Koteyo highlight that in the 'representations' of MRS, the *dramatis personae* are multiple and their roles can dramatically change during the 'drama'; the same actors can be both forces for good and negative ones. This is particularly relevant for the present study. As the data and the analysis presented in the following chapters will show, 'actors' normally thought of as benevolent in health communication can be — and indeed are — often cast in negative roles. And as the two researchers point out (*ibid* p. 166), the type of metaphorical representation of scenarios and actors which is used, and — as I will argue in chapter four — the evaluations of such scenarios and actors, has implications for behaviour and actions, such as the abandonment of a particular prescribed pharmacological regimen.

1.2.4 The 'illness narrative' genre: pathography and autopathography

No overview of the literature on (and of) health communication can be complete without reference to the study of *illness narratives*, and the two related genres of 'pathography' and 'autopathography'.

These two labels refer to experiences of illness told in the first (autopathography) or third (pathography) person. Such works are authored by a range of individuals with wholly different backgrounds: medics, journalists, teachers, housewives, to name only a few. Brody (2003: 28) is of the opinion that 'we can best understand what it means to be sick by attending carefully to the stories people tell about sickness.' They can vary greatly in length and quality and are published in a variety of forms, in printed and — increasingly — electronic form. These vary in length from brief accounts to book-length memoirs written (or ghost-written) by individuals, some famous some unknown, with a particular condition that can be chronic — like arthritis — or acute, like cancer. Often, they are 'survivor stories' and can be seen as a sub-type of the 'confessional' literature. Over the past thirty years or so, these writings have been increasing in number and popularity, especially in the English-speaking world. As stated, they are of interest not only to the general public but also to researchers keen to shed light on the illness experience as *lived and understood* by the patient.

Each pathography highlights a different aspect of illness from the perspective of the particular author in question. As a genre that, as noted, has been gaining in popularity, the pathography or illness memoir could be studied in its

own right; its linguistic practices and *topoi* share common features and aims (Hunsaker Hawkins, 1998; Brody, 2003). Many of these can be found in the data collected for this thesis, as chapters four and five will show. Thematically, they present the author's life as a narrative interrupted by the onset of illness; there is clearly a 'before' and an 'after' which requires a number of adjustments. Often the author presents a new self which has emerged a result of being ill. What forms this new self takes and the overarching aims of the narrative varies, often according to the type of illness experiences (chronic vs. transitory; mild vs. life-threatening). Such texts may have different, often co-existing aims: affirmations of life and personal strength, exemplary testimony, tribute.

1.2.5 The narrativisation of the illness experience

Within the social sciences, the attention to the structuring of the illness experience through narrative forms and attention to the biographical element in the experience mark an important shift⁷. Mirroring, as argued by Riessman (2008), what is probably a concern of Western society with the primacy of the individual, increasingly many studies have been concerned with the shaping of a sense of *self* through narratives of illness. As Mishler (2006) points out,

⁷ Although the present research focuses on lay narratives (i.e. narratives told from the patient's perspective), a study of health and illness narrative from the point of views of science and medicine, two name just two, would be equally legitimate and fruitful. Indeed, such points of view cannot be ignored in any broad study of health communication as previously defined.

researchers within the healthcare field have been particularly interested in the potential of illness, especially chronic, to shape patients' identities. This shift signals the change from a state of affairs where the experience of the individual (the *biographical datum*) makes the transition from unhelpful verbiage — often dismissed or overtly ignored especially by medical professionals — to an essential element for a fuller understanding of the patient's experience and, more generally, of health communication. This holds true whether the analysed narratives are produced by sufferers themselves or whether they are collected by researchers through mainly qualitative interviews (as is the case in this thesis).

Over the past thirty years a number of important works have appeared that apply the methods of narrative study to the experience of illness. They include (but are not limited to) the following: Kleinman's seminal work (1989); Frank's equally perceptive books on being ill and in pain, stemming from his own experience of illness (1997; 2002; 2005); Mattingly, (2001); Hurwitz, Greenhalgh, and Skultans (2004); Charon (2008); and Radley (2009).

As Radley (1993: 1) points out, the narrative approach to understanding sickness and health 'stresses the biographical and cultural contexts'.

[It] emphasizes the need to understand illness in terms of the patient's own interpretation of its onset, the course of its progress and the potential of the treatment of the condition.

The need to pay attention to social, cultural, and institutional contexts to better understand the experience of illness — and as an antidote to methods that rely solely on the biomedical model — has also been investigated by Mishler (1981), whose work also looks at the role of narrative in the shaping of personal identity (1999).

The increasing body of literature on the illness experience highlights the interconnectedness of societal (culture) and personal (biography) values in understanding both health and illness. In these accounts, the linguistic element is obviously crucial. Health and illness (and pain) are construed, conceptualised, and presented through processes of narrativisation that assign different roles to the various elements and characters in a patient's story (the *actors*).

A number of researchers have looked at the social and biographical data in narratives of illness to highlight different themes. Pollock (1993) has looked at ideas on 'attitudes of mind' in relation to health and illness. He has shown that popular conceptions of these two states involve moral judgements and often determine what patients and those around them consider 'appropriate' responses to the biographical disruption brought on by illness, as well as to the preservation of health. His findings show that it is often the case that people believe they have a degree of influence over their health but are more 'reluctant to accept responsibility for illness' (p. 67). As chapters four, and especially five, of this thesis will show, the informants in this research clearly show awareness of societal judgements about 'appropriate' behaviour in responding to illness and maintaining health. Various linguistic 'strategies',

such as the frequent use of epistemic evidentials to stress the veracity of statements about their pain highlight this.

Williams (1993) collected and analysed in-depth, qualitative interviews with a chronic condition. His work — like this thesis — investigates the experience of rheumatoid arthritis (RA) sufferers and is particularly interesting for its attempt to show how an individual experience can reflect various societal forces at work in the *context* of which the individual sufferer is part. Although his stated aim to dissect ‘the characteristic ways in which society is represented through individuals’ discussions of the impact of chronic illness and disablement upon them’ (p. 93) leads him to some debatable, politically-situated conclusions, his study is relevant for the ways it shows how the interplay between the social/political and the personal finds its ways in narratives of illness.

In terms of thematic analysis, Williams (*ibid* pp. 95-96) highlights the following in his informant’s narrative: trust in her doctors and relinquishment of control over her body for the purposes of treatment in order to achieve ‘independence’. This shows an ‘abandonment of responsibility over [the] body as a receptacle of disease’ which — however — does not result in a ‘passive stance’ towards the disease’s disabling consequences and does not mean ‘giving up on her life as a whole’. As the analysis in chapters four and five will show, my informants show varying degrees of ‘relinquishment’ (to use Williams’ term) of control over their bodies. All display degree of ‘resistance’ which might be a function of a different culture (Italian vs British) and of a different consciousness regarding the body which has been emerging in recent years. In common with Williams’ informant, the individuals I interviewed have clearly not ‘given up’ on life as a whole, as shown by several instances

of personal agency and positive evaluations vis-à-vis various aspects of their lives. The social value given to self-control and independence is reflected in subjective stances where the chronically-ill, faced with the limited effectiveness of treatments or their heavy side-effects, takes responsibility and makes judicious use of drugs or — as one of the informants for the present study related — stops taking them altogether.

Another theme identified by Williams is the desire not to become an encumbrance (Okada, 2011). This desire, common in experiences of chronic illness, is often the source of internal conflict for the sufferer and of a degree of ambivalence towards carers. Linguistically, the creation of this ‘active’, still-independent persona is achieved through frequent use of active forms and construction that display the individual as maximally agentive. However, Williams makes the important observation (p. 103) that for most people affected and — to a degree, disabled — by chronic illness ‘life [...] is not the heroic overcoming of dramatic obstacle, but the daily struggle with the mundane activities through which identity is expressed and confirmed.’ As the respondents in the ALOMAR Plus corpus show, such activities are ‘simple’, quotidian things like washing up, shopping for food, carrying a carrier bag, chopping vegetables, and so on. This is an important theme which differentiates the ‘heroic’ narratives which often appear in the (auto)pathographies of celebrities, especially sportspeople, from the narratives of ‘ordinary’ individuals.

1.2.5 *The experience of self in healthcare settings*

More recently, the issue of how the self is experienced in healthcare settings has been explored by Rapport and Wainwright (2006). They rightly point out that when talking of our personal experiences, and especially of health related issues, we can hardly do so without talking about *self*. The two researchers observe that although medical technology can and does provide a plethora of information about the workings of the body and its component parts, they tell nothing about the way a person feels ‘in his or her self’ (*ibid* p. 1). This is an obvious, but for this reason not less important, insight which — as the interviews collected for this thesis show — is often overlooked by those who come into contact with the chronically-ill. Rapport and Wainwright rightly point out that it is principally through language that this important information is accessed. Quoting Brunner (2002), the two scholars affirm that the self is the ‘common coin of our speech: no conversation goes on long without its being unapologetically used’ (*ibid* p. 1). Indeed traces of the self are abundant in narratives of illness. They can be uncovered in a number of ways; the use of *Appraisal Theory* in chapter four of this thesis is precisely an attempt to highlight this individuality, the informants’ first-person stance through their use of evaluation. Crucially, Rapport and Wainwright note that patients and clinicians tend to have, and often *do* have ‘different frames of reference for the experience of illness or disease’ (*ibid* p. 1). This makes it possible for different ‘stories’ to emerge which — as the data in the present thesis shows — can be conflicting. This is a point also made by Kinsella (2006), in her study on the ways in which the self is constructed, through narrative, in three perspectives:

unitary, dialogical, and fragmented. These selves are linguistically constructed, which results in language wielding considerable power. Importantly for the present study, Kinsella (*ibid*) states that the way the self is constructed through discursive and narrative practices, whilst appearing to be a theoretical, somewhat 'abstract' matter has important, practical consequences, especially in healthcare settings.

1.2.6 Language and the experience of bodily pain

As noted, the majority of the studies mentioned thus far deals mostly with the linguistic structuring of the experience of illness. Although — for many of the conditions addressed by the aforementioned studies — bodily pain is an important element, it is not the central focus. This is not the case for two recent studies: Hellström Muhli (2010) and Vickers, Zychowicz, and Morones (2010).

Hellström Muhli uses a discourse and communication based approach in the context of care for the elderly to reflect on the experience of pain. The study, conducted in a Swedish institutional setting, makes use of recorded interactions between elderly patients and their professional carers. It focuses on how the elderly patients initiate narrative moves aimed at talking about their experiences of bodily pain.

At the same time, the study looks at how the healthcare professionals orient towards such accounts. It is, in this sense, 'dialogical'. Pain-talk encounters are seen as an activity type and analysed to highlight 'activity-specific coherence and incoherence' (p. 57). Unlike the present research — which is more definitely grounded in SFG — Hellström Muhli's analysis utilises concepts of 'frame' and 'face-work' derived from Goffman (1974), as well as those of 'identity' (Zimmerman, 1988) and 'accountability' (Briggs, 1986).

The Swedish researcher suggests (p. 55) that the experience of pain — especially chronic — can be characterised as a social, as well as pathological experience. She also suggests that the cultural, as well as physical, constraints of ageing make the experience of pain in old age unique. On this point a degree of caution is necessary. It is true that, as Hellström Muhli writes (*ibid* p. 55), 'the roles older people occupy and the stereotypes they encounter, may strongly influence the experience and expression of pain' (*ibid* p. 55). This can be seen, for example, in the commonly-held (and heard) assumption that pain is inherent in the ageing process and therefore 'normal' and may result in underreporting of pain-related issues and underprescribing (or — in some cases — overprescribing of analgesics). Yet, one must be aware of the dangers of a sort of self-fulfilling prophecy, whereby the expectation of similarities in elderly patients' discourse on pain contributes to a homogenizing view of a group (the 'elderly') which instead is far from homogeneous and that such analysis should contribute to dispel, rather than confirm. Indeed, throughout her paper, Hellström Muhli appears to use the 'elderly' label unproblematically.

This limitation notwithstanding, the study is interesting and of value because it addresses the two-way nature of pain and — more generally — health communication: not only how it is communicated but also, importantly, how it is received. The importance of this factor is an issue that this thesis addresses in chapters four and five, by focussing on my informants' reports on how their communication about pain is received by lay individuals and medical professionals.

However, unlike Hellström Muhli's study, this thesis focuses more on the linguistic encoding of the pain experience through the lexicogrammar without resorting to the concept of communicative activity type (CAT). This is in part a result of the data for the present project having been collected through qualitative interviews rather than consisting of recorded interviews in health care settings, as well as — obviously — different research agendas. Hellström Muhli concludes (p. 61) that her informants make physical pain 'an issue about identity construction, social and relational suffering, and accountability.' In addition, she states (*ibid*) that '[p]ain-talk seems to be constitutive of ambiguities' and that 'a common feature [of pain-talk] is that identity is central in the accounts of pain.' Although, as noted, the present work differs from Hellström Muhli's for theoretical orientation and research questions and priorities, her findings about the ambiguity of pain-talk and the centrality of identity to it are common features which emerge from the analysis in the following chapters.

The study by Vickers et al. (2010) stems out of an ethnographic investigation conducted among Mexican female immigrants to the US. It concentrates on naturally-occurring narratives about experiences of the Mexican and American health systems as experienced by one of the informants. In this particular study, bodily pain is rather peripheral and is only one of the elements that engender narratives on the woman's encounter with two different, but equally disappointing — in their apparent inability or unwillingness to treat the cause of the woman's pain (i.e. a damaged knee) — healthcare systems. Vickers et al. use their analysis to argue, rather unsurprisingly, that individual experiences shape an individual's ideology of healthcare which, in the case they present, is negative. Narrative, in these researchers' view, is indexical of the larger cultural context that gave rise to it. Like most of the informants in the present study, Vickers et al's informant was prompted to seek medical advice following an injury that caused her to experience pain. However, pain *per se* is not the topic of this paper but rather the experience of healthcare. For the present research, the study's main interest lies in the fact that it addresses the complex issue of the patients' agency in making choices about their own healthcare. This issue will be addressed in chapter five of the present research.

1.2.7 Studies focussing on the lexicogrammatical encoding of pain

Of direct interest for this thesis (especially chapter three) are a number of studies by linguists.

Peters (2004) provides an analysis of the lexicon used to talk of the concept of pain in English, from a historical perspective. He offers an overview of the semantic changes involved in what could be broadly termed 'the vocabulary of pain'. His discussion is very interesting as a documentation of the 'genealogy' of pain-descriptors in one particular language. However, more important is Peters' acknowledgement of the relevance of the cultural context as a shaping force for pain-vocabulary. Language, thought, and culture exert mutual influence on each other. When it comes to pain, some concepts and construals come, so to speak, 'ready-made' and are adopted by speakers. However, culture, in its broadest sense, is also influenced and shaped by language, and so are speakers' cognitive processes (Deutscher, 2011; Malt and Wolff, 2010).

Starting from the point of view of cognitive semantics, Peters stresses the importance of metaphor and, crucially, metonymy in processes of semantic categorisation and change and utilises them to study the diachronic evolution of pain vocabulary in English. Although his analysis relates to English, some of his observations hold cross-linguistically. For example, he notes that the conceptualization of pain is threefold (p. 198):

- 1 The sensation of pain is a result or a corollary of certain processes. The relationship between these processes and pain is predominantly a *causal one* (my emphasis).

- 2 Pain is identified with a hostile agent, who causes the sensation. The causal relationship is still present; the process brought into being or the

action performed by the *agent* (see chapter five, below) is not made explicit.

3 The experience of pain is related to the 'container' metaphor.

Point two, in particular, can be clearly verified in the ALOMAR Plus corpus, where pain frequently is indeed identified, in many cases, with a hostile agent. As will be seen, pain is often identified with a weapon, an angry volitional entity, a burden and an oppressor; pain is also an agent that diminishes a person's abilities.

With regards to point three, the Italian speakers of the ALOMAR Plus corpus conceptualise pain as an entity that, although itself without precise boundaries, is a quantity that resides within the body which contains it. Pain is somehow also like a liquid: it can flood; it comes in waves; it surges and fills body and self (again, conceptualised as containers). And, finally, pain is a possession: it can be had, held, and given (in the sense of inflicted upon somebody); however, unlike ordinary possessions it cannot be disposed of at will.

One of the interesting observations that Peters makes is that, in present-day English, 'there is a tendency to disguise and play down pain' (p. 216). This can be seen in the rise of euphemisms like *discomfort*, *distress*, and *inconvenience*. This may be the result of cultural conditioning: one only admits to being in pain with reluctance, especially in a cultural context where even

the natural processes that are inherent in ageing, and that eventually result in death, are increasingly seen as undesirable, even illegitimate.

In the ALOMAR Plus corpus, Italian equivalents of such euphemisms are not found, although the tendency to minimise one's pain is clearly discernible but it is achieved more discursively than lexically. Given the limited size of the corpus, however, it is not possible to make claims as to the general trend in Italian.

Peters concludes his analysis by stressing the importance of taking into consideration the cultural contexts in which pain is spoken of. It is certainly true that different cultures, and different contexts within the same culture, allow the expression of pain to different degrees. Within particular age-groups, older individuals for example, talk about various physical problems, such as illness and pain, seems to be viewed as more legitimate. This type of talk is known as 'trouble-telling' (Coupland, Coupland, and Giles, 1991) and has been shown to serve a number of functions (Coupland et al. *ibid* and Poullos, 2008)

As noted in the introduction, it was Halliday (1988) who provided the first systematic account from the point of view of linguistics of the construal of pain by language. As I shall explain in more detail in chapter three — which contains a more detailed overview and discussion of his study — he provided a paradigm of English pain expression from the point of view of *transitivity*, as understood by SFG. After Scarry's work (1985), it was Halliday's paper that

provided much of the motivation behind the present research and a considerable portion of the theoretical orientation it adopts.

Halliday's work is important for several reasons, the first of which is that, as observed, it constitutes the first attempt to systematically study the linguistic encoding of pain from a lexicogrammatical point of view, thus including the grammar *and* the lexicon.

The language he analyses consists of an authentic - albeit, as noted limited - corpus of doctor-patient interactions. In his paper, Halliday shows how the 'cognitive' and meaning-making potential of language is utilised to construe the experientially complex experience which is pain. For Halliday (and, generally, for SFG) the grammar of a language is its 'semantic powerhouse' and a 'theory of experience'. It follows that, by paying attention to the way(s) in which language construes experience can shed light on both the way individuals and, potentially, cultures construe a particular domain of experience. This observation opens up the path (and invites) cross-linguistic studies, of which this thesis is part.

Directly inspired by Halliday is Hori (2006). Hori explores pain expressions in Japanese. Using a corpus of doctor-patient interactions, she analyses the encoding of pain in Japanese; like Halliday, she employs the notion of *transitivity* to shed light on how pain is encoded in the speech of her informants. She concludes that they conceptualise pain as residing 'in the

body of the speaker [...] invisible [to other people]' (p. 222) and, ultimately, inaccessible to them. Hory's study is particularly important in that it shows the applicability of Halliday's paradigm to a language such as Japanese which, typologically, is far removed from English.

Without referring to Halliday, Pugh (2005) discusses the language of pain in India, within the Hindi and Urdu traditions. In particular, she addresses metaphoric language and observes that '[e]veryday speech, popular mythology, village love songs, modern novels, and classical poetry in North India are replete with metaphors of pain' (p. 115). Her observation that Hindi and Urdu metaphors of pain draw heavily on 'familiar images from the realms of home, field, workshop, and weaponry, to describe pain's sensory qualities' (p. 115) sheds light on two already-noted facts. First, the importance of culture in understanding and encoding pain. Pain, as also Melzack and Wall (1996) imply, is experienced by the body and understood by the brain, which interprets it culturally. Pugh makes the important point that, for Indians, 'pain reflects the integrated mind-body system of Indian culture' (p. 118). The sharp, familiar western distinction between physical and psychological pain is, Pugh maintains, absent in Indian thought. Physical pain has psychological elements and psychological pain is embodied too.

Secondly, in noting the importance of metaphorical language in the encoding of the experience of pain in India, Pugh indirectly supports Gwyn's (2001) argument against Sontag's (1977, 1988) rather dismissive treatment of metaphorical language in speech about illness and pain. The use of metaphorical language is a testament to the resourcefulness of language in tackling complex issues and phenomena, rather testimony to its limitations. As

Lakoff and Johnson (1981) and Kövecses (2002, 2003, 2006) argue, metaphorical language is an important cognitive, as well as communicative, tool that facilitates and enhances both the understanding and the communication of the experience of complex phenomena such as pain.

Overlach's (2008) study is an investigation of 'the language of pain and of pain-talk' in German. Using a corpus of doctor-patient interactions involving chronic pain sufferers, the author takes a discourse analytical, grammatical, and semantic approach to highlight various aspects of the language of pain. Like Lascaratou (below) and Hori, Overlach takes inspiration from and expands on Halliday (1998), thus adding an important cross-linguistic dimension. In his work, Overlach includes etymological observations on pain lexis in German. This is particularly interesting because it opens up the possibility of studying the language of pain diachronically, as well as synchronically.

Similarly to Italian, modern German has two basic terms to refer to 'pain': *Schmerz* and *Weh* (*dolore* and *male* in Italian), which are an example of 'the primary terms' (Fabrega and Tyma, 1976) displayed by a language to refer to pain. The etymology of *Schmerz* is unclear, but may derive from an Indo-European root meaning 'to bite'. Its current meaning evolved through usages that mainly referred to (painful) damage of the skin to refer to bodily pain in general. *Weh* was originally an exclamation of lament which was found, from quite an early stage, in most dialects of German. The term has correspondences in many Indo-European languages: O.E. *wa*, Lat. *Væ*, Gr. *oa*, It. Spa. Port. *guai*. It survives in the English *woe*, where it is attested in the language as a noun from the interjection from the late 12c. In German, the

great diffusion of the interjection *weh!* has its origins in biblical translations from Greek and, ultimately, Hebrew. In its nominalised and often adverbial use, the term made the semantic transition from a more general sense of 'being unwell' to the more restricted one of bodily pain, in expressions such as *wehtun* 'to hurt'.

Broad in scope and depth of analysis are Lascaratou and Hatzidaki (2002), Lascaratou and Marmaridou (2005), culminating in Lascaratou (2007). The latter, a book-length study, is 'the outcome of a long-term, large-scale, data-based investigation of the linguistic manifestation of physical pain in Modern Greek' (p. 1). The study looks at the 'linguistic patterning (lexico-phraseological choices, grammatical structures, and linguistic metaphors) of pain. The study is both qualitative and quantitative. Aside from its application of Halliday's paradigm to yet another language, its importance resides in the size of the corpus, comprising 131 interactions 'between pain-suffering patients and health care professionals' (p. 1).

With regards to the way in which Greek speakers ordinarily construe pain, Lascaratou maintains that they mainly do so by construing it as a *process*, through verbs: *I hurt, I'm hurting (here), it hurts, my arm's hurting, that's hurting me*. As will be seen, chapter three of this thesis reaches a different conclusion with regards to an admittedly smaller corpus of Italian 'pain-talk'. Lascaratou interestingly argues that 'it is the degree of involvement of the sufferer's self in the painful experience which greatly determines the character of its lexico-grammatical construal' (*ibid* p. 184). Agreeing with Wierzbicka (1992), the Greek scholar claims that by framing emotions as verbs, speakers reflect their conceptualisation of such emotions as 'inner activities'.

Obviously, one cannot make overarching claims about the way a speaker, let alone a whole 'culture', conceptualises an experience or a phenomenon. However, I am of the opinion that as Halliday (1998) articulates, and both Lascaratou and the present research show, attention to linguistic data can reveal a great deal about how sufferers view and position themselves vis-à-vis their conditions and pain. Part of the importance of Lascaratou's work lies in the fact that it synthesises different perspectives: Halliday's Functional Grammar, semantics and elements of cognitive grammar. In addition, it pays attention to insights gained from philosophy, literary and cultural studies. More references and detailed discussions of points of Lascaratou's work will appear in chapter three.

Chapter 2: Methodology adopted in the thesis

This chapter will be concerned with methodological issues for the present research. To begin with, the nature and composition of the corpus — on which the subsequent analysis is based — will be addressed. The chapter will illustrate how the informants were selected and on what basis. It will also address the ethical considerations involved in the research. A biographical section will present personal information about the participants — including information about their medical condition — with a justification for the inclusion of such information and some field notes. The chapter will also address transcription conventions and further information on the overall theoretical framework of the present research.

2.1 The corpus

At an early stage of the planning for the research, the decision was made that the data would consist of spoken (rather than written) speech. A written corpus on the experience of living with pain and illness would have been easier to assemble, since — as noted — the genre that has become known as ‘pathography’ has been gaining increasing popularity since the 1980s and is now well established. According to Hunsaker-Hawkins (1999: 3), ‘[a]s a genre, pathography is remarkable in that it seems to have emerged *ex nihilo*.’ Hunsaker-Hawkins (*ibid* p. 3) notes that ‘book-length personal accounts of illness are uncommon before 1950 and rarely found before 1900.’ Several volumes are now in print and easily available, at least in English

From the beginning, however, the idea was to make use of spoken language for a number of reasons. First, spoken and written language differ in a number of ways, which have received attention from a number of scholars over the years (Tannen, ed., 1982, *inter alia*). As Chafe (1982: 45) points out, '[s]peakers and writers have different relations to their respective audiences.'

Both modes are interesting and worthy of study but here the intention was to focus on language which had undergone minimum pre-planning and was shaped at least in part by direct interaction with an interlocutor.

Secondly, the present research aims to be situated within the existing tradition of health communication studies that make use of spoken data. As noted, the research that, after Scarry's work (1985), provided the inspiration for the present study, namely Halliday's (1998), makes use of spoken data. Part of the aim in conducting this research was to further test and explore communication around illness and bodily pain by utilising a Halliday's analytical framework, with similar data but from a wider corpus (as the size of the corpus in Halliday's pain study is rather limited) in a language other than English.

The initial ambition was to collect a corpus of naturally-occurring talk. However, the definition of what exactly constitutes 'naturally-occurring' speech is not without problems. One interpretation is to think of naturally-occurring speech as any linguistic output that would have occurred without the researcher's intervention, for example by covert recording. What is meant here by 'covert' includes both recordings made without the informants being aware of it, i.e. surreptitiously, as well as recordings whose real purpose (but not their being conducted) is kept from the informants. Collecting data in this

fashion would have presented both practical and ethical problems⁸. This method was therefore discarded in favour of overtly recorded speech, through semi-structured interviews. (Bowern (2008: 122) refers to semi-structured interviews as ‘naturalistic’ data.) The aims of the research were clearly and openly stated to each interviewee, notwithstanding the possible consequences of what has come to be known as the ‘Observer’s Paradox’. The effects of the ‘paradox’, however, may have been overstated — at least in this researcher’s view. While it is true that there are cases where making an informant aware of the true purpose of an observation, or that an observation is taking place at all, may affect the type of talk produced (the use of particular phonological or lexical features, for example), it is far from obvious that making the presence of the observer and the purpose of the investigation known will have a *detrimental* effect. As Cameron (1992: 132) points out:

[C]overt recording simply produces a different kind of data, interesting for that reason but not intrinsically superior to utterances produced in researcher-informant dialogue.

Returning to the topic of naturally-occurring language, as Cameron (2001) explains, arguments as to what exactly constitutes ‘natural’ language or not do indeed raise ‘complicated issues’ (p. 20). It is certainly true that the type of communicative event (e.g. interview, rather than phone conversation) shapes, the kind of talk produced. Yet, as Cameron (*ibid*) argues, the manner in which

⁸ On both ethical and technical problems related to surreptitious recording, see Cameron (2001), Coates (1996), and Johnstone (2000).

talk is elicited, observed, and recorded becomes part of the situational context. As long as this factor is clearly acknowledged and kept in mind, there is no reason why this type of linguistic data should be any less 'natural' than so-called spontaneous or 'naturally-occurring' talk.

2.2 *The ALOMAR Plus corpus*

Having opted for spoken language, and given the aforementioned considerations, I decided that the appropriate way to proceed was to identify a group of speakers who had personal experience of living with chronic pain of various origins and who would be willing to take part in the present study.

Initially, the idea was to contact pain-clinics with the aim of recruiting informants from amongst their patients. One possibility was to ask for permission to record doctor-patient interactions (as in Halliday (1988) and Lascaratou, 2008, *inter alia*). However, the idea was discarded because of the difficulties in accessing and obtaining consent from the relevant regulatory authorities in Italy.

The second option was to identify and contact support groups for people suffering from chronic, painful conditions. This avenue proved more productive, as an initial internet search yielded several results, one of which was ALOMAR. ALOMAR is the acronym for *Associazione Lombarda Malati Reumatici*, (the Lombardy Association for People with Rheumatic Diseases). Founded in 1986, it is a voluntary entity run by and for people affected by rheumatic diseases. Its stated aims are⁹:

⁹ Adapted from: ALOMAR website, 'Associazione'. (Translation by the author.)

- To fill the institutional void by offering help and moral support;
- To assist patients by engaging in active volunteering in hospital wards;
- To organise information exchanges between patients and medical professionals;
- To organise and deliver courses to help affected people to better cope with their conditions.

Wider 'societal' aims include:

- Advocacy on behalf of sufferers;
- Raising awareness about rheumatic diseases amongst the wider public.

Initial contact was made with one of the volunteers and, subsequently, with Annamaria¹⁰, a woman with *Systemic Lupus Erythematosus* (henceforth: SLE) and at the time president of the association (see below for lengthier biographical information on this and the other informants, as well as notes on medical conditions).

Annamaria and I established contact via email and telephone; during these exchanges, I explained the aims of the research and asked if she would be

¹⁰ The names of all the informants have been changed to preserve anonymity.

willing to be interviewed. She agreed and informed me that she would ask other members of the group if they too would be willing to take part.

From the outset, one of the most pressing ethical concerns was not to mislead or cause further, unnecessary stress to people who, presumably, had already been enduring a number of difficulties. Therefore, I immediately disclosed that I was not a medical student and that the purpose of the research was humanistic, rather than scientific (in the common sense of the term). I also explained that it was to form the basis of my PhD thesis and its aims were in no way therapeutic. I did express the hope, however, that it might help in promoting a better appreciation of the implications of being affected by, and living with, a chronic, painful condition.

I first met Annamaria in person in January 2004 at the Milanese HQ of the association. The office is located within the main orthopaedic hospital in Milan. After enquiring further about the research project, she agreed to be interviewed. Having asked for permission to do so, I placed a tape recorder on the table between us. We talked undisturbed (except for one phone call) for about forty-five minutes, with nobody else present. The same procedure was followed with the other informants, whom I met on my second visit to the association a month later. The only two informants to be interviewed in other locations were Veronica, whom I met and interviewed on the hospital ward, and Fabio, who is not an ALOMAR member and whom I met and interviewed at his domicile (see below for further information).

All informants were clearly told about the possible uses of the data (for my thesis, journal articles and academic presentations) and of their right to withdraw consent, without providing any reasons, at any time between the

interviews and the publication of the first results. They were also informed that their names and any information that might identify them would be altered to retain anonymity. All participants were given the possibility of asking questions about the project, the reasons behind my interest, and my background. This was also done with the aim of fostering trust and building rapport.

The second round of interviews took place on a day when the members/volunteers¹¹ were holding one of their regular meetings; consequently, I was not alone with any of the interviewees and our conversations could be overheard. The fact that the volunteers had other business to attend to on that day meant that none of these interviews lasted as long as the first one, with Annamaria. Each of the interviews in the second group lasted between 15 to 30 minutes. The fact that the location afforded privacy only to a limited degree might have influenced the content of the interviews.

The corpus for the present research also contains an interview with a male individual who, not suffering from an autoimmune disease, was not a member of ALOMAR. During my sojourn in Italy to collect the aforementioned interviews, an acquaintance to whom I had mentioned the topic of my research informed me that he knew a man who had been a chronic-pain sufferer for a number of years. He asked if I would be interested in talking to him; on hearing my positive reply he put us in touch.

I met Fabio at his flat in Milan on 1 September 2004, where he lived alone. I informed him of the aims of the research and of the ethical safeguards; he

¹¹ All the ALOMAR members interviewed for the present research were also — at the time — volunteers for the association, with different degrees of involvement.

consented to being interviewed. The interview lasted around thirty-five minutes and, because of the comfortable setting, was friendly and relaxed.

Unlike ALOMAR members, Fabio does not have an autoimmune disease. He suffers from chronic back pain due to spinal problems (see section below for more detailed information). After some consideration, I decided to include his interview because, in view of his different pathology and gender, it might contribute to giving a broader view of the verbal representation of the experience of chronic pain by speakers of Italian. Ideally, the corpus would have contained an equal number of female and male informants, so as to allow some generalisations on gender-based differences in the encoding of the experience of chronic pain. The fact that this is not the case may be considered as a limitation of the present work. Throughout the present research the label 'ALOMAR Plus corpus' refers to all the interviews, including Fabio's.

Before approaching ALOMAR and being introduced to Fabio, I conducted a pilot interview with Antonio, a thirty-six year old male living in Milano. Antonio had been brought to my attention by a friend who believed he might be interested in taking part in the research. Although Antonio accepted to be interviewed and was informed of the aims of the research, during our meeting it emerged that — contrary to the information I had been given — he was not living with any painful, chronic condition. His main experience of pain was due to a minor accident years earlier. Although the interview was recorded and transcribed, it was not included in this thesis mainly because, unlike the other informants', Antonio's experience did relate to a distant, acute condition rather than a chronic one.

2.3 Biographical sketches of informants and field notes

As noted, I visited the ALOMAR offices twice in 2004. The medium-sized office consisted of a single room, sparsely furnished (a desk, a small table, some chairs and a couple of bookcases) within the perimeter of a large orthopaedic hospital in Milan with a specialised rheumatic unit. On my first visit, I was alone in the office with Annamaria (ALOMAR's president), whom I interviewed. On my second visit, on 24th February 2004, as well as Annamaria, four other women were present. Their reason for being there was to hold a periodic meeting to prepare the association's monthly newsletter. All agreed to be interviewed individually.

Following are brief biographical sketches of all the informants. All the information was obtained during the interviews, following specific questions or volunteered by the informants themselves. This information is given to better contextualise the experience of each participant in the study. Although biographical information is less relevant for the first of the analytical chapters (chapter three), it is more important for a fuller appreciation of the issues arising in chapters four and five. Included, is also some contextual information that might assist in giving readers a better understanding of the topics discussed, as well as the informants' perceived disposition towards the interview and the topics discussed. Information about age is precise only when the informant has openly mentioned it. In the other instances, it is estimated based on contextual and co-textual cues.

2.3.1 *Annamaria*

Annamaria, ALOMAR's president, is in her 50s and has SLE. She is married with children. She began experiencing symptoms in her twenties; at the time she was working full-time as a weaver in a textile factory. SLE has caused her a number of complications and forced her to leave paid employment. In receipt of incapacity benefits, she is now able to dedicate all of her energies to her family and to volunteering for the association, which she values enormously.

Annamaria presents as very resilient and full of energy. She does not want to succumb to the disease, although she is fully aware of its seriousness and has obviously suffered significantly because of it. Having been my first point of contact, she is eager to help and proves very helpful throughout the time I spend at ALOMAR and later, when I contact her by phone to clarify some points.

2.3.2 *Gina*

Gina is in her early fifties, married with children. She has RA. Typically, her hands are deformed by the disease.

During the interview, she looks tired and seems shy and reserved. Initially, she is not very talkative; she smiles but seems to be doing so to mask a degree of embarrassment. As the interview proceeds, she opens up more; she looks especially happy when she talks about her work as a volunteer, particularly with other patients. She is an active member of her local church.

She particularly enjoys sharing her experiences with members of the association and spreading knowledge about rheumatic diseases among the wider public.

2.3.3 Veronica

Veronica is fifty-eight and has been living with RA since she was a teenager. She is married with children. When she began experiencing symptoms, she was a professional athlete (a runner).

I met Veronica in the hospital ward of the same hospital where ALOMAR is based, recovering from her eighteenth operation to correct RA-related skeletal problems.

She tells me that she is not in severe pain during the interview but cannot turn her head to look at me, otherwise her neck would hurt. Notwithstanding the circumstances, Veronica appears serene, even cheerful, and definitely displays a positive attitude throughout the interview. She shows no signs of bitterness.

In the bed next to her, there is a woman who has had surgery very recently. She is in obvious pain and while talking to Veronica I cannot help noticing her. I feel rather awkward in the presence of someone in pain, especially because this is an unanticipated situation.

2.3.4 Sandra

Sandra is the youngest of the ALOMAR informants. She has SLE and was diagnosed when she was still a schoolgirl.

At the time of the interview, she is married and has no children. She is somewhat shy and states that she feels slightly apprehensive, since she has never been interviewed before. I reassure her. As the interview progresses, she opens up and shows a lot of interest for the research. She states that she is especially curious about possible differences in the expression of pain between Italy and the UK.

Sandra has suffered significantly, mainly because of the pharmacological therapies. Due to her condition, she had to leave full-time employment and now works part-time for the same company.

2.3.5 Marta

Marta is sixty-five and has RA. She is married and without children (she miscarried when she was young).

She presents across as well-adjusted but has obviously suffered because of her condition. To her, it is very important to fight the stigma that still attaches to RA. Throughout the interview she appears happy but it takes her some time to open up and mention her feelings.

2.3.6 Anna

In her 60s, Anna suffers from RA. She is married and has children. Of all the interviewees, she comes across as the most distressed. Pain is a particularly severe problem for her, and has been throughout her illness.

She admits to having experienced very low moments and depression. She finds comfort in her family but often finds it difficult to describe her pain and her suffering, especially to doctors. She is glad to belong to the association and finds solace in it.

2.3.7 Fabio

At the time of the interview, Fabio is in forty-one. He is single with no children. He has been suffering from SDH (see below for information about the condition) for a number of years.

Pharmacological treatments were ineffective; therefore he has had to undergo surgery. Physically very active, he went skiing not long after the operation; this meant that he did not heal properly and so the pain has returned.

Fabio tries to maintain a positive outlook and not to let the condition interfere with his life. Unfortunately, this is not always possible. A qualified nurse, he is very accurate in the descriptions of his symptoms. The interview took place in his flat.

A summary of the biographical information and place and length of the interviews is provided in Figure 2.1 below:

Pseudonym	Gender	Age	¹²Condition	Place of interview	Duration of Interview
Annamaria	Female	50s	SLE	ALOMAR HQ, Milano	49mins.
Gina	Female	50s	RA	ALOMAR HQ, Milano	26mins.
Sandra	Female	Late 20s	SLE	ALOMAR HQ, Milano	32mins.
Marta	Female	65	RA	ALOMAR HQ, Milano	28mins.
Anna	Female	60s	RA	ALOMAR HQ, Milano	25mins.
Veronica	Female	58	RA	Orthopaedic Surgical Ward, Milano	35mins.
Fabio	Male	41	SDE	Own flat, Milano	43mins.

Figure 2.1. ALOMAR Plus corpus.

2.4 Notes on the medical conditions mentioned in this thesis

This section is only intended to provide the reader with some general information on the medical conditions that afflict the people interviewed for this research.

2.4.1 Autoimmune diseases

All the women whose interviews are collected in the ALOMAR Plus corpus suffer from one of two autoimmune diseases. Such diseases are

¹² See section below for a brief description of these conditions.

characterised by 'altered function of the immune system of the body, resulting in the production of antibodies against the body's own cells' (Mosby, 2009: 171-172). Consequently, the immune system produces autoantibodies which attack healthy cells, causing localised and systemic reactions. 'These reactions can affect almost any cell or tissue and cause a variety of diseases. Most autoimmune diseases occur in women' (*ibid* p. 172).

2.4.2 Systemic Lupus Erythematosus (SLE)

SLE is a 'chronic inflammatory disease affecting many systems of the body' (*ibid* p. 1805). Its pathophysiological characteristics include 'severe vasculitis [a condition in which involves inflammation of the blood vessels], renal involvement, and lesions of the skin and nervous system' (*ibid* p. 1805).

SLE is more prevalent in women. People with SLE can experience fatigue (especially in the initial stages), weakness, weight-loss, photosensitivity, fever, skin lesions on the neck and alopecia. 'Depending on the organs involved, the patient also may have glomerulonephritis [a disease of the kidney characterised by inflammation of the small blood vessels known as *glomeruli*], pleurisy [an inflammation of the linings around the lungs], pericarditis [an inflammation of the *pericardium*, the sac which surrounds the heart], peritonitis [an inflammation of the *peritoneum*, the serous membrane that lines part of the abdominal cavity and viscera], neuritis [an inflammation of a nerve or part of the nervous system], or anemia [a condition in which your blood has

a lower than normal number of red blood cells]. Renal failure and severe neurologic abnormalities are among the most serious manifestations of the disease' (*ibid* p. 1805). In some cases, SLE can be fatal.

2.4.3 Rheumatoid Arthritis (RA)

RA is a 'chronic, inflammatory, destructive, and sometimes deforming disease that has an autoimmune component' (*ibid* p. 1624). Its characteristics are a 'symmetric inflammation of synovial membranes [the soft tissue found between the articular capsule (joint capsule) and the joint cavity of synovial joints] and increased synovial exudates, leading to thickening of the membranes and swelling of the joints' (*ibid* p. 1624).

Usually, RA appears between the ages of 36 and 50, mostly in women. 'The course of the disease is variable but is most frequently marked by alternating periods of remission and exacerbation' (*ibid* p. 1624). The disease can have different degrees of severity (I to IV), characterised by joint stiffness and deformity, muscle atrophy, soft tissue lesions, subcutaneous swelling, and definite bone and cartilage destruction. RA 'is not always progressive, deforming, or debilitating; most patients may continue in their jobs' (*ibid* p. 1624).

2.4.4 Spinal disc herniation (Prolapsus Disci Intervertebralis)

In common parlance, this condition is often (erroneously) referred to as 'slipped disc'. It is a condition affecting the spine. In it, a tear in the outer ring of an intervertebral disc lets the soft portion at the centre bulge out. The tear in the disc may cause the release of chemical material that can result in severe pain, even in the absence of root nerve compression.

Often SDH is not diagnosed immediately, since patients can present with symptoms in the legs, knees, feet, as well as back. Other symptoms can include numbness, tingling, paralysis, muscular weakness, paraesthesia, a sensation of tingling, burning, pricking, or numbness of a person's skin; reflexes can be affected too. When the condition does not heal itself, treatment consists of anti-inflammatory drugs and, as last option, surgery. Symptoms can reoccur.

2.5 Transcription and translation of the data and data-analysis

The methods used to transcribe spoken language can prove a thorny issue. Ochs (1999) has famously pointed out how apparently inconsequential choices in how to transcribe talk can have important consequences, for example by unwittingly providing an interpretative key. Several authors (Schiffrin, *op cit*; Hutchby and Wooffitt, 1998, Poland, 2001, *inter alia*) address transcription conventions and discuss some of the inherent problems in transcribing spoken discourse.

One of the first decisions to be made in any transcription is the level of detail to include. All transcription is conceptualisation and favours (even points to) certain interpretations over others. Even in ordinary written language, for example, punctuation guides, as well as aids, understanding. Typeface too, it can be argued, is not neutral.

In a transcript, what analysts include or exclude can be indicative of their focus and research interests (Whetherell, Taylor and Yates, 2001). Discourse analysts, conversational analysts, critical discourse analysts, dialectologists, and interactional sociolinguists – to name just a few – all use different conventions and levels of detail dictated by their research aims and theoretical orientations. Different methods highlight different interests and draw on different academic traditions. Conversation Analysis – for example – with its attention to the smallest details of spoken interaction has provided a template for the transcription of spoken language and the same can be said of Discourse Analysis. As Cameron points out (2001: 43):

There is no 'standard' way to transcribe talk. Analysts may use a variety of conventions for just about every aspect of transcription, including how they lay out talk on the page, how to present prosodic, paralinguistic and nonverbal features, and whether to use nonstandard spelling [...]. Since talk is varied, and is collected [...] for various purposes, it is no bad thing that there are choices about transcription [...].

Mishler (1986: 50) rightly points out that in transcribing interviews for analysis at least a minimum level of detail is necessary. However, how fine-grained this detail is obviously 'depends on the aims of the particular study and remains a matter of judgement.' The implications of different transcription methods, and

the 'risks' posed by favouring one method over another, are also pointed out by Riessman (2008). Riessman (*ibid*) also warns against the dangers of 'reifying' transcripts, although she underlies the importance of careful transcriptions. I have opted for a transcription method that does not attempt to reproduce in detail the flow of the spoken language. My questions and my informants' contributions are reproduced in paragraphs, in a way which is similar to the way interviews are reproduced in journalistic pieces. I use common punctuation but keep it to a minimum, in an effort to convey the sense of how the linguistic output was produced. This way of transcribing talk is common in sociological and (auto)biography studies, including in those on illness experiences (Radley, 1993; Ramanathan, 2010; McPherron Ramanathan, 2011). In works that discuss finer morphosyntactic issues, researchers often provide the original accompanied by a 'grammatical' gloss and a translation into the language of the target readership. For the present work, the decision was made to utilise only an English gloss. Extralinguistic clues, such as gesturing, and paralinguistic ones (such as stress, pauses, intonation) have been included only when they were deemed relevant to the point under discussion. The only conventions used in the transcriptions that appear in the following chapters that depart from common punctuation are the following:

[] contain relevant contextual information;

< > contain non verbal/paralinguistic utterances;

... indicates hesitation, often with lengthening of preceding syllable;

One of the first choices to be made in transcribing the data for the present project was the issue of language. All interviews were conducted in Italian. Clearly, when they were first transcribed Italian was used. Yet, a decision had to be made as to the language in which they should appear in the final version of the thesis. The primary concern was obviously intelligibility for the reader. The two available options were to reproduce the text in Italian accompanied by an English gloss (a broad translation) or to provide only an English translation. Both choices have advantages and disadvantages. Providing the original Italian, together with an English translation, allows the reader to better appreciate the full quality of the linguistic output, especially for readers with some knowledge of the source language. Furthermore, it can be more difficult to discuss discursive and lexicogrammatical points in the source text by providing only a translation. Other researchers, however, have done so. Tannen (1989, 2007) for example, - in her discourse analytical work - makes use of Greek conversational data by presenting it only in English, occasionally accompanied by a transliteration of the original. Riessman (2008: 42) rightly points out that '[c]onstructing a transcript from a translated interview involves difficult interpretative decisions.' This is true also when the interviews were translated, as they are here, by the researcher who conducted the interviews in the first instance and who is a native speaker of the source language. Although it can be argued that in this case the risks of misinterpretation are somewhat lower, they are not entirely absent.

An appendix containing the full transcripts, in raw data form, of all the interviews is to be found at the end of the thesis. The appendix includes both the Italian and English versions.

2.6 The interview format

The linguistic data presented in this work was gathered through semi-structured interviews. What is meant here by 'semi-structured' is that although some topics were on the agenda (e.g. beginning of the illness, type of symptoms, impact on daily life, among other things), there was no set of predefined questions to be submitted to the interviewees. Morse (2001: 324-325) refers to interviews such as this as 'unstructured'. 'The unstructured interview is a research strategy that permits the persons being interviewed to tell their stories at their own pace, in their own ways, and within their own time frames.'

The overall design of the research and, consequently, of the interviews can be rightly considered to be of a qualitative, rather than quantitative, nature. As Warren (2001: 85) notes, "[q]ualitative interviewing is a guided conversation [...] in which the researcher carefully listens 'so as to *hear the meaning*' of what is being conveyed' (emphasis in the original).

Yet, unlike casual conversation, the interview format does introduce elements of power-imbalance (Gubrium and Holstein, 2001), as the interviewer might come to be perceived as in a position of authority in view, for example, of his status as researcher. Unlike ordinary conversational partners, interviewer and interviewee bring different expectations to the communicative event: the right to the conversational floor, for instance, is unequally distributed, or there is an assumption that it will be so.

From a topic point of view, even in a semi-structured interview the selection of items to be discussed is often skewed in favour of the interviewer's interests;

the topics themselves are in large part a consequence of the questions asked and the stated aims of the interview¹³. As Warren (*op cit* p 3) says:

At first glance, the interview seems simple and self-evident [but this is not the case]. Questions elicit answers in more or less anticipatable format until the interviewer's agenda is completed and the interview ends. [...]. [The respondent] is usually well aware of the routine and waits until questions are posed before answering. [...] Respondents are relatively passive in their roles, which are delimited by the interviewer's coordinating activity and the available repository of answers. [...] This is the familiar asymmetrical relationship that we recognize as interviewing.

Notwithstanding these limitations, it was hoped that the resulting talk would be as 'natural' (in the sense of unconstrained) as possible. Precisely this attempt to obtain 'unconstrained' talk, as well as 'situational' circumstances, may account for the differences in the amount of language devoted to specific topics, such as pain, by different speakers in the corpus. Another factor in the amount of attention devoted to specific items may have been the topic's prominence in the speaker's mind at the time of the interview, as well as the quality of the rapport that developed between interviewer and interviewee. Such differences may also help to explain the different overall length in interview time among informants.

¹³ For an outline of the interview as a genre, see Platt, (*op cit* pp. 33-54).

2.7 The challenges of interviewing the ill

No interaction (verbal or otherwise) is without challenges. Interviewing the ill, however, poses unique problems. Although primarily referring to those afflicted by acute conditions, Morse's observations (*op cit* p. 318) on interviewing the ill are worth quoting in full:

The [...] ill are frequently silenced by their disease or injury and muted by their treatments, and can be in shock or severe pain. The rapidity of the physical and/or mental changes they experience places them in an unfamiliar and often frightening environment – frightening because of the intensity of pain [...] and the threat to life and self-integrity.

However, as the same author (*ibid* p. 320-321) points out, in the case of the chronically ill an interview may be less problematic. Yet, this is by no means without challenges.

For example, as noted, in the case of the present research, one of the informants — Veronica — was in a hospital bed recovering from surgery when the interview took place. Her discomfort was obvious. Another informant — Anna — was still clearly distressed by her experience of pain, although at the time of the interview she reported feeling relatively fine and pain-free.

One should also remember that the onset of chronic illness can be a long, overdrawn process. Time gives the chronically ill the opportunity to develop a degree of familiarity with their conditions and, in some cases, a modicum of detachment. This is apparent in most of the interviews collected here.

Often, the chronically ill have 'rehearsed' the interview in numerous encounters with medical professionals, family-members and friends. This

accounts for the depth of detail and ‘structure’ which is often found in narratives of chronic illness.

Telling one’s illness may even be seen as therapeutic and may contribute to reconstituting one’s sense of self (Morse, op cit; Myers, 2010; Frank 1995). This does not mean, however, that a chronically-ill individual may not be experiencing, at or around the time of the interview, a relapse or may be undergoing painful treatment. As stated, this is precisely what happened when I interviewed Veronica (see below). Unexpectedly, I was led to her hospital bed where she was recovering from surgery performed on her the previous day. In the bed next to her was another woman, also recovering from surgery. This unforeseen situation certainly influenced both the content and length of the interview, as well as my psychological response.

2.8 Theoretical and methodological orientation of the present research

As mentioned in the introduction, the overall aim of this thesis is to investigate the linguistic encoding of the experience of chronic illness and—in particular—of its attendant bodily pain. It stems from a longstanding interest in spoken language and interaction and its outlook owes much to sociolinguistics, discourse and narrative analysis, and to functional approaches to language studies, particularly Systemic Functional Grammar. For this reason, the analytical approach taken may be described as ‘eclectic’, drawing on different traditions and methodologies.

Chapters four and especially five, for example, are clearly more indebted to narrative approaches to language, although not in the stricter, sociolinguistic Labovian sense but rather in the broader tradition familiar to the social

sciences which today — as Kohler Riessman (2008: 14) points out — ‘is a veritable garden of cross-disciplinary hybrids.’ In her edited introduction to qualitative methodologies in health and social care research, Rapport (2004: 5-6) includes in the list of narrative-based methodologies in health research discourse analysis, personal narrative, and socio-linguistic analysis. The latter is not the same as *sociolinguistics*, but it shares similarities with it in its emphasis on the social and the linguistic elements of narrated experience.

This research is ‘exploratory’ in the sense that although it was begun with — and animated by — some overarching questions (e.g. “how do speakers encode the experience of bodily pain and chronic illness through the lexicogrammar of Italian?”), it does not set out — from the outset — to ‘test’, ‘prove’ or ‘disprove’ any particular assumptions; it is data-driven. This, obviously, does not mean that there were no assumptions at all when the project started. For example, as noted one of the expectations was that — overall — my informants would evaluate their diseases and concomitant bodily pain mainly negatively. Perhaps the main sense in which this work is ‘exploratory’ is in that it does not set out to proceed on a definite course and is open to new discoveries, some of which – on further analysis – might certainly be interpreted differently. However, paraphrasing Tannen (2007: 6-7), it can be said that to claim that a work is not monolithic is not ‘to exempt individual works (or individuals’ work) having and having to make clear theoretical, methodological, and, when appropriate, empirical frameworks.’

As noted, the view of language in which this thesis is grounded is a functional one. More specifically, I share many of the assumptions put forward by Halliday and his followers, in what is known as SFG. It is not possible to fully

synthesise SFG's theoretical assumptions here. Suffice to say that, according to SFG, human language is a complex tool that developed to allow communication and human interaction. One of Halliday's most insightful intuitions is that language operates simultaneously on more than one level. Specifically, he identifies three 'metafunctions' of language: the *ideational*, the *relational*, and the *textual*. The *textual* metafunction deals with how the message (text) is organised, how it is presented; the *ideational* metafunction with how language, through grammar and the lexicon (the lexicogrammar) construes experience. Grammar, therefore, is 'a theory of experience' (Halliday, 1988). Finally, the *relational* metafunction identifies the task of building and maintaining relations and, through it, language continually operates to position speaker (or writer) and hearer (or reader) vis-à-vis each other. With these functions in mind (consciously or subconsciously), each locutor continually makes choices (in SFG, systems entail the possibility of making choices, hence the "systemic" in SFG) whenever she or he uses language. Various researchers have made use of insights derived from SFG to pursue their particular interests within their different approaches to the study of language. In the present work, especially chapters three and four, this orientation will appear clearly.

The 'social' nature of this research lies in the fact that it is preoccupied with language in a specific social context and — like traditional sociolinguistic work — relates language form to extralinguistic factors. As noted, the research is also indebted to discourse studies in that its object is wide in scope; not only the individual lexeme or phoneme but 'language beyond the sentence'. Or 'simply *language* – as it occurs' (Tannen, 2007; emphasis in the original).

In chapter four, which—as noted earlier—deals with evaluation in the language of the ALOMAR Plus informants, the analytical framework will shift from general SFG grammatical theory to the particular framework known as Appraisal Theory (AT). For reasons of relevance, chapters three and four will include more detailed discussions of the theoretical frameworks (SFG and AT respectively) as well as of the relevant literature within which each section is situated.

This research is also indebted (and should be seen as a contribution) to the field known as *Medical Humanities*. Again, it is not possible here to go into detail as to what specifically researchers in this field are interested in¹⁴. Suffice to say that this burgeoning discipline aims to be the interface between biomedicine and the insights into the human experience as traditionally understood by the humanities. Several scholars (e.g. Kleinmann *op cit*), many of whom are qualified doctors, have contributed immensely to our understanding of what it means to be ill and in pain, and to the role of language in this experience. The heterogeneity of approaches and insights used for this thesis is perhaps less suited to providing certainties but it nonetheless offers the possibility of gaining new insights when employed.

A research on the experience of pain and illness that claims to be grounded in linguistics cannot ignore the fact that words *mean* in more than one way. From early work on denotation and connotation to more recent studies in fields such as sociology (Bourdieu, 1992) linguistics (Irigaray, 2002), Critical Discourse

¹⁴ For more details see, among others, Evans and Finlay, 2001 and Evans et al. eds. 2008.

Analysis (Fairclough, 1995) and performativity (Butler, 1999)¹⁵, research has shown that, to use Irigaray's (*op cit*) phrase, language is never neutral. Any terminology carries a number of overt and covert meanings; it offers, often imposes, interpretative keys which can be biased in a number of ways. In the case of this thesis, the problem became apparent shortly after the writing up process had begun. How, for example, ought the individuals who took part in the research, giving their consent to being interviewed, be referred to?

In sociolinguistic and sociological studies, such individuals are variously referred to as 'subjects', 'informants', 'participants' or, in sociolinguistics, simply 'speakers'. These commonly-used labels offer advantages, such as the possibility of protecting people's identities. With their anodyne, supposedly neutral sound/tone, they also contribute to claims of objectivity, scientific precision and detachment, something that the social-sciences appear to envy the so-called 'hard-sciences', such as biology, chemistry, and physics¹⁶. Such supposed detachment, however, comes at a cost: depersonalisation. One thing that became obvious during this research was the intensely personal nature of the experiences collected. Pain may be invisible and intangible, but it is always experienced by someone: a woman or a man with a unique biological and psychological make-up, a unique history. Pain is always embodied and, crucially, personal (see Heshusius, 2009). Other terms

¹⁵ Obviously, this is not meant to be a full list of works on language as a tool for 'creating' reality, rather than merely 'reproducing' it. It should also be noted all of the scholars cited agree with each other's views. For example, on Butler's and Fairclough's criticism of Bourdieu's approach to language, see Myles (2010).

¹⁶ As Halliday (in Webster, ed. 2003: 199) points out, 'those who study language have often been concerned with the status of linguistics as a science [...] us[ing] other, earlier developed sciences as a model.'

employed in the literature, especially discourse studies on medical language, or works from the medical humanities, include *sufferer*, and the obvious *patient*. They too are unsatisfactory. The former, 'sufferer', provides an interpretative key: the person as 'victim'; the latter medicalises the individual and assigns a role that may be far from the truth and this is true whether one concentrates on the etymological sense of the word or on the current meaning of 'someone in the care of a medical institution or professional.' Like the terms mentioned earlier, these too depersonalise the individual. In addition, they can be seen and perceived as patronising and can perpetuate stereotypes often seen as demeaning and disempowering. The fact that words applied to certain groups of people or employed by certain communities of practice is at least problematic has been noted by linguists but the point has been made particularly forcefully by authors involved in social work (Thompson, 2001) and in advocacy (Morris, 1991). As Thompson writes (*op cit* p. 31) 'what is needed is not a simple list of proscribed words but, rather, an awareness of, and sensitivity to, the oppressive and discriminatory power of language.'

Therefore, in light of the above, choosing how to refer to the women and the one man who accepted to take part in the research has been challenging. I have opted for a mixed approach: in many cases, in what follows, I shall be referring to the individuals whose language is the topic of the present work by their first names (albeit modified, to protect anonymity). I shall also be using terms such as *patient*, *informant*, *subject*, *speaker*, and *sufferer* as more or less synonymous. This represents, in my view, a less than satisfactory choice and I am aware of the problems it entails.

2.9 Some brief remarks on authorial stance in this thesis

Academic writing, like the research it follows from, is socially and historically situated; it has an *I* (the author or authors), a *you* (the readership), and an *it*, or a *them*, the topic and subjects of investigation. Yet, it is often the case that the practice of academic writing seems to imply that these three entities do not interact or influence each other, or do so only minimally.

This is reflected in authorial practices, often enforced prescriptively, such as the avoidance of first-person pronouns (*I, me, my, mine*), and the use of agentless constructions (e.g. *the research was conducted ...*). Impersonality is often taken to represent a *sine-qua-non* for the achievement of the necessary detachment and academic rigour, as if the latter necessarily implied the former, and if the former automatically excluded the latter. With customary acumen, philosopher, psychoanalyst, and linguist Irigaray (2002: 1-2) is particularly forceful in her critique of the language of scientific and academic research. Referring to her own experience as an academic researcher and writer, she says:

I felt irritated and amused by the language of science [...] the reality of scientific requirements, those norms or criteria of a so-called rigorous process. I stand before them as if I had to answer to them, to submit to being judged. A kind of tribunal of discourse [...]. This idealism, and its ideological consequences, require the ascendancy, or the authority, of a sentence or formula of the type: *one says that x is equal to, greater than, or less than y*. That is nothing more than an encoding of the world from which subjectivity is removed, and which is subordinated, under cover of the universal, to one single subject, or to several subjects. No feelings apparently ... A language

divested of all *pathos*, absolutely neutral and detached [...]. [*S*]cience does not say 'I,' or 'you,' or 'we.' (my emphasis)

As I embarked on this research-project, I operated with many of the same assumptions¹⁷. However, the more I interacted with the people whose stories this research aims to present and analyse, the more I read and thought about their words, the clearer it became that impersonality, let alone detachment, were neither truly possible nor, in my view, desirable. Cameron et al. (*op cit* p. 5) reflect on the myth of impersonality with lucid words that deserve quoting in full:

[T]he subjectivity of the observer should not be seen as a regrettable disturbance but as one element [...]. Similarly, research subjects themselves are active and reflexive beings who have insights into their situations and experiences. *They cannot be observed as if they were asteroids, inanimate lumps of matter: they have to be interacted with* (my emphasis).

Therefore, I made the stylistic and intellectual choice of not shunning the personal in what follows, hence the presence of first-personal pronouns alongside generic ones; agentive as well agentless constructions. The hope is that this will be seen as a sign of intellectual openness and ownership, rather than of an inflated ego; of involvement coexisting with rigour. In the words of Ivanič (1998) who has written on issues of identity in academic writing:

¹⁷ "The foundation for academia is what could be termed 'proper science' [...]. As students, researchers and professionals, we are the products of a long process of socialization into academic life, often heavily reliant on the value of science and objectivity above all else" (Dickson-Swift et al., 2008: 82). Bourdieu (1988) refers to the professional socialisation of academics as the 'habitus'. This habitus relies heavily on a set of linguistic practices, including (but not limited to) the ones mentioned here.

Who am I as I write this book? I am not a neutral, objective scribe conveying the objective results of my research impersonally in my writing. I am bringing to it a variety of commitments based on my interests, values and beliefs which are built on my own history (p. 1).

Chapter 3: The lexicogrammatical construal of pain in the *Alomar Plus* corpus: a Systemic Functional Grammar perspective

The aim of this present chapter is to investigate the ways in which my informants construe — thorough the lexicogrammar of Italian — the experience of bodily pain. It should be pointed out that, in *Systemic Functional Grammar* (see below), the term *lexicogrammar* refers to the level of wording; it comprises both syntax and vocabulary. For *Systemic Functional Grammar* (SFG), 'grammar and vocabulary are not two separate components of a language – they are just two ends of a single continuum' (Halliday and Matthiesen, 2004: 7).

More specifically, the aim of this chapter is to offer an inventory of the lexicogrammatical resources through which pain is encoded and communicated by my informants through the lexicogrammar of Italian. At the same time, my intention is to comment on such tools and to offer insights on how they contribute to giving embodiment, in a linguistic sense, to this most unique of human experiences. Fundamental underlying questions of this chapter on the construal of pain in the corpus will be:

What type of element is pain? Is it process, participant, or circumstance? Is it a quality of something? If participant, or quality, is it construed circumstantially? Does it involve the relationship between one process of configuration and another? And, in terms of any of these elements, is it simple or complex? And is it consistently construed in one way, or does it vary among different modes of construal? In other words, where does pain fit into the configuration of everyday experience?

The chapter also aims to extend Halliday's (1988) findings regarding the lexicogrammatical construal of bodily pain in English by applying the same analytical tools to a larger corpus of transcribed spoken data and to a language other than English. As previously noted, the investigation of the linguistic encoding of pain in languages other than English through SFG has been undertaken for Greek by Lascaratou and Hatzidaki (2000), Lascaratou (2003; 2007), for Japanese by Hori (2006), and for German by Overlach (2008). Where appropriate, elements of such works will be referred to and commented upon here.

As pointed out in the introduction, this thesis as a whole and this section in particular can be understood as a further expansion of the investigation of this particular domain of experience using Halliday's paradigm. As Lascaratou (2007) rightly points out, this domain of experience (bodily pain) is still underexplored by linguists.

The use of SFG for the analysis of health communication is not new (as the above references indicate); and not limited to speech about the experience of bodily pain. This analytical paradigm has been used, for example, to investigate the speech of individuals with mental health issues. In his work, Fine (2006) adopted SFG to instruct mental health professionals in the identification of 'deviant' speech, which might be indexical of a number of disorders, such as schizophrenia, psychosis, and mood disorders such as depression. In the introduction to his study, Fine points out that speakers affected by psychiatric disorders may show them only through the language they use. He therefore argues that 'a functional [i.e. relating to how, through language, they *mean*] study of [their] language is not the study of a side

phenomenon or an epiphenomenon' (p. 5). Instead, it is a central tool in 'seeing' what might amount to an anomaly or a serious condition. Although the topic of this thesis present research is not psychiatric disorders but the experience of pain, there is similarity. As I shall argue later, for people who experience bodily pain — whose cause often takes a long time to be diagnosed and in some cases is never satisfactorily diagnosed — language is often the first, and at times the only, indicator of distress. However, as Fine (*ibid* p 7) points out, it is not only pathological conditions that language is indexical of. It 'is also sensitive to disruptions in other areas of functioning — such as shyness — and is indexical of them too.

3.1 *A brief overview of SFG*

Before proceeding to the analysis, it is appropriate to provide a brief overview of some aspects of the theoretical framework which, for the most part, informs it: *Systemic Functional Grammar*¹⁸. Particular attention will be paid to the notion of *transitivity*, as understood by SFG, and its relevance to our comprehension of the construal of real-life events through the grammar.

3.1.1 *Grammar as theory of human experience*

As previously noted, according to Halliday (1998: 2) the grammar of a natural language is a 'theory of human experience, and it is a powerful theory in that it

¹⁸ It should be noted that although the theoretical framework known as Systemic Functional Grammar has its origins in the work of M.A.K Halliday, it is now practised widely and numerous researchers (many of whom are quoted here) have been making important contributions to the paradigm.

covers every aspect of that experience both real and imaginary.’ Through language, experience is filtered and construed and a certain ‘order’ is assigned to it.

Referring specifically to the clause, Halliday and Matthiesen, (2004: 170), argue that it ‘is also a mode of reflection, of imposing order on the endless variation and flow of events.’ Indeed, in SFG, the clause is understood as a basic grammatical unit. As will be seen in more detail later, in a clause, participants, processes, and attendant circumstances are organised together. Within the clause, the central feature is the presence of a finite verb, which expresses the main process. For, SFG ‘processes’, or ‘going ons’, are what speakers consider reality to mainly consist of, rather than merely entities. Thus the clause (and — at a wider level — the grammar) is a ‘theory’ in the sense that through it we describe, order, and make sense of what surrounds us. Halliday and Matthiesen (*ibid* p. 24) argue that ‘we use language to make sense of our experience.’ Within the lexicogrammar, grammar – as Butt, Lukin and Matthiesen observe (2004: 270), the grammar has a remarkable power, because it lies and functions below the speaker’s conscious awareness; which leads them to talk of grammar as ‘covert operation.’

Therefore, it could be said that this chapter aims to ‘uncover’ such operation; to make explicit *what* the grammar does; how it construes a particular domain of experience – and through which linguistic means. It is, in other words, an exercise in ‘metagrammar’ or – to use Halliday’s term (2002: 373) – ‘grammatics’, in order to ‘reflect consciously’ on how the grammar of a specific natural language (Italian, in this case) helps us to grasp a certain area of our lived experience. As pointed out earlier, by scrutinising the grammar the hope

is also to shed light on how a particular group of speakers understand pain, both as an 'entity' and as an experience.

Presumably, bodily pain has been part of the human experience from the earliest times. This, together with its complexity in terms of the sensory experiences it consists of, is bound to be reflected in the lexicogrammar of natural languages. Bearing in mind the cautionary words on the limitations of working with a relatively small corpus (see chapter 2 on methodology and corpus design), it is tempting to say that an analysis of the grammar of pain can help us understand how not only individuals, but also particular cultures understand it.

Various researchers (e.g. Melzack, 1973; Cohen 2010; Rey 1995, *inter alia*) have noted that the experience of pain is very much a cultural product. Its role, value, and more generally the understanding of it vary across time and cultures. Paraphrasing Lascaratou (2003), at some point it might well be worth investigating not only what pain is for language, but also what language is (and does) to pain; how language, in other words, shapes the reality it tries to capture.

3.1.2 How language construes experience: the SFG perspective

Language construes human experience in multiple ways. At the most basic level, and arguably the most noticeable one, it categorises it by naming entities in the real and mental worlds. These are – broadly speaking - the entities (concrete and abstract; visible and invisible; real or imaginary) that we

perceive or believe to exist (Halliday and Matthiesen, 2004). However, Wolff and Malt (2010: 3) rightly point out that ‘although language may be crucial to human cognition, the basic units of cognition are clearly not words.’ They note that ‘people can have thoughts that are difficult to express’ and highlight the fact that logical — as well as other types — arguments indicate that ‘there must be a medium of thought that is independent of language.’ Nonetheless, language is still a potent tool for the formulation of thought (in its broadest sense) and for organising it. It is not only ‘things’, like *house*, *river*, or *pain* that are classified by language but also ‘happenings’, like *walk*, *cut*, and *hurt*. This, of course, is what lies at the base of the distinction between categories such as *nouns* and *verbs*, which has been familiar to grammarians since ancient times (Robins, 1997).

Grammar simplifies reality, by making it more manageable and, arguably, less threatening. Some aspects of it are picked up and focussed upon at the expense of others. Yet, the grammar of a natural language also allows for complexity. It recognises that ‘human experience is too complex, and has too many parameters to be construed from any angle alone’ (Halliday, 2002: 374). Alternative views, at times conflicting ones, coexist in the grammar. This leads Halliday (*ibid* p. 374) to note that *concurrence* and *complementarity* are the salient characteristics of the ‘grammar of daily life.’

As I shall show in more detail in the following sections, a relevant example of this fact is that in the grammars of languages like (among others) Italian, English, and Greek, pain is construed at times as a *thing*, at times as an *event*, and at times as a *quality*, and realised respectively as a noun, a verb,

and an adjectivally. Furthermore, and more importantly, Halliday and Matthiessen (2004: 29) point out that:

These elements are configured into complex grammatical patterns [...]; the figures can be built up into sequences related by time, cause and the like - there is no facet of human experience which cannot be transformed into meaning. In other words, language provides a **theory** of human experience, and certain of the resources of the lexicogrammar of every language are dedicated to that function (emphasis in the original).

Crucially, it is not only what happens 'out there', in the physical world, that language can construe and provide representations of. As previously mentioned, language is just as good at construing what happens 'in here', inside the speaker's mind and – more relevantly for what we are dealing with - within his or her body, below the skin surface. As pointed out by Fine (2006), effectively, what remains invisible to the eye is often apprehended by language.

3.1.3 *Ways to mean*

The 'representational' function of language is known in SFG as the 'ideational', one of the three¹⁹ 'metafunctions' of language. It is one of the three kinds of meanings that language encodes. The two other functions are the *interpersonal* and the *textual*.

¹⁹ Thompson (2004: 30) recognizes that other theoreticians have suggested other functions, such as 'expressive'.

The interpersonal function relates to language as an exchange. Through it, the interaction and negotiation of meaning between speakers is constructed and negotiated. In essence, interpersonal meaning expresses how the speaker relates to the ideational meaning of an utterance, for instance by considering it a question, a request, or a demand. Through it, we try to influence and change other people's behaviour, we express our opinions about what goes on in the world and attempt to influence and modify those of other people. More generally, language is a favourite tool for establishing and maintaining relationships with our fellow human beings.

Textual meaning relates to the organisation of the message. Fine (2006: 26) observes that 'textual meaning is the meaning created when fitting an utterance into its context.' It emerges in the choices a speaker makes in how to convey ideational and interpersonal meaning.

In SFG, these three categories are used, in the words of Thompson (2000: 30):

[A]s the basis for exploring how meanings are created and understood, because they allow the matching of particular types of functions with particular types of wording to an extent that other categories do not

These are, of course, broad functions and this is why they are referred to as *metafunctions* (Thompson, 2004). Furthermore, according to Halliday and Matthiesen (2004: 30-31) the term *metafunction* is adopted in SFG to highlight the fact that what is being talked about is not merely the 'purpose or way of using language'; using the term *metafunction* 'suggest that function [is] an integral component within the overall theory.' Coffin, Donohue, and North

(2009) observe that an approach to language such as SFG — which is *communicative* in nature — is particularly interested in linguistic *forms* in relation to which purposes they are used for.

3.1.4 *The ideational metafunction and the construal of pain*

As Thompson (2004: 86-87) points out, language, at its simplest level, ‘reflects our view that the world consists of ‘goings-on’; these involve *things*, which in turn may have attributes and ‘go against background details of place, time, manner, etc.’. Such understanding is encapsulated, as stated above, by the *ideational metafunction* of language. As mentioned, in the grammar, this understanding is reflected in the fact that clauses – the fundamental units of meaning – consist of at least one main verb and of one or more participants (these ‘things’ can be material, but do not have to be), usually ‘realised’ (or ‘actualised’) by nouns and noun-groups. ‘Things’ may also have attributes, normally realised by adjectives. In addition, the background details of time, place manner, and so on, are normally realised by adverbials, or adverbial groups. However, as Fine (2006: 40-41) points out, the elements that are combined in the grammar ‘are not things, events or circumstances directly, but rather the linguistic expression of them.’ Things are expressed in terms of linguistic categories labelled ‘participants’. Based on the meanings they encode, some of the most important types of participants are: *Actor*²⁰, *Goal*, *Senser*, and *Phenomenon*, of which more will be said later.

²⁰ In SFG, it is customary for participants to be capitalised. This convention will be adopted throughout the present work.

The construal of the experience of bodily pain through the ideational metafunction will be the main topic of this present chapter. Thus, what I shall be dealing with here are the ways in which my informants construe both their pain and the experience of having and being in pain through the grammar, in particular that of the clause.

If, as McCaffery (1972) puts it, 'pain is whatever the experiencing person says it is, existing whenever he says it does', then the relevance of a close scrutiny of the grammar of pain in the clause becomes obvious. It is tempting to go so far as to say that linguistic analysis is probably one of the most accurate tools for finding out what pain truly is for an individual.

3.1.5 *Transitivity*

Within the *ideational* metafunction, the system that embodies the nature of reality as consisting of 'goings-on' is that of *transitivity*.

Transitivity, in SFG, has a broader sense than the one it has in traditional grammar. Although in the SFG understanding of transitivity the focus is maintained on the main verbal group in the clause, 'it refers to a system for describing the whole clause, rather than just the verb and its object' (Thompson, *op. cit.*, pp. 88-9). It is the type of process expressed by the main verbal group, in fact, that determines to a large extent how the participants are labelled. According to Halliday and Matthiesen (2004: 170), the transitivity system:

[C]onstrues the world of experience into a manageable set of **PROCESS TYPES**. Each process type provides its own model or schema for construing a

particular domain of experience as a figure of a particular kind (emphasis in the original).

What is important to bear in mind is that the way a particular event, situation, or happening is construed, is only *one possible option among many*. The grammar – and (albeit unconsciously) - through it, the speaker(s) – has ‘chosen’ to construe it in a particular way, thus interpreting reality, favouring and perpetrating a particular world-view. The sum of these grammatically construed (and constituted) world-views constitutes ‘ideology’. Ideology, as argued by Butt et al (2004: 27):

is a function of the fact that we can construct multiple versions of the ‘same’ physical, biological, social and semiotic events.

3.1.6 Processes and the clause

As noted, in SFG, the clause is seen as the basic unit of grammar. This is ‘because it is at this rank that we can begin to talk about how things exist, how things happen and how people feel [...]’. It is also at the rank of the clause that we usually use language to interact with others²¹ (Bloor and Bloor, 2004:8).

Clearly, not all processes (or happenings) are of the same type. It is indisputable that, although *hitting* and *thinking* are both types of happenings, they also differ in some fundamental ways. The former is a more stereotypically ‘material’ process. It entails someone or something *materially*

²¹ Other researchers, for example Chaika (2000) who is not — however — a systemic functional grammarian, consider the phrase to be the fundamental unit of grammar.

doing something to something or somebody else. *Thinking*, however, can still be seen as a kind of 'action', but in a more abstract or 'private' way. The process, in other words, happens entirely inside the speaker's mind and is a product and a manifestation of his or her consciousness. This is not to say, of course, that the act of thinking cannot present some outward manifestations (body language that indexical of it, for instance) or that a physical act, realised linguistically by a verb indicating a 'material' act, like *hitting*, does not involve or follows from some act of mental activity.

3.1.7 Types of process identified by SFG

The main types of process identified by SFG theory are: *material*, *mental*, and *relational*. These are not the only types of process and a full list can be found in Halliday and Matthiesen (2004) and Thompson (2004). However, these three process types are responsible for the linguistic encoding of the majority of events.

The criteria for recognising a particular 'going-on' as typifying a certain process are based, according to Thompson (*ibid* p. 79), on 'a combination of common sense and grammar: common sense to distinguish the different kinds of 'goings-on' [...], and grammar to confirm that these intuitive differences are reflected in the language and thus to justify the decision to set up a separate category.' In the following section, I shall give a synopsis of each of these processes and of the participants that are typically involved in each process.

3.1.8 Material processes

These are processes of 'doing', and involve physical actions, such as: *writing*, *binding*, *hitting*. These processes mainly express the experience of the world existing outside of the individual. In this type of process, there is most clearly a 'doer', which is given the label *Actor*. In the clause, the Actor can be mentioned explicitly or omitted. When the action of a material process involves two participants, the 'done-to' is labelled *Goal* 'since the action is, in a sense, directed at this participant' (Thompson, 2004: 90). Halliday and Matthiesen (2004) note that another term sometimes used in other traditions for this function is *patient*, 'meaning the one that "suffers" or "undergoes" the process.' (p. 181). The two scholars comment that, in reality, neither of the two terms is completely adequate, the relevant concept being more like that of 'one to which the process is extended.' As Fine (2006: 40) notes, 'some of these material are rather abstract but nevertheless express happenings in the world (e.g. 'They were *absolved* of all wrong-doing'; emphasis in the original). Interestingly, from a pragmatics point of view, *to absolve*, for example in reporting on the decision taken by a court of justice, would be an example of a speech-act: a verbal action which effectively alters a state of affairs in the real world.

In a material process, the *Actor* may be human and the *Goal* inanimate, but this need not be the case. It is perfectly possible, and indeed quite common, to have an inanimate or abstract *Actor* and a human *Goal*. Figure 3.1 shows some examples of this, the first of which is taken from the ALOMAR Plus corpus:

Participant 1 Actor	Process	Participant 2 Goal	Circumstance
The coach	hit	me	beneath my foot [the sole of my foot]
The rock	hit	her leg	
The fear	paralysed	the crowd	

Figure 3.1. Material processes.

3.1.9 Mental processes

Clearly, not all verbs can be easily described as ‘verbs of doing’. It follows that the labels of *Actor* and *Goal* given to the participants in a clause where such is the case are not really appropriate. Verbs that refer to happenings going on in the speaker’s mind, such as *liking, agreeing, seeing, hearing, thinking*, intuitively belong to a separate semantic category. They relate to the individual’s inner world and include processes of perception (e.g. *she heard the phone ring*), of affection (e.g. *he loves her*), and of cognition (e.g. *they realised what he was up to*). The person in whose mind they occur is labelled *Senser*, with whatever is liked, agreed to, seen, heard, and so on labelled as *Phenomenon*.

All mental processes potentially involve both a *Senser* and a *Phenomenon*. This does not mean that they must be overtly expressed in the clause each time. There can be a *Senser* without a *Phenomenon*: *Lucy understands*; and also a *Phenomenon* but no *Senser*: *He only did it to surprise*.

Unlike material processes, mental ones are ‘reversible’. What this means is that in a mental process, the role of grammatical subject can be filled either by the person in whose mind the process occurs, or by the *Phenomenon* itself. Compare *he was surprised by her arrival* to *her arrival surprised him*.

3.1.10 Relational processes

Relational processes 'serve to characterize and identify' (Halliday and Matthiesen, 2004: 210). They are processes of *being* and *having*. They allow the individual to make generalisations by relating one kind of experience to another one. Typically, as Bloor et al. (2004: 120) note, relational processes are 'realized by the verb *be* or some verb of the same class (known as *copular verbs*); for example, *seem, become, appear* (as in '*she appeared cheerful*') or sometimes by verbs such as *have, own, possess*.'

Consider the following clause, uttered by one of the informants, Annamaria (3.1) *era un dolore, acuto* 'it was an acute pain' (Am I: 6).²² Here a relationship is established between two concepts ('pain' and, in this case, 'acute'); here the predicator ('is') does not so much indicate a process as establish a relationship between an entity, labelled *Carrier*, and an *Attribute* of that entity. Indeed, in SFG this is called an *attributive* relational clause. Unlike for processes of doing, in the real world there is only one participant in this kind of process.

But there is also a second type: *identifying* relational processes. Here, one entity is identified in terms of another; in this type of process, the *Predicator* functions more or less like an 'equals' (=) sign. *The promotion was his goal* is an example (*the promotion=his goal*). In identifying clauses, the order of the

²² The codes following quotations in chapters 3 – 6 refer to the participant, type of data, and the page of the original first version of the transcript (in Italian) where the quotation appears. The page number refers to the single interview transcript. In this case, for example Am I=Annamaria's interview; 6=page six of the original transcript. The codes for each informant are: Am-Annamaria; A=Anna; S=Sandra; G=Gina; V=Veronica; M=Marta; F=Fabio.

participants is reversible (*his goal was the promotion* is also possible), although not fully interchangeable²³. To reflect the difference in functions between the participants in identifying clause and those in an attributive one, those in the former are given the labels *Identified* and *Identifier*, as shown in Figure 3.2:

Carrier	Process: relational, attributive	Attribute
The pain	Was	acute
The promotion	Was	his goal
Identifier	Process: relational, identifying	Identified

Figure 3.2. Relational processes.

Two additional relational processes are *behavioural* and *existential*. They both share some of the characteristics of the main types and can in fact be seen as ‘sub-categories rather than as groups on a par with the four main types’ (Thompson, 2004: 103).

Behavioural processes are processes of physiological and psychological behaviour. They share similarities with material and mental ones. They are typically human processes and include, following Halliday et al. (2004: 248), *breathing, smiling, dreaming* and *staring*. Characteristically, behavioural processes have only one participant, which is the human *Behaver*. However, in some cases, there might be what Thompson (*ibid* p. 104) calls another ‘apparent participant’, which normally functions as a complement. This other

²³ See Thompson (2004: 118-19) for a discussion of the reasons for the non-interchangeability of ‘reversed’ identifying clauses.

apparent participant is referred to as *Range*, or *Behaviour*. It is not, writes Thompson (*ibid* p. 104), ‘a real participant but merely adds specification to the process’.

One should note that ‘many of [the] verbs [in behavioural clauses] also occur non-behaviourally’ (Halliday and Matthiesen, 2004: 251): ‘contrast *think* as behavioural process, in *Be quiet! I’m thinking*, with *think* as mental process, in *they think we’re stupid*.’

Finally, existential clauses are those that represent something that exists, or happens. The clause *there are two additional processes: behavioural and existential* is an example. These are very common in narrative texts: (for example: *there was once a princess*). The element or event whose existence is thus predicated, is labelled *Existent*. The *Existent* can be concrete or abstract, human or non-human, as long as it can be construed as a ‘thing’.

In order to better illustrate the way language configures experience into processes, and by way of summary, let us look in closer detail at an extract from one of the interviews (the speaker is Annamaria).

(3.2) I had a very strong pain when breathing (Am I: 4)

In the above example, Annamaria has set up, through the grammar, a configuration where two separate entities (things) are identified (*I* and *a very strong pain*).

In this instance, one of the two entities — or participants — is the speaker herself. The particular configuration that she has set up is one which indicates possession (albeit, as we shall see in more detail later on, of a somewhat

peculiar kind), where X possesses A. A process where a relationship is set up between participants is identified, as we have seen, as *relational*. Admittedly, it can seem quite odd to consider ownership as a relational process. The reason for its inclusion – according to SFG theory – within such processes is that ‘something possessed can be seen as a kind of attribute’ (Thompson, 2004: 94). This is more apparent when ‘the thing possessed is an inherent part of the possessor: ‘She’s got *long, dark hair*’ (*ibid* p. 94, emphasis in the original). Yet, as Thompson argues (*ibid* p. 94), other kinds of possession (like the above quotation from Annamaria’s interview shows) differ from the prototypical relation of ownership ‘not in essence but only in terms of how temporary the possession is.’ For this reason, in a relationship of this type, the possessor is identified as the *Carrier*, while the possessed is seen as the *Attribute*. Figure 3.4 illustrates this:

I	Had	a very strong pain	when breathing
Participant	Process	Participant	Circumstance
Carrier	Process	Attribute	

Figure 3.4. Possession as a kind of relational process.

As previously noted, this (the possession of pain) is indeed a peculiar kind of possession. For a start, the owner has not acquired it willingly and cannot get rid of it when she pleases. Semantically, it is not the prototypical kind of ownership. It is now therefore easier to see, from a semantic point of view, the similarities between this special type of possession and a personal attribute

(like hair colour), as well as their relationship with the *Owner/Carrier* of that attribute.

We can also note that this configuration construes pain as a separate entity; it is 'other than', although related to, the possessor. This has several advantages, one of which is that it allows, through the grammar, for different degrees of proximity to (or of distance from, depending on the point of view) the 'owning' subject. Through the use of possessives and demonstratives, for example, speakers are able to increase or reduce the cognitive and psychological space between themselves and their pain. They can, in other words, construe pain as more or less disembodied, more or less alien. This is an example of reality not only being represented but construed *in* and *by* language. Especially in the case of pain – which we cannot observe other than by observing the words of the sufferer - language becomes the means whereby the experience of pain is presented both to the sufferer him/herself and to the outside world. The fact that the grammar of pain is so varied and multifaceted should not surprise us, since it not only construes pain (in itself highly variable) but also the *experience of it* by the individual.

3.2 *The lexical realisation of 'pain' in the ALOMAR Plus corpus: 'key lexical items'*

As explained in the preceding section, language — through the lexicogrammar — configures the experience of pain in a number of ways. As we shall see, analysing language in terms of the system of *transitivity* (within the *ideational* metafunction) can shed light on the ALOMAR Plus speakers' 'theory' of the pain experience.

However, to begin with I shall look at the individual items in the corpus which lexicalise the entity 'pain'. What I have termed 'key lexical items' are the lexical realisations of pain in the corpus. They comprise nouns, verbs, and adjectives, reflecting the way in which the experience is construed and (re)presented.

In the following sections, a quantitative account of these 'key' items will be provided and become the focus of analysis. Such items belong to different word classes. They are summarised in Figure 3.5 below:

Lexical Item	English Equivalent	Word Class
<i>dolore</i>	pain	noun
<i>sofferenza</i>	sufferance/suffering	noun
<i>doloroso</i>	painful	adjective
<i>dolente</i>	sore	adjective
<i>dolorante</i>	painful	adjective
<i>far male</i>	to do (give) pain	verb
<i>far soffrire</i>	to make/cause to suffer	verb

Figure 3.5. Key lexical items for 'pain'.

Italian nouns and adjectives are morphologically marked for gender and number. As customary, the above list gives forms in the masculine singular, although in the corpus each form is analysed separately. The list is a relatively short one; and yet, as will become apparent, it is in the high number of configurations in which pain enters that the complex, multifaceted nature of the pain experience is revealed. This apparent paucity in the lexicon of pain might be perplexing at first. Cohen (2010), in her studies of pain in the late Middle Ages, gives a first answer by suggesting that, in order to make

accurate communication and diagnosis possible, the lexicon of pain has to remain fairly stable and relatively limited.

The relative scarcity of lexical items denoting the concept 'pain' in its various manifestations and effects should not mislead us. For a start, pain, when construed nominally, can be modified adjectivally in order to portray and specify all its nuances. This can clearly be seen if one has a cursory look at the Italian version of the shorter McGill Pain Questionnaire (1985). This widely used diagnostic tool asks sufferers to choose from among seventy-eight adjectives the ones that best describe their pain. These include, *tremolante* 'trembling', *stancante* 'tiring', *intenso* 'intense', *torturante* 'torturing'. But the lexicon, it must be kept in mind, is not the only means whereby meaning is created. Speakers of natural languages have a very powerful tool: the grammar. It is through the grammar, 'the semiogenic powerhouse of language' (Halliday, 2000), that a great deal of meaning potential is actually realised. A similar point is made by Wierzbicka (1998: 9). She argues that meaning is jointly conveyed by grammatical constructions and words. Meaning, she argues, 'is conveyed by the utterance as a whole'.

What element does more of the work in the transmission of meaning depends significantly on the mode of communication. As Halliday and Matthiessen (2004) note, different modes of communication – written as opposed to spoken, for example – rely more on one than the other. These modes respond to different communicative and pragmatic constraints. The state of constant flux of the spoken language – especially in its less constrained forms, like conversation – is reflected in its rich patterns of semantic, and hence also grammatical, variation. The spoken language relies more on grammar to

achieve what the written language achieves lexically. It would be interesting to look closely at a corpus of written language dealing with pain, like literary texts, to see whether the inventory of lexical items used is somewhat richer. This is beyond the scope of the present work; however, it may represent a future direction and an expansion of the current study.

As will become clear in the presentation and analysis of the data, speakers do make use of the full range of grammatical resources at their disposal to convey their experience. It is interesting to note how, on more than one occasion, they comment on the difficulty in finding the 'right word' to describe their pain. After all, the lexicon represents, for the majority of people, the most visible example of what constitutes language. We commonly say that we lack the words for something that we find difficult to express, not the grammar. However, the ALOMAR Plus speakers immediately resort to the richness of the grammar to compensate for it.

3.2.1 Different lexicogrammatical realisations of 'pain' in the corpus

Already from the brief list of key items given above, it can be seen that pain is at times realised by a noun, at times by a verb, and at times as an adjective; this is as true of Italian as it is of English (as shown by Halliday, 1988). Given the complexity of the pain experience, this is hardly surprising. A closer look at the frequency with which each realisation appears in the corpus will begin to reveal some patterns.

3.2.2 Frequencies for different lexicogrammatical realisations of ‘pain’ in the ALOMAR Plus corpus

‘Dolore’, in the singular and plural forms, appears 197 times; its quasi-synonym *male*, six times. The adjectives *doloroso* and *dolorante* both appear three times; *dolente* also occurs three times. *Sofferente*, used in the same sense, appears twice. *Far male* ‘to cause pain/to hurt’, in its various realisations according to tense and person, occurs thirty-one times; *far soffrire* (lit. ‘to make/to cause to suffer’) is only found once. A summary is given in Table 3.1 below:

Type	Occurrences	Percentage of total
Process (verb)	32	12.95%
Participant (noun)	203	82.18%
Quality (adjective)	12	4.85%
Total number of lexical items referring to pain	247	100%

Table 3.1. Pain realisations in the corpus.

As the preceding table clearly shows, speakers in the ALOMAR Plus corpus overwhelmingly construe pain as participant, nominally. Doing so is likely to be due to the context in which talk about pain occurs. The informants in the present research are — for the most part — narrating their *past* experiences of pain and not relating an extant painful sensation as one would do when communicating the problem during a medical consultation. Other researchers have obtained different results. Lascaratou (2003; 2007), who investigated a larger corpus of doctor-patient interactions, is an example. Her participants mainly construe pain as process, which led her to conclude that the Greek language in general favours this configuration. Part of her conclusion is that

the degree of the patient's involvement of self in the painful experience is a determining factor in the choice of the linguistic framing. She also argues that when pain is construed and communicated via nominal constructions (through the word *ponos* 'pain' in Greek), 'the role of pain utterances is undoubtedly descriptive' (2003: 18); whereas when construed verbally, their role is more 'expressive', resembling in function the primitive, spontaneous groan of pain. It is possible that, as stated above, the overall aim and the context of the verbal exchange are important factors in the way the pain experience is encoded linguistically. Someone who is actually in pain *at the time of speaking*, who might be seeing a doctor at the local surgery, like Lascaratou's participants, or in a casualty department in order to seek help, is clearly under specific constraints. Such an individual's aims and priorities are quite different from those of a chronic sufferer being interviewed by an academic researcher. Nevertheless, when construed as *thing*, pain can easily enter configurations where it is represented as a foreign entity. As such, it can also be seen as possessing and showing agency to varying degrees: not only does it *exist*, it also *does* something to you, often displaying a high degree of volition. The following are three examples, from the corpus:

(3.3) Like it had disappeared, similarly it came back again (F I: 1)

(3.4) When the pain got to here there was [it felt like] an explosion (A I: 1)

(3.5) It would get slightly inflamed, then it [the pain] would affect [take] all the tendons (A I: 2)

In all three cases, pain appears as participant in processes that are normally associated with a volitional *Actor*. *To disappear* and *to reappear*, *to arrive*, and *to take* (in the sense of ‘to take hold of something or somebody’), are all processes of this type. In all the examples above, pain is construed as participant – an *Actor* – in material processes, occupying the position of grammatical subject. This type of configuration, with pain as a discrete entity, is consistent with the common view of it (and, more generally, illness) as external to the body, ‘other than self’, an example of which is the first of the three above extracts. An ‘objectified’ pain, in addition to allowing a representation of it (the pain) as foreign, also makes the very act of talking about it possible.

Before continuing, additional comments on the aforementioned scarcity of lexical items in Italian – nouns, to be precise – to denote pain should be added. As already highlighted, one of the ways in which language construes experience is by giving things a name. Since it is not uncommon to see culturally relevant aspects of reality encoded in, and reflected by the richness in the lexicon of a particular domain of experience, the scarcity of synonyms for pain can be, as mentioned earlier, puzzling.

One of the ways that language compensates for such scarcity, is by providing lexical items which can be seen as metaphorical; *bruciore*, ‘burning (noun)’ (the body, or body part is not actually on fire, but it may feel as if it were), *fitta* ‘a piercing pain’, and the like are, after all, kinds of pain. They imply an ‘as if’ scenario: *un bruciore alla gola* ‘a burning at the throat’ is a pain ‘as if it were burning’. Yet, even if one considers words like *bruciore*, *fitta*, and so on, as synonyms for pain, they are still relatively infrequent in my corpus.

So, the full scale of the variety of pain and of its experience by the suffering individual is encapsulated by the transitivity system. By alternately construing it as *thing*, *process*, *quality* and *circumstance*, the grammar allows the speaker to encode differently the various aspects of pain, often within the same text. The ‘semantic work’ is therefore conveniently split – albeit rather unequally – between lexicon and grammar.

3.3 The grammatical properties of pain as participant

Having established that in the majority of cases pain – in the Alomar Plus corpus – is construed as participant and realised by a noun, I shall now look in more detail at the types of process it takes part in.

In his work on the grammar of pain Halliday (1998: 11-13) lists ‘seven grammatical properties that are associated with pain as a participant’ (i.e. an entity or ‘thing’ that takes part in a process). They are ‘grammatical’ in the sense that they are inherent properties of pain that find a reflection in the lexicogrammar.

The fact that pain has temporality, for example, is made ‘visible’ in the grammar through – among other devices – the tense system. Consider the following clauses: *I got a headache this morning, and it still hasn’t left me.* Here, through the tense system (as well as the adjunct ‘this morning’) the grammar is able to capture the fact that the entity we call pain has temporal extension; the moment of its inception can be precisely located in time. The temporal extension of pain can also be seen in the use of the present perfect tense in the second clause.

As mentioned, temporal adjuncts, such as *this morning* and *still* also contribute to giving this property of pain a lexicogrammatical instantiation. Of course it is not only verbs that can be relied upon to show the temporal qualities of pain. Adjectives can be used to the same effect; a pain can be described as *costante* 'constant' or *continuo* 'continuous'. In the case of adjectives, however, the temporal extension is given by their semantic content and of course both (adjective and the tense/aspect systems) can be used jointly for greater accuracy and effect as in: *ho avuto un dolore costante/intermittente per quattro giorni* 'I've had an intermittent/constant pain for four days.' The complete list of the grammatical properties of pain that Halliday (1988: 13) identifies is reproduced below:

- a) -pain may be a bounded thing, realised as a count noun;
- b) -it is a thing which is possessed. As such, it can be acquired, kept in possession, and lost. Such possession may be in the past;
- c) -pain has temporality, i.e. location in time and duration;
- d) -it has variable intensity and there may be an external agency bringing about the degree of intensity;
- e) -it has various locations within the body. The location may be construed circumstantially as a locative of place or as a class of pain, such as *mal di testa* 'headache';
- f) -pain has different qualities; these include burning, aching, throbbing, stabbing, shooting, etc. It is obviously not a closed system and – interestingly – 'it lies at the intersection of the technical register of medical practice with the non-technical register of the everyday discussion of personal ailments' (*ibid* p. 13);
- g) -pain has conditions; these 'can be construed as a temporal nexus, showing accompanying (simultaneous) circumstances.'

In the following section, I shall refer to these properties to verify if and how they appear in the ALOMAR Plus corpus.

3.4 Possession

Italian, together with many other languages, frequently configures pain as an entity in possession of an individual, as in ‘Mary had a pain in her shoulder’. This individual is the one affected by the pain. As we have seen this is, in SFG terms, a relational process of possession. There is a *Carrier* (in this case the person who has the pain), and an *Attribute*, the pain itself. This type of configuration does indeed appear frequently in the ALOMAR Plus corpus, although the frequency with which individual speakers use it varies. Only one informant (Fabio) does not use it at all; two of them (Anna and Gina) use it once, while all the others (Annamaria, Veronica, Sandra, and Marta) use it more frequently.

In the vast majority of cases, the speaker is the *Carrier*, realised either by a verb ending or – as it is often the case – by an overt subject-pronoun. Unlike English, Italian is a pro-drop language and the presence of the subject-pronoun in the clause is marked. However, from the point of view of the clause as representation – the ideational metafunction of language – this does not make any difference. It is interesting to note that, although the grammar allows it, never in the corpus do we find configurations of possession with a body part as *Carrier*. So, although a clause like: *la mano ha un dolore* ‘the hand has a pain’ is perfectly grammatical, it is never employed. Although the question of the centrality of the individual will be explored in more detail in

chapters 4 and 5, here it is possible to briefly suggest a possible reason for this. To do so, it is necessary to temporarily shift our attention away from the ideational metafunction of language and onto the textual.

3.5 The textual metafunction of language: language as text-language in context

The textual metafunction can be broadly defined as the one that deals with the way we structure our messages, and 'how they fit in with the other messages around them and with the wider context in which we are talking and writing' (Thompson, 2004: 30). Within the textual metafunction, a number of structural and non-structural relations that express different kinds of meaning are included. One of the structural devices is the *thematic structure*, through which the speaker encodes information as given and new, and in so doing assigns topical prominence.

The theme is 'the point of departure of the message', or 'that which locates and orients the clause within its context' (Halliday and Matthiesen, 2004: 64). Earlier, Halliday (1995: 39) had suggested glossing the theme as 'I'll tell you about...'. The *theme*, in other words, is what the message is about.

A clause like: *ho un dolore al polso*, '(I) have a pain in the wrist', from the point of view of the textual metafunction has *ho* (have-PRES: 1Sing., which conflates *io* 'I' and *ho*, 'have') as the theme, making the speaker the theme that the rest of the clause elaborates on. The speaker, in other words, and not the pain or the wrist is what the message is about. So, although possible (and possibly more accurate) a clause like: *il (mio) polso ha un dolore*, 'the [my]

wrist has a pain' is not favoured by speakers. Such a configuration would in fact make the clause about a body part. Yet, it is the person in its entirety — holistically, one might say — not body parts that experiences pain. Figure 3.6 sets out the relationships in the SFG framework. It is worth reiterating, however, that language attends to all the three metafunctions simultaneously and it is only for convenience that here we deal with them separately.

Carrier	Process: relational. possession	Phenomenon
Io I	Ho Have	un dolore al polso a pain at the wrist
Theme		

Figure 3.6. Message structure of a 'pain clause'.

The use of possessive markers 'also brings out the understanding of pain as a possession' (Lascaratou, 2004:121). Yet, remarkably, in the present corpus both interviewer and participants never use them; a finding consistent with Lascaratou's, in whose corpus possessive markers are used only marginally and predominantly by doctors when examining their patients.

This lack of possessive markers in conjunction with the noun *dolore*, is consistent with the treatment, in Italian, of body parts, which are not normally accompanied by possessive markers but by the definite article: *ha le* [definite article, feminine plural] *mani sottili e i* (definite article, masculine plural) *capelli neri*, 'she/he has got thin hands and black hair'.

In turn, this is consistent with SFG's understanding of possession as a relational process akin to the possession of a physical attribute (hair length, colour, and so on). Just as it does with physical attributes, the grammar of Italian allows the use of possessive markers with pain, yet it does not favour them, and when used they appear to be marked. In this aspect, the possession of pain appears to be quite unlike ordinary possessions (at least from a grammatical point of view).

Like other possessions, though, pain can be acquired and received, owned and lost. Yet, unlike prototypical possessions, pain becomes the property of its owner entirely on its own terms. It is not usually sought after and – once it makes its appearance – it is certainly not welcome. Again unprototypically for a possession, the owner cannot get rid of it when she pleases: it is the possessed that 'decides' to leave the owner, not the other way around. This understanding is enshrined in the grammar of the language and is likely to be at the base of popular models of pain and illness. As Butt et al. (2004) point out, it is these grammatically-construed world-views that constitute ideologies. In some cases, these construals have undergone a further process of crystallisation; proverbs and sayings – which may well be universal – are a case in point. Following is a Lombard proverb about the apparently capricious nature of illness, its quick onset and slow departure:

El mal el ven a cavall e el torna a pé

disease [or pain] arrives on horse back and leaves on foot

The grammar of the two clauses above is quite revealing. In both of them, disease is the *Actor* and grammatical subject; by assigning it roles that are normally occupied by humans (riding a horse and walking on foot), the volitional nature of disease is highlighted even further. An already quoted extract, from Fabio's interview, portrays in a similar manner the unpredictability of pain by casting it in the role of *Actor* and grammatical subject of an intransitive verb in a material clause:

(3.6) Like it had disappeared, similarly it came back again. (F I: 1)

Similarly, Sandra recollects the following remark (possibly by a doctor) on an occasion when, while on holiday, she began experiencing severe pain in her knees:

(3.7) They explained to me that the only thing [to do] was rest; when it [the pain] felt like it, it would leave. No point in [taking] tablets; no point in [using] creams. (S I: 3)

It is interesting to note not only the volitional, but also the capricious nature attributed to pain by the speaker. Pain – Sandra is told – will leave *quando c'ha voglia* 'when it feels like it.' Again, it is the construal of pain as *thing* that allows its 'personification' and this type of characterisation. There are therefore many insights to be gained on an individual's and a culture's understanding of how pain works by scanning the grammar of the clauses in which it appears, in particular as a possession.

3.6 *The temporality of pain*

As noted, pain has temporal location as well as duration. Often temporal location and extension are represented in the clause as *Circumstance*, often realised by an adverb or adverbial group but also by prepositional phrases. It is worth remembering that, in SFG, circumstantial elements are ‘optional augmentations of the clause rather than obligatory components. [They] are not directly involved in the process’ (Halliday and Matthiesen, 2004: 176-7). That is not to say that they are not relevant; on the contrary, they can provide information which is essential from a narrative and textual point of view. For example, to say that a particular pain is experienced at night or, say, after eating can be an essential piece of information but is not, strictly speaking, part of the process itself. Circumstantial elements ‘augment [the experiential centre of the clause] in some way – temporally, spatially, causally and so on’ (Halliday and Matthiesen, *ibid* p. 176).

(3.8) In October I’ve had, at night a pain here, at night I had very strong pains in my hands. (Am I: 8)

(3.9) [the pain] made its appearance in the hand. (V I: 1)

(3.10) it is constant thing pain in the sense that more or less intense: I’ve always had it. (V I: 4)

(3.11) I remember that one afternoon it was an acute pain, fixed, uh: that [...] as it had appeared so it left. (V I: 2)

(3.12) I had many joint-pains [...] joint-pains especially went on for about ten years. (Am I: 1)

However, as both Halliday (1998) and Lascaratou (2003: 122) point out (for English and Greek respectively), ‘the duration of pain may also be metaphorically expressed as a quality in the form of an adjective’. In this case, the adjective may function as either an *Epithet* or an *Attribute*. In the latter case, a quality (labelled *Attribute*) is ascribed to an entity (labelled *Carrier*).

(3.13) Annamaria: They were, they were, yes, yes; they were persistent. (Am I: 10)

(3.14) Fabio: [the pain] was a constant thing; that is a constant pain. (F I: 6)

Contrary to initial expectations, in the ALOMAR Plus corpus there are not many occurrences of duration being construed as *Attribute* in a relational clause with pain as *Carrier*. This could be because of the relatively little precision that such a construction offers; the duration of pain in an attributive clause gives pain a temporal dimension but it does not anchor it chronologically. If the overall aim of the linguistic exchange is to give a ‘history’ of one’s pain, it might be that the speaker is more likely to encode references to time circumstantially, situating pain by giving it a beginning and an end, rather than merely characterising it as, say, constant or intermittent.

The onset of pain and its duration are obviously particularly relevant, both for the sufferer and for those around her or him. The moment that pain started can often take on quasi-mythical status for a sufferer, and it can be remembered (and mentioned) with a high degree of precision. There is a

'before' and an 'after'; entirely new identities can come into existence following the appearance of pain. Following is an example of the precision with which the genesis of illness and pain are remembered:

(3.15) Well, I am 32 years old. I became ill in 1983. I was 11 years old; I have been ill for 21 years [...] I began to have fever pains. (S I: 1)

Apart from the general onset of pain, sufferers can also be quite specific about the occurrence of specific pains within the more general experience of pain. Pain can be both intermittent and constant.

(3.16) While before it was a constant thing now, at intervals it reoccurs, the pain. But in a sudden way. (F I: 6)

Since a correct understanding of the temporal characteristics of a sufferer's pain are important for a precise diagnosis and prognosis, references to it appear often especially in questions by doctors and medical staff (Lascaratou, 2003). Yet, one ought to remember that, for the person in pain, there are two types of time: one objective and the other subjective.

(3.17) Luckily it didn't [last] I think more than a minute a minute and a half; for me it was an eternity. (A I: 7)

As well as with adverbials or adjectives, the temporal dimension of pain can also be expressed by means of accompanying (i.e. simultaneous) conditions, in the form of a *temporal nexus*. Each *temporal nexus* simultaneously shows a particular condition or situation that seems to favour the onset of pain; at the same time it indicates the point in time when the pain begins.

(3.18) I had a very strong pain when breathing. (Am I: 4)

(3.19) The moment in which I'd fall asleep, there was this pain. I'd wake up and it would reappear. (F I: 4)

(3.20) Whereas those at the feet where pains [that would appear] while walking. (V I: 3)

(3.21) Even if I'm still the pain is there. (S I: 3)

3.7 Pain has variable location within the body

The entity we call pain, although immaterial, resides within the body. Often it is static, but it can also move and make its way from one point in the body to another, and back again. It can make its presence felt in a very definite, circumscribed area or it can be perceived over a wider, less precisely defined (and definable) portion of the person's body.

Perhaps even more than its temporal location, the topical aspect of pain is of particular relevance, both for sufferers and for those around them, especially doctors and, more generally, those in charge of diagnosing and curing disease. It is therefore of little surprise that requests as to where exactly pain occurs are to be found in the questions of doctors and, more generally, those who have to assess and cure.

Certain areas of the body seem to be more prone to aching than others. A minor pain in the head is – for instance – more common and, arguably, less worrying (unless particularly intense or persistent) than one in the chest. This, however, is a highly idiosyncratic matter. One of my informants, Antonio (whose interview was later left out of the corpus (see chapter 3, on methodology) mentioned that to him, a pain is all the more worrying the closer it is to the head, regardless of its intensity.

Some languages, English among them, lexicalize pain in some areas of the body by means of compounding. So we have words like *headache*, and *backache*. A kind of thing, an *ache*, is assigned to a class through a lexeme denoting a body part, *head*. The result, *headache*, ‘is a complex entity, and it forms part of a taxonomy of aches’ (Halliday, 1988: 3). These kinds of compounds, where the compound is a hyponym of the grammatical head are also known as *endocentric compounds* (a *headache* is a kind of *ache*, an *armchair* a kind of *chair*). This type of compounding (in English), however, is not possible with all parts of the body; one cannot have a **fingerache* or an **elbowache*, although one can, and does get pain in a finger or an elbow. It appears that, because of their high frequency and cultural relevance certain locations of pain have become linguistically ‘formalised’.

Unlike English, Italian does not allow this type of compounding, which is characteristic of the Germanic languages²⁴ (cf. Dutch, *hoofdpijn*; German, *kopfschmerz*, Swedish, *huvudvärk*, and so on). More typically for Italian, these common pains are lexicalized with the locus of pain as circumstance in a nominal group: *mal(e) di testa* ‘headache’, *di pancia* ‘tummy ache’, *di schiena* ‘backache’, and so on, that – like compounds – behave like single lexical items. Perhaps surprisingly, there is only one occurrence of this kind of structure in the corpus. It was used by the speaker to compare a phase of his pain to a mild headache: *un mal di testa con intensità bassa*, ‘a headache with low intensity.’ One of the possible reasons for this is the highly idiosyncratic nature of the pain experienced by the speakers in the ALOMAR Plus corpus. It is often unlike any other pain they may have experienced before; and perhaps one of its main characteristics could be said to be its unpredictability and mobility. In other words, the locus of pain has to be specified each time. This explains why, by far, the most used means of expressing the location of pain in our corpus is circumstantially, through locatives of place.

(3.22) I had pains in the thorax. (Am I: 4)

(3.23) These strong pains in the muscles. (F I: 3)

(3.24) Because I feel them from, in the toes, under the toes. One feels them, at the sides, at the metatarsum or, on top, even at the heel let's say. (A I: 4)

²⁴ Compounds made up of two common nouns are, in English, ‘by far the most productive type of compounds’ (Bauer, 1983: 204).

Adverbials such as *qui/qua*, 'here', are also employed (with varying frequency) by my informants, together with gestures. The use of these deictics is obviously dependent on the context of the linguistic exchange: oral and face to face, in this case. Verbal deixis occurs with a lot of actual, extralinguistic pointing. Interestingly, not all speakers in the corpus rely on these adverbials of place with the same frequency; some of them do not use them at all whereas one of them, Anna, uses them often.

Before continuing, it is worth considering the possible reasons for Anna's high use of adverbials. To do so, we must give some background information on her interview. Of all the participants, Anna came across as the more distressed. Although she told me during the interview that she was not in pain, her appearance, posture, gestures, and manner of speaking were very much those of somebody in pain or for whom pain was still a very vivid memory. As she began articulating, her speech was characterised by false starts and was also slightly agitated. Tellingly, the initial part of her account is in the present tense, bringing her experience vividly to the fore as something ongoing and still affecting her.

That pain had had a devastating effect on Anna soon became clear. She displayed a high number of devices to illustrate her pain: metaphor, simile, onomatopoeia among them. What soon became apparent was that what she was doing was giving a 'dramatic' representation of her experience. The use of adverbials as locatives of the pain was always accompanied by pointing gestures, and in fact one of the most striking features of the whole encounter was its 'dynamicity'. Anna, like the other speakers, could have easily resorted

to a wholly linguistic account, with locatives of place used to inform about the location of pain; but she did not.

Although a detailed analysis of the role of para and extralinguistic features, such as gestures, is beyond the scope of this thesis, it is worth referring briefly to what Heath (1989; 2002) has to say on the subject. In his work, which looks at the visual and verbal aspect of doctor-patient interactions, he highlights how the patient's gestures serve to transform generic and 'invisible' complaints into subjective, relevant, and visible ones; how through gestures:

Patients can render their experience of their difficulties visible [...]. Through gesture and bodily conduct, patients transpose inner suffering, their personal subjective experience of their complaint, to the body's surface and particular parts and areas of their physic. *The inner and the subjective are overlaid on the outer surface of the body and rendered visible and objective.* Moreover, [...], *patients take symptoms experienced on another occasion and transpose them to the present. They reveal their symptoms, and their experience of their symptoms, here and now,* revealing the very characteristics that they have been invited to describe (Heath, 2002: 603; my emphasis)

Therefore gestures in this case are to be seen not as an alternative but rather as a complement to Anna's verbal rendition of her experience. In her account the linguistic and the extra linguistic are used together to give her story a more vivid character.

3.8 Pain has different degrees of intensity and variable qualities

As one informant explicitly acknowledged, describing pain is not easy: 'It is not easy. Well, there are different types.' The different qualities of pain can be probed by questions such as: *What is the pain like?* Indeed such questions often appear in doctors' consultations with their patients, or whenever someone is interested in finding out about somebody else's pain. The fact that pain can take many guises, that both its quality and intensity vary, is probably obvious to all human beings. It is part of our experience of everyday life; as such, this knowledge is incorporated into the grammar. We all know, and language shows an awareness of this knowledge, that the pain of a toothache is not like the pain of a broken leg, or a scalding. These types of pain vary mainly in terms of quality.

The different types of pain are part of a semi-structured taxonomy which, however, is not a closed system. If it is true that some of the labels used to describe types of pain are routinely employed both by doctors and sufferers (for example, *burning, shooting, stabbing, acute, chronic, dull, sharp*), some are new, *ad-hoc* creations produced in response to specific need. Some of these new labels are used only once and subsequently discarded; others may remain in the individual's repertoire for much longer, even be adopted by those around him or her, like family or friends.

As noted earlier, it was the difficulty in assessing painful sensations that prompted the creation of verbally-based tools of evaluation by researchers like Melzack & Torgerson (1971). But pain descriptors do not always distinguish between quality and degree of intensity of pain clearly. As Lascaratou notes (2003: 128), '[pain descriptors] seem to merge in the form of adjectives that

often combine semantic features related to both.’ Lascaratou (*ibid* p. 128) reports the use, in her corpus, of adjectives such as one meaning ‘sweet’, which, together with a particular (possibly idiosyncratic) quality, also refers to low intensity. Even in terms of quality, she goes on to comment, the same adjectives can be interpreted as expressing more than one quality. ‘Deep’, for example, ‘refers to spatial characteristics of the sensation but may also imply sharpness, by virtue of its ability to be sensed deep in the body’ (*ibid* p. 128). In addition, ‘duration of pain may also be metaphorically configured as a quality’. An example she quotes is ‘continuous’, which with a synonym, is also found in the ALOMAR Plus corpus, as shown by the following examples:

(3.25) The pain [...] was a constant thing; I mean a constant pain. (F I: 3)

(3.26) They were all acute pains but fixed [not moving, static but also continuous]; it was not that they alternated, one moment more or less strong. They were always fixed. (V I: 2)

The speakers seem to favour as descriptors nouns that embody both the quality and intensity of the pain sensation: *bruciore* ‘a burning sensation’ (note that English construes the ‘burning’ element adjectivally, whereas Italian incorporates it in a noun), *fitta* ‘a quick, sharp pain’, *pugnalata* ‘stab’, *fastidio* ‘a fastidious light ache or sore’, *lampo* ‘lightning’, *deflagrazione* ‘deflagration, detonation²⁵’, *dolorino* ‘a little pain’ are some examples.

²⁵ Technically, a deflagration is not the same as a detonation. The former is a slow, rapid burning, whereas the latter is defined as a rapid chemical reaction, an explosion. It is clear from the context that the speaker who used this term meant it in the latter sense.

All of these nouns are complex pain descriptors, in the sense that they amalgamate quality, intensity and in some cases physical extension of pain. They all incorporate the basic notion of pain *plus* quality, intensity and – in some cases – extension. A pain defined as a stabbing (*una pugnalata*) presumably implies depths as well as acuteness. Similarly, a pain referred to as a ‘deflagration’ (*una deflagrazione*) carries similar connotations.

3.9 *Traces of the subjective*

As already noted, pain is a very personal experience; it is not solely what it *is* that matters, it is also what it *is for* and *what it does to* the experiencing individual that matters. There is, in other words, an *affectual* element to the experience of pain which is often – if not always - captured by language. It was this observation that prompted Melzack and Torgerson to include words describing affective qualities under a separate section in both versions of their famous pain questionnaires (MPQ and SFMPQ). Although Melzack and Wall (1988: 38) distinguish between words that describe ‘affective’ qualities and ‘evaluative’ words, my use of the term *affectual* includes all those cases where the personal experience and perceptions of pain by the sufferer are foregrounded; where the subjective rather than the objective is highlighted.

In the Alomar Plus corpus, these mainly take the form of adjectives, such as *tremendo* ‘tremendous, terrible’, *atroce* ‘atrocious’, *sopportabile* ‘bearable’, *insopportabile* ‘unbearable’, *controllabile* ‘controllable’, *fastidioso* ‘fastidious’. There is clearly an evaluative component here, but it is a subjective evaluation; what is unbearable or atrocious for one person, may not be so for another.

It is to this inherent complexity of pain that we should attribute the variety of ways in which its quality and intensity are realised linguistically. De Souza & Frank (quoted in Lascaratou, 2003: 128-9) note that the majority of people provide varied and rich accounts of their experiences of pain. This 'may be due to their inability to discriminate between various components of pain. [...] subjects may envisage the amount of pain [...] as a concept of time, while others may use spatial characteristics to quantify [it].' It is often the case that sufferers use a combination of concepts and lexicogrammatical resources. The lexicon and the grammar are thus exploited in all their semiotic potential in order to give voice to the individual's experience and construal of pain. Some examples follow:

(3.27) It is not easy to describe pain. It is not easy: well, then there are different kinds, because pain I'd say a burning sensation but it isn't, it isn't a burning, it's really something acute. (Am I: 9)

(3.28) Pain, of the kind, like, initially cramps, lightly, afterwards the intensity was much higher, these, these very strong cramps. (F I: 3)

(3.29) Almost immediately pain [...] strong, and it grows, and, at least in my case becomes very acute, so much so that there have been times ... before, and even during the cure that it would get so acute (A I: 1)

(3.30) The pain is really strong, even this one, bearable let's say certainly then, pain becomes like lightening [tchin, tchin]. (A I: 5)

(3.31) And then, at least the one I feel is really a pain, an acute pain, really dull, of the really strong kind. I can't find a term, an appropriate term, pains that do not allow you to, to live, to live let's say a normal life. (S I:2)

What extracts 3.27-3.31 above show is a common verbal strategy used by sufferers to describe their pain. Rather than relying on a single descriptor, an adjective for example, speakers use a combination of lexicogrammatical devices. False starts, self repairs are common, indicating that it is often the case that descriptors are looked for and found in 'real time'.

In extract 3.27, Annamaria begins her turn with a metalinguistic comment on the difficulty of describing pain and the multiplicity of pain-types. She then describes her pain with a noun *bruciore* 'a burning sensation', which identifies a particular quality of the pain. However, obviously feeling that the characterisation she has given is not accurate, she adds that 'it isn't a *bruciore*, it's really something acute.' A burning sensation *can* indeed be acute, yet she felt that the term did not convey precisely the intensity, which was obviously foremost in her mind. In her rephrasing, pain is construed again as *thing*-participant, but this time realised as the more general *cosa*, 'thing', with the intensity, *acuta* 'acute' as its *Attribute*.

Extract 3.30 demonstrates an interesting combination of lexicogrammatical devices to characterise the pain, in particular its quality and intensity. Anna begins with a configuration of pain as a relational process, where pain is the *Carrier* and *forte* 'strong' its *Attribute*. She goes on to add another *Attribute*: *sopportabile* 'bearable', which is an even more subjective element. Anna's pain, however, is not static, it has a 'progression'. Pain – she adds – 'really becomes like lightning' (*diventa proprio un lampo*). Here we find a complex pain descriptor in the form of the noun, which can indicate quality, intensity and presumably also spatial extension. Interestingly, in an attempt to get the message across more clearly, she resorts to paralanguage ([tchin, tchin]), in

an attempt to evoke verbally the repetitive, flashing nature of the pain sensation, like that of a blacksmith hitting an incandescent piece of iron. Asked if the pain is intense, she confirms and specifies twice, with a superlative, that it is indeed 'very intense': *intensissimo*.

Finally, in extract 3.31, Sandra provides a more discursively built characterisation of her pain, its quality and intensity. She begins by relativising the experience: this is *her* experience; it may be different for other people. She then goes on to characterise it twice more attributively, with adjectives (*sordo* 'dull', *forti* 'strong, masc. plural'), each time preceded by the intensifier *proprio* 'truly, really'. Following is the familiar comment on the inability to find appropriate descriptors (*non riesco a usare un termine vero e proprio*, 'I can't find an appropriate term'). Equally familiarly, where the lexicon fails, grammar comes to the rescue: these are pains – Sandra says – that 'do not allow you to lead a normal life'. The quality and intensity of pain are thus realised as a relative clause, where pain is represented as a volitional agent that *does* something to *you*.

In conclusion, we can say that the intensity and even more so the quality of pain are its most problematic and varied aspects of it. It is in these two domains that the complexity of pain is most apparent, as well as its subjectivity: no two pains are alike. Unsurprisingly then, the grammar of pain dealing with these aspects reflects such richness; nouns, adjectives, similes and – in one case in the corpus – onomatopoeia are among the devices deployed for the task.

Even a cursory look at the data tells us that single lexical items alone are not preferred pain-descriptors. Sufferers generally prefer to rely on a combination

of lexicogrammatical tools as descriptors of pain intensity and quality. Even when single pain-descriptors are utilised, speakers resort to a variety of terms, often idiosyncratic ones. This is supported by Lascaratou (2003 138), who notes that ‘the pain descriptors observed in [her] authentic doctor-patient dialogues, cannot easily be mapped onto those of the [SFMPQ] questionnaire’ she (*ibid* p. 139) goes on to conclude that:

[T]he variety of observed quality descriptive adjectives and the difficulty of mapping them onto the GR[reek]-SFMPQ terms indicates that it is extremely difficult, if not impossible, to devise exhaustive lists of pain descriptors so as to classify types of pain. It appears that new pain categories and new members of the categories can actually result from everyday experience and medical practice.

It should also be noted that it is by construing pain as *participant* (in the SFG sense) that it can be shown to possess all these different qualities. The ‘objectification’ of pain, which – as seen – allows its construal as participant, presents the speaker with a visible (if only linguistically) entity that can be measured, assessed and described. It can become part of a taxonomy and categorised, thereby losing some its power to frighten. In other words, its elusiveness is reduced, at least partially.

3.10 Pain as process

In the previous section, I have looked at those cases where pain is construed as *thing*-participant in a process of some kind. In this section, I shall look at

the instances in which it is represented as the process itself. I shall illustrate the frequency with which it is done, how it is done (through which grammatical means), and what some of the advantages of representing pain this way might be.

3.11 The complexity of pain

As previously argued, pain is typically a complex phenomenon, both inherently and from a perceptual point of view. It varies along parameters such as quality, intensity, temporal and spatial location. It can be present in a relatively limited area, or extend over larger portions of one's body. It can be felt on the surface, or penetrate the inner layers of the body. It can be static or move around the body, continuously or intermittently. Pain can arrive suddenly and then leave as quickly, or linger on before disappearing. Once gone, there is no guarantee that it will stay away.

In addition, the entity we call 'pain' is not something that, once there, merely exists, like an object whose presence we merely acknowledge. We become aware of it because it *does* something to us. In its mildest forms, it may merely make its presence felt; and even this type of pain can hinder one's everyday activities. We cannot perceive pain other than when it is doing something to us. Pain, then, is the constant 'doer'. It is never immutable and cannot be entirely ignored; in its constant flux, it can be thought of as epitomising what it means to be active. As Van Hooft (2003: 255) writes:

[P]ain is an experience. It makes no sense to say that a person is in pain but that he does not feel it. A person may suffer an injury or a malady of a kind that typically causes pain but, unless they feel it, they are not in pain.

It is this variability, this state of constant flux that I refer to as the *dynamic nature* of pain. This characteristic is perhaps best captured by it being construed by the grammar as a process of various kinds, through a verb. In addition, the processual construal of pain, as we shall see in more detail below, allows more than one of its aspects to be attended to.

For example, an excellent way of capturing its temporal dimension is through the categories of *tense* and *aspect*. Duration and temporal location are, as we have seen, very important dimensions referred to by sufferers, doctors, and those who care for patients. Pain can be represented as having existed in a very distant past, or definitely subsisting in the present. A language like English, for example, can rely on the present continuous (what Halliday refers to as ‘present-in-present’: *my leg’s hurting*), and on the implied contrast with the simple present, to situate the event firmly in the here and now and evolving.

3.12 Pain as process in the ALOMAR Plus corpus. Constructions by type

In the ALOMAR Plus corpus, as we have seen, the construal of pain as process is not prevalent. Of all pain construals, there are a total of twenty-nine occurrences of *(mi) fa male* ‘to me (it) hurts/is hurting’, and one of *mi fa soffrire* ‘me (it) makes suffer’. Included in the number are those cases where the tense and/or mood employed are something other than the simple present

(indicativo presente), as in *mi faceva molto male* 'it would/used to hurt' or *sapevo che mi avrebbe fatto male* 'I knew it would hurt'. It should be noted that the occurrences of pain-as-process are unequally distributed among the speakers in the corpus. As previously noted, the majority are to be found in the accounts of two speakers, Annamaria and Veronica; and two of the participants, Fabio and Gina use none at all.

Lascaratou (2003: 73) provides a classificatory grid to give a taxonomy (reproduce in Figure 3.8) of the processual pain constructions in her corpus. She assigns each expression to one of the following types of structure:

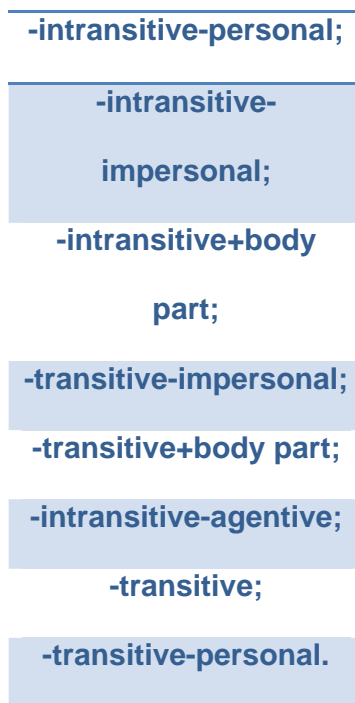


Figure 3.8. Taxonomy of processual pain constructions (Lascaratou 2003).

This classification follows from the specific characteristics of her corpus, and can only be used in part to catalogue the constructions that appear in the

ALOMAR Plus interviews. I shall therefore use it where appropriate, departing from it when the particular nature of my data requires it.

3.13 *Intransitive-personals*

These are constructions of the ‘I hurt/am hurting’ type. It should be remembered that, like Greek and unlike English, Italian is a pro-drop language. Consequently, subjectless structures and those where the grammatical subject is overtly expressed are not computed separately. Furthermore, Italian does not display a simple present – present continuous morphological distinction that matches the one in English. There exists the possibility of using a construction reminiscent of the ‘progressive’ in English. This is the *stare+gerund* (*sta leggendo/dormendo/parlando* ‘s/he’s reading/sleeping/talking’); such constructions ‘serve to present the verb as a progressive, sustained, developing action’ (Maiden and Robustelli, 2000: 302). However, ‘there exist a number of constraints on the *sta leggendo* type. [And] the difference between, say, *Legge il giornale* and *Sta leggendo il giornale* is not necessarily that between English ‘She reads the newspaper’ and ‘She’s reading the newspaper’ (*ibid* p. 303). Unlike English, even when the action is simultaneous with the time of speaking, Italian allows both. So, although a construction like *mi sta facendo male (in questo momento)*, ‘it’s hurting me (at this very moment)’ is possible – and it would underline the developing nature of the event – there is no instance of it in the corpus. This, of course, does not mean that it would not be found in a larger, or simply a different one.

According to Lascaratou (2003: 75), the intransitive-personal construction is particularly important; not only does it function ‘as a pain avowal approximating the primitive cry’, it is also used by sufferers to introduce themselves as ‘suffering sel[ves] before describing [their] painful condition’. It has, in other words, a discursive function as a statement announcing the suffering self; both justifying the patient’s presence at the doctor’s surgery and as an introduction and a preamble to the narrative which generally follows.

The grammar of Italian allows an intransitive-personal construction of this type with the verb *soffrire* ‘to suffer’. *(Io) soffro* ‘I suffer/am suffering’ does indeed appear in our corpus, although only four times. Yet, the semantics of the verb *soffrire* ‘to suffer’ are quite complex. It can refer to both the experience of physical as well as moral or psychological pain. Its meaning can comprise the perceptual experience of physical pain but rarely – and never in the ALOMAR Plus corpus – only that. Out of the four occurrences we find, three appear to indicate mainly physical pain but never in a clear cut-manner. In each case, contextual evidence is necessary to disambiguate. In the following extract, Annamaria expands on the topic of the intense thoracic pain she experienced at some point during the course of her illness:

(3.32) Yes, sharp pains at the thorax, yes, yes, yes. Yes and that was the thing that made me suffer the most, because obviously it limited my life. Also the fact of having had to sleep sitting [on the bed with a number of pillows behind the back, as opposed to lying] all this time, because lying down wouldn’t let me, I mean lying on the bed would not let me breathe. (Am I: 3)

Here *soffrire* can be interpreted as referring both to the physical pain experienced, as well as having to live with the ensuing emotional impact. Suffering includes feeling pain, but is not limited to it.

There are, in Italian, other expressions that can be thought of as approximating not only the meaning but also the discursive function of the English 'I hurt/am hurting'. *Stare male* 'to be in a bad state/unwell' is one. It indicates a condition that can range from malaise to intense pain, both physical and psychological. Like the English construction in question, it can be used to introduce the individual as a whole, suffering self. However, in the Alomar Plus corpus it is only used once, and again not in a straightforward way, appearing to indicate more than just the sensation of physical pain.

A corpus of Italian medical consultations, or simply a larger corpus of what we may call 'health talk' is needed if we are to generalise on what constructions are normally used as pain avowals, to use Lascaratou's (2003) terminology. For the moment, anecdotal evidence and native speaker's intuitions (which, however, should be tested against a corpus of real data) suggest that general statements such as *sto male* (or its variant *mi sento male*), *soffro*, *sono pieno di dolori* 'I am full of pains', or *ho i dolori* 'I've got the pains,' can be used to that effect.

In one of the interviews – for example – following a question on the evolution of her illness, Veronica characterised her form of RA as 'aggressive'. She then went on to say that she had never experienced truly unbearable pains and illustrated one of her coping strategies. After a brief pause, she stated that 'she's got pains' and – in a transition from the personal, but still general, to the

more specific – she said that while speaking to me she was experiencing some pains, but they were bearable:

(3.33) I think I have never had pains like many say they have, that one cannot bear. I have the pains, and for example now my hands are hurting, but I have, they are bearable pains. (Am I: 6)

3.14 Intransitive-impersonals

These constructions are those of the ‘it hurts/is hurting’ type. Lascaratou (2003) terms them ‘impersonal’ because in them, the painful event is not located within the individual as a whole. From a grammatical point of view, a clause like ‘I hurt’ has the individual – the *suffering* individual – as grammatical subject and, typically for English, as focus of the message in thematic (initial) position. The message of the clause, in other words, is about ‘I’.

In the intransitive-impersonal structure, however, the suffering individual is not the focus of the message; pain itself is. Like its Greek counterpart, the Italian third person singular suffix ‘incorporated in the verb form [*fa*, in *fa male* ‘it hurts’] functions as an impersonal setting, like the *it* in *it hurts*’ (Lascaratou, 2003: 94). This, of course, is not to say that here there is no understanding of the individual as sufferer, as the one being affected; there is, however, a shift of perspective and of focus. What this kind of clause predicates, is the existence of pain somewhere in the body. Pain is seen as an existential process; existential clauses being those that simply represent that something, or someone, exists or occurs.

Halliday and Matthiesen (2004: 257), note that, overall, existential clauses are not very common in discourse. They do, however, make an important contribution in some kinds of texts, like narratives, for example. There they introduce central participants in the initial or subsequent stages of narration (cf. *There was once a princess ...*). Although existential clauses typically have the verb *be*, other verbs can also occur: *exist*, *remain*, *happen*, and these are only some of the possible candidates. Existential clauses often contain 'a distinct circumstantial element of time or place, as *in there was a picture on the wall* (*ibid* p. 258). In the Greek corpus, this is often realised by *eδo* 'here' as in *it hurts here*.

Thus, *hurt* in this type of clause functions existentially. However, it is also similar to verbs indicating atmospheric phenomena in 'weather clauses', like *it's raining/snowing/hailing* (*piove, nevica, grandina*, in Italian). This is still an existential process, but of the occurring type. Whereas in English existential clauses of the latter type normally employ a verb in the present-in-present, Italian can have both the present indicative and the *sta+gerund* construction, with the aspectual distinctions referred to above. It is appropriate to interpret these intransitive, impersonal clauses as existential ones, since what they do is announce the presence of a kind of atmospheric condition or other phenomenon or, in this case, the presence of pain. *Fa male* could be rephrased as, 'there is/exists a pain'. Or, highlighting the similarities with the weather example, 'pain is happening (here)'.

As noted, in the *fa male* construction the sufferer is, in a way, absent. However, in the corpus we find a construction which shares characteristics of both the personal and impersonal intransitives identified by Lascaratou

(2003). *Mi fa male* 'to me (it) hurts/is hurting', which can be subjectless or accompanied by a body part (or the disease itself) as subject, as in Veronica's statement: (3.34) *mi accorgo che anche quell'articolazione mi fa male* 'I realise that also that joint (to me it) hurts' (V I: 3). In Lascaratou's (*ibid*) classification, the former are called *transitive-impersonal* (it hurts me), while the latter are *transitive+body part* (my+body part hurts me).

In the ALOMAR Plus corpus, of all the instances of pain as process, the transitive+body part are the majority. Because of the pro-drop nature of Italian, it is often the case that the entity that functions as grammatical subject has to be recovered from the co-text. In some instances, this is easy, and the grammatical subject can be found within a span of just a few words either side of the verb:

(3.35) The moment in which to me it hurts even only a finger. (S I: 4)

(3.36) [walking] is very difficult because it hurts anyway, the foot. (A I: 5)

(3.37) If for example I am here sitting, for example, (to me it) hurts the knee.
(V I: 5)

It is worth noting that, in extract (3.36) above, the process is an intransitive one, where *foot* is the subject, the originator and locus of pain. There is, however, no visible presence of the sufferer, unlike in the first and last quotations, where it appears in the shape of the familiar *mi*.

In other cases, however, the subject is to be found relatively far away, making it more difficult to determine whether we are dealing with a structure transitive+body part or if it is a case of a subjectless *mi fa male* type. Lascaratou (2003: 102-103) argues that by locating pain in a body part, the sufferer configures it as a more 'localised' experience, rather than 'holistically', residing in the self as a whole; it represents a way of distancing him or herself from it.

This construction (transitive+body part: *my arm's hurting me*) is indeed very interesting. The grammar sets up a configuration where there is a process involving two entities: the body part and the individual. The process shares, at least in its grammar, characteristics of mental (of perception, for instance), material, and existential processes. If interpreted as a material process, what are the roles that the two participants (body part and person) assume respectively? Lascaratou (*ibid* p. 103) argues that, unlike in a typical material process, they are that of *Phenomenon/Agent* (the body part) and *Senser* (the individual), rather than *Actor* and *Goal* in a typical material process. This is also Halliday's (1988) position.

This view, however, is not without problems. For if it is true that, if interpreted as 'I feel/perceive a pain in my joint/arm/etc.', those roles of *Phenomenon* and *Senser* are appropriate, an interpretation where the body parts are assigned quasi-personified status can be seen as an entity afflicting pain upon the individual. In support of her argument, the Greek researcher quotes Theophanopoulou-Kontou (p. 115). The latter argues that the body part, 'despite the fact that it functions as an external argument, cannot be the *Theme* and receive the functions of *Agent* or *Cause*, because it is part of the self, i.e. of the *Experiencer*. Hence, this pattern is distinguished from

causative structures.’ This, in my view, is not necessarily the case. The interpretation where the body part is an *Agent* is acceptable, especially if seen as a further trace of disembodiment. One should keep in mind that linguistic construals of reality are done subconsciously. It is also worth pointing out that the two understandings are not mutually exclusive and can coexist.

If interpreted as a mental process of perception, then the person is obviously the *Experiencer*. It can also be interpreted as an existential process, where the pain is obviously the *Existent*. At this stage, what should be noted about this construction is that it introduces the person in the picture by thematising it. In Italian, as in English, there is a tendency for the theme to appear in initial position (Vincent, 1988; Maiden and Robustelli, 2000).

These are complex clauses in that they share aspects of the process types mentioned above. They present a picture where a body part is the locus in which pain resides as well as being the cause of it. If it is true that by situating pain in a body part it is somehow pushed away from the whole self, it is also true that the personal pronoun in thematic position does not allow it to be pushed too far. Since Italian, as mentioned above, has no exact grammatical equivalent to the ‘I hurt/am hurting’ type, this structure can function discursively as pain avowal and introduction/justification for subsequent, more detailed pain talk.

There are no instances, in the ALOMAR Plus corpus, of intransitive-agentives. These are constructions of the ‘that hurts’ type, where *that* refers exophorically to ‘some entity or nominalised process [...] ‘what you just did to me’ (Halliday, 1988: 21). It is ‘agentive’ because of the presence of an *Agent*, the external cause of, in this case, the pain.

It is not surprising that this construction is not attested in the corpus. All the participants were relating their experiences of pain; there was no action occurring at the time, some kind of physical contact, for example, that might have caused pain. A corpus of doctor-patient (or, even more, of, say, physiotherapist-patient) interactions is likely to contain a fair amount of these.

Equally absent from our corpus are transitives, of the 'that's hurting me' type, where *that*, again refers exophorically to an event, a happening in the real world which causes pain. This differs from the previous construction in that a second participant (*me*, in this case) is present. Again, the nature of the communicative situation in which our interviews were gathered accounts for the absence of this construction from the data.

3.15 Pain as quality

As well as a *noun* and a *verb*, 'pain may be worded as an adjective, realizing a quality' (Halliday, 1988: 13). It is to this type of construal that I shall turn my attention in this section. As for the previous sections, I shall mention which lexical items are used, in what constructions, and subsequently comment on the findings.

In the ALOMAR Plus corpus, the lexical items realising the construal of pain as a quality are, *doloroso* (3), *dolorante* (3), *sofferente* (3), and *dolente* (3); all could be translated into English as 'painful', 'sore', or 'aching'. So, given that pain here is a quality, it follows that the next question to ask is, as Halliday (1988) does, of what it is a quality. Halliday (1988) identifies (based on his

limited corpus) four settings in which this particular construal appears. They are:

- 1) -Pain as a quality assigned to a part of the body, where it may function as *Epithet*, as in *a sore stomach*²⁶; such body part may of course be possessed, as in *my sore throat*.
- 2) Pain may also function as *Attribute*, as in *it [the stomach] didn't seem to be particularly tender*.
- 3) -Pain may be 'a quality assigned to the whole person' (p. 13); this is a case in *he's sore there, he's just a bit more tender*. In this case, it functions only as an *Attribute*.
- 4) -Pain as quality 'may be assigned, as *Attribute*, to a general setting, with impersonal *it* and often with spatial location: *it's tender there, show me where it's sore*.' However, it is not always easy to decide whether 'it is functioning in this way, with the clause as an existential attributive (cf. *The weather*, as in *it's cloudy today*), or is anaphoric to a previous *pain* or *ache*. But such instances seem to be blends rather than ambiguities - a listener does not need to resolve them one way or the other'.

Using the above principles as guidelines in this analysis, I shall look at the examples taken from the ALOMAR Plus corpus and make adjustments wherever required by the particular nature of the data.

²⁶ All examples are from Halliday, 1988: 13.

In the majority of the constructions, adjectives function as *Attribute*. An *Attribute*, in SFG, is defined as one of the two participants in a relational clause. Relational clauses, as mentioned, are those of *being* and *having*, and there are two parts to the 'being' and 'having'. A relationship is set up between two separate entities, one of which is a 'quality', rather than a 'thing'. As Thompson (2004: 96) rightly points out, it should be remembered that 'strictly speaking, neither of the basic experiential terms, 'process' and 'participant', are completely appropriate for this category.' There is no process in the sense of something happening. Besides, 'although there are always two concepts - one on each side of the relationship - there is only one participant in the real world.' Keeping this in mind, let us consider the following two examples:

(3.38) If a joint is painful. (V I: 3)

(3.39) But it is a painful finger. (A I: 4)

Here *dolorante* 'painful' is an *Attribute* and the second participant in the relational clause. Although, strictly speaking, it is true that, as Thompson points out, this is not a process in the canonical sense, there is something in the choice of adjective that maintains a trace of pain as a 'doer' and, consequently, of a more prototypical process. *Dolorante* is one of a number of adjectives in Italian originally derived from verbs. Often, these adjectives maintain a meaning closely related to the verb they came from. Traditionally

referred to, in Italian grammars, as ‘present participles²⁷’, they are normally almost identical to the gerund; the former ending in *-ndo*, the latter in *-nte*: *occupando-occupante* ‘occupying’. Frequently, adjectives ending in *-nte* are very close in meaning to English verbal adjectives ending in *-ing*. Therefore, I suggest that although not a prototypical process with one or two participants and a ‘happening’, or ‘doing’, the choice of *dolorante* over *doloroso* preserves traces of the dynamic nature of pain referred to above.

3.16 A quality of what?

In fifty per cent of cases (six out of twelve), we are dealing with a quality of a body part: a joint, a finger, hands, knees, and a foot. In two cases, it is a physical, ‘abnormal’ entity on the sufferer’s body possessing the attribute of painfulness: ‘spots’ (*macchie*) on the skin in two cases and small lumps (*noduli*) under the skin in the other. In the two remaining instances, the quality is ascribed to pain itself. In one case (F I: 6), it is a quality ascribed to an action (here expressed nominally), a series of ‘small pinches’ (*questi pizzicottini*). Finally, in one case painfulness is ascribed to a series of events affecting the body. Following Marta’s description of a number of symptoms (burning sensation and acute night pain in the hands, swelling of the ankles etc.), I asked her whether the first ‘manifestation’ (*manifestazione*), meaning the first symptom to appear, was pain itself. To which her reply was:

²⁷ For reasons why this label is potentially misleading, see Maiden and Robustelli, 2000: 58.

(3.40) No no [...] the hands, it [the 'manifestation'] was painful. (M I: 4)

In this case, painfulness is ascribed to a physical event; what Marta is saying is that the first symptom was the appearance of pain itself rather than, say, a painless swelling or colouring of the skin.

A first observation is that, in the ALOMAR Plus corpus, in no case is pain represented as a quality ascribed to the whole person, holistically. *Sono dolorante* ('I am [all] sore'), which is grammatical in Italian (but less frequent than its English counterpart), is not used by my informants. Pain, in other words, is almost exclusively a localised phenomenon, the attribute of a body part or an entity located somewhere on the body.

3.17 Identifying relational clauses

All the clauses referred to above exemplify attributive relational clauses. This, however, is not the only type of possible relational process; the second type is called an 'identifying relational process'. These serve to identify one entity in terms of another. Consider the following example from the corpus:

(3.41) The hands and the knees have always been the most painful parts.
(Am I: 3)

Here Annamaria equates her hands and knees with the most suffering body parts; one entity is identified in terms of another. In an identifying relational

process the predicator (*sono sempre state* ‘have always been’, in this case) is - in the words of Thompson (2004: 96) - ‘equivalent in a way to an equals sign’. This explains why they are reversible, so that ‘the most painful parts have always been the hands and knees’ is propositionally equivalent²⁸.

In an identifying clause, a specific realisation is related to a more generalisable category. In SFG, the former is labelled *Token*, while the latter *Value*. So, in this example *the hands and the knees* are the *Token*, the specific embodiment while *the most painful parts* the *Value*, as shown in Figure 3.9:

<i>Le mani e le ginocchia</i>	<i>sono sempre state</i>	<i>le parti più sofferenti</i>
Token	Process: rel, ident	Token

Figure 3.9. Identifying clause.

The second example of relational, identifying clause is the following, by Gina:

(3.42) The most acute, fastidious, let’s say painful pain is when it gets me here. (G I: 3)

²⁸ However, as Thompson points out, the two versions are not interchangeable in use. For a detailed discussion of why this is the case, see Thompson (2004: 118-20).

Here the embodiment, the token of a more general category, the value, is *the most acute, fastidious, It's let's say painful pain*. In these latter two examples too, as in the previous ones, the locus of pain is not the whole self, nor a general setting; it is again a body part, or body space.

3.18 Localisation as detachment?

Talking about pain, like talking about other experiences, implies a structuring of the experience itself, achieved, as frequently pointed out, through the lexicogrammar. It was quite surprising to observe that in the constructions examined in this section, pain was always located at the periphery and did not reside in the whole person. The painful entity is always, for the ALOMAR Plus speakers, a peripheral, localisable part.

Even in the constructions considered in the previous sections, this 'peripheral' construal is prevalent. A natural question to ask is, therefore, whether this de-centring is determined by the language itself or whether it is somehow favoured, if not determined, by the context in which the stories were told.

I have already pointed out that the grammar of Italian does allow constructions where the quality of painfulness is ascribed to the whole individual (*sono dolorante* or *sono tutto dolorante*, 'I'm (all) sore'²⁹). It is therefore not because of a linguistic lacuna that we do not find holistic adjectival constructions in the corpus.

²⁹ The expression *sto male* 'I'm unwell' might be added to the list.

A promising avenue in the exploration of why it is only body parts that are referred to as 'painful' might be to look at their possible discursive function. A common characteristic of all the collected interviews is that they are told by chronic sufferers; that is people who have been living with their particular condition for a long period of time. The telling of their stories does not possess the same urgency it would have if told in another context like, say, a consultation with a doctor where the novelty of the problem guarantees its foregrounding. When illness and pain make their first, often sudden appearance, they tend to occupy a centre-stage position in the sufferer's world; they are often overwhelming. This pre-eminence of the pain experience can have its linguistic counterpart in the way it is structured and presented. As seen in the previous section, when pain is construed as a *process* the centrality of self can be reflected in what I referred to as *personal-intransitive constructions* of the *I hurt/am hurting* type. This holistic approach can be maintained when configuring pain as a *quality*, by making it a quality of the whole person.

However, for patients experiencing chronic pain, pain acquires a certain familiarity; it gets, in other words, 'historicised'. By making pain more localised, sufferers may be signalling, albeit unconsciously, their detachment, their ability to talk about it more objectively. One should also note that of all the adjectival constructions none appear in a configuration of possession, accompanied by a possessive adjective. In a language like English, this might be a further sign of disembodiment. This is not the case in Italian, where one's body parts are normally referred to using the definite article, rather than the possessive.

3.19 Concluding remarks

The aim of this chapter has been to present and discuss an inventory of the lexicogrammatical forms through which the experience of bodily pain finds its linguistic embodiment in the speech of a group of Italian chronic pain sufferers. In the opening section of the chapter, I presented a brief overview of Halliday's Systemic Functional Grammar (SFG), the main theoretical framework which informs the analysis. In particular, I outlined the part of SFG that deals with the 'clause as representation' of reality: the so-called 'ideational function', introducing and explaining the relevant terminology. Reasons were given for selecting this particular framework; they include SFG's view of grammar as a 'theory of human experience'.

Having identified a number of 'key lexical items' present in the corpus for each possible construal (i.e. *participant*, *process*, *quality*), the items were counted. It emerged that by far the most common construal of pain is as a *thing-participant*, normally realised by a noun. In second position, for number of occurrences, is the 'processual' construal of pain, through a verb. Finally, with a total of twelve occurrences, the least common construal is that of pain as a quality of either a body part, or of what I have termed a 'body formation'.

When construed as *thing-participant*, pain is realised lexically by *dolore* and only marginally by the less specific *male* and *sofferenza*. In only one case a more complex figure is set up, where the location of pain is used to construe a particular kind of pain: *mal di testa*: 'headache'. This kind of compounding (body part+ache) is common in English and other Germanic languages.

As a participant, pain may enter into various configurations of possession. Ownership can be indicated with a possessive, such as *il mio* 'my'. However, although grammatical in Italian, constructions of the *il mio mal di testa* 'my headache' or *il mio dolore* 'my pain' do not appear at all in the corpus. This is not, however, the only way through which possession can be encoded by the grammar. Far more commonly in the corpus, speakers configure possession of pain through a relational process, where the possession of pain (the Attribute) by the individual (the Carrier) is indicated with the verb *avere* 'to have', as in *io ho un dolore al polso* 'I've got a pain at the wrist.'

Interestingly, although the grammar of Italian allows it, there are no occurrences of a configuration where a body part is the *Carrier*. It was suggested that a possible explanation for this is that such configurations would shift the focus of the message to the body part in question, by thematising it. The speakers are, after all, telling a story about themselves; and it is they who are suffering and have suffered, not a body part. Throughout their narratives it is their point of view, their perspective which is constantly represented and carried through.

Pain is a prototypical possession in that it can be acquired and received, owned and lost. Unlike other possessions, however, it cannot be disposed of as easily. It is not uncommon for pain to occupy the position of grammatical subject, often displaying a degree of agency. It was noted that often pain becomes the property of its owner entirely on its own terms. It was also noted that this understanding of pain as a free-agent is at the base of many folk models of both pain and illness.

Pain has temporal location as well as duration. When pain is a participant, these are normally represented in the clause as *Circumstance* through adverbials, adverbial groups, and prepositional phrases. The duration of pain can also be represented through adjectives, which may function both as *Epithet* and *Attribute*. It was observed that, contrary to expectations, there were not many instances in the corpus of duration of pain construed as *Attribute* in a relational clause (cf. *il dolore era costante* ‘the pain was constant’), with pain as *Carrier*. It was therefore suggested that this might be due to the relatively little precision that such constructions offer. The precise onset of pain is highly relevant for the sufferer and for those in charge of treating it.

Pain has spatial as well as temporal dimensions. The locus of pain is normally represented circumstantially, through an adjunct of place. For some kinds of pain, - normally more common ones – where English resorts to compounding (*headache*), Italian lexicalizes them by making the locus of pain a prepositional phrase following the head in a noun group (*mal di testa* ‘pain of head’).

As well as linguistically, it was noted that speakers resort to extra-linguistic devices, namely gestures, to indicate the locus of pain. With reference to the work of Heath (1989; 2002), I suggested that such gestures have more than a simply deictic function: they help the sufferer to ‘re-enact’ (‘dramatically’, so to speak) the progress of pain on the body surface for the interlocutor to see.

The intensity and quality of pain are obviously very relevant, both for the sufferer and for those in charge of assisting her or him. When pain is construed as *participant*, its quality and intensity are often represented

adjectivally. In many cases, where English resorts to an adjective to represent the quality of pain (as in *a burning pain*), Italian construes it nominally, as in *un bruciore*. Some terms are blends of type and intensity of pain; a *pugnalata*, (a 'stab wound') for example, is presumably a deep, sharp, intense pain. As noted, pain is a highly personal experience. Traces of this subjectivity are to be found in many of the adjectives used to describe it. *Sopportabile* 'bearable', *controllabile* 'controllable' obviously embody a subjective perspective and an evaluative component.

As intensity and quality of pain are two very problematic and varied aspects of the pain experience, speakers in the corpus rely on a combination of lexicogrammatical strategies to construe it. Construing pain as a *participant* in a process of one kind or another allows the speaker to attribute to it a number of characteristics. What I referred to as the 'objectification' of pain makes its assessment, measurement, and evaluation easier. Through its nominalisation, pain can be categorised, thus allowing the sufferer to gain a degree of control over it and consequently reduce its power to frighten, as the unknown tends to do.

Second in number of occurrences is the construal of pain as *process*, realised by a verb-form in a number of tenses. Construing pain as a process, it was argued, highlights its 'dynamic nature', its changeability, its persistence through time, and the fact that pain is something that *does* something, and it does it to the individual. Following Lascaratou (2003), a classificatory grid was used to offer a taxonomy of the various constructions where pain appears as a process. I have commented on the fact that Italian lacks a *personal-intransitive* construction equivalent to the English 'I hurt/am hurting', *soffro* 'I

suffer/am suffering' being more generic in meaning and occurring only four times in the whole corpus. A construction of the 'I suffer/am suffering' type configures the experience holistically, residing in the whole individual. Preferred by the ALOMAR Plus speakers are constructions which place pain in more impersonal settings, such as *fa male* 'it hurts', akin to existential clauses. Also common are transitive constructions which thematise the individual, with or without a body part as grammatical subject: *mi fa male anche solo un dito* 'to me it hurts even only a finger'. In the corpus, constructions of the latter type are the majority. Such constructions could also be paraphrases as in *I feel/perceive a pain in my arm*. The body part, in other words, is depicted as the locus where pain resides. It was suggested that this 'de-centring' may follow from the historicisation of the pain experience by the chronic sufferer.

Pain is construed as quality, adjectivally, only nine times in the corpus. In the majority of cases it is construed as an Attribute of a body part in a relational clause. There is no instance of pain being attributed to the whole person; it is almost exclusively a localised phenomenon. It was suggested that this localisation may be a result of the diminished 'urgency' of the experience, deriving once again from the chronic nature of the patient's problems and signalling a degree of detachment.

Chapter 4: *Evaluation* in experiences of bodily pain and chronic illness: An analysis based on *Appraisal Theory* (AT)

Pain: [...] an unpleasant sensory and emotional experience [...]. Pain is perceived in the cerebral cortex [...] and is always subjective (Marcovitch, 2005: 27; my emphasis)

The previous chapter looked at the lexicogrammatical encoding and construal of bodily pain and its experience by speakers in the ALOMAR Plus corpus. It analysed the different ways in which the lexicogrammar of Italian allows speakers to encode and construe the complex phenomenon which is physical pain.

As already noted, this particular domain of human experience – which is complex and multi-faceted - is highly subjective, in the sense that its experience (by a socio-historically located individual) varies greatly from person to person. In other words, the ‘lived’ experience of being *in*, and coping *with* pain *and* chronic illness (or *not* coping, as the case might be) shows great variation from one individual to another, adding to the apparent ineffability of pain.

The opening quotation, which is taken from a medical dictionary, illustrates how, in recent years, this particular insight (i.e. the ‘subjectivity of the pain experience’) has also become part of current medico-scientific thinking. More than other areas of human experience, bodily pain appears to be the realm of subjectivity and perhaps an ideal breeding ground for it. This was insightfully and poetically expressed by the French writer Alphonse Daudet, in his *La Douleur* (Pain), where he annotated the feelings and sensations caused by advanced syphilis, a disease which — typically for his times — he had

contracted in his youth and that in its final stages burdened him with considerable pain:

No general theory about pain. Each patient discovers his own, and the nature of pain varies, like a singer's voice, according to the acoustics of the hall³⁰.

As Scarry (1985) notes, the lexicon of pain is often limited (it certainly is in English and Italian, as the previous chapter illustrated). However, language amounts to more than just the lexicon, as also discussed in the previous chapter. At clause level and beyond (e.g. at discourse level), it offers the one in pain several tools with which to encode his or her experience. Furthermore, the lexicon sits at one end of the expressive spectrum: it can pinpoint the specific nature of an ache (*stabbing*, *throbbing*, and so on) but it does not exist in a vacuum, linguistic or experiential. Thus, structures of increasing complexity like the clause and the surrounding contextual and co-textual resources aid sufferers to voice their experiences and to provide additional information.

4.1 Subjectification through APPRAISAL

One of the ways in which speakers 'subjectify' their accounts is by 'colouring' them with personal evaluations, or opinions, concerning the events, entities, and characters which populate them. The 'personal' thus makes its way into language in several ways.

³⁰ Daudet, Alphonse. *La Doulou* (1930). English translation by Julian Barnes, (2002: 15).

As I explain below, the study of the individual's point of view offers numerous insights into this kind of lived experience and, if approached systematically, can also reveal a great deal about the tools offered by language to achieve encode the individual's point of view.

4.2 What the study of the linguistic encoding of subjectivity can reveal

First, the encoding of subjectivity as expresses by evaluation, it is one of the main tools whereby the 'linguistic individual' (Johnstone, 1996) takes shape and is maintained. Furthermore, Huntston and Thompson (2000: 6) argue for the importance of studying evaluation (their term of choice for speaker's perspective, or point of view) on the basis that it serves three important functions in discourse, and these are ever-present (only the first two are addressed in this chapter):

1. it expresses the speaker's or writer's opinion [...];
2. it constructs and maintains relations between speaker or writer and hearer or reader;
3. it organizes discourse.

Of course, these functions are not mutually exclusive. On the contrary, a single evaluative utterance may perform, and usually does, all three simultaneously.

Using one particular analytical paradigm (see below), the aim of this chapter is to look at how informants in the ALOMAR Plus corpus 'subjectify' their

experiences by evaluating things (entities), situations, events and people, and especially by expressing their own feelings about being chronically ill and in pain, (with all that this entails).

In what follows, I shall argue that telling their experiences, and especially mentioning their feelings, serves social, as well as 'descriptive', functions for sufferers, such as the creation of solidarity and the building of rapport with interlocutors — actual or potential — thus enlisting them as supportive listeners and, in a way, as 'co-authors' of their narratives.

The analysis in this chapter will also serve to further problematize Scarry's (1985) notion of bodily pain as 'language-destroying'. As the analysis in this chapter demonstrates, the experience of bodily pain may indeed be challenging for language, but it also shows how resourceful an instrument it can be.

4.3 Terminological issues in the study of perspective or point of view: stance, evaluation, appraisal

One of the main ways in which speakers achieve this 'subjectification' – in which the 'personal' makes its way to, and *through*, language - is through what has been variously referred to as *stance* (or *stancetaking*), *evaluation*, or *appraisal*. By using these terms, as we shall see, researchers may be referring to different (albeit similar) phenomena, and showing allegiance to different theoretical orientations and research interests. However, broadly speaking it can be said that all these terms refer to the displaying by speakers of personal attitudes and points of view.

4.4 *Stance, appraisal, evaluation*

Both in its common and more specialised meaning, *stance* is a good superordinate term under which a number of phenomena of the linguistic display of self, personal attitude, and so on can be grouped. One of the most recent scholarly contributions to the study of *stance* is Jaffe (2009). This study offers a number of contributions on stance from a sociolinguistic perspective. Jaffe (*ibid* p. 3) writes that *stancetaking* - taking up a position with respect to the form or content of one's utterance – is central because speaker positionality is built into the act of communication. She makes the important point (*ibid* p. 5) that *all* acts of communication are acts of evaluation and they *all* act as 'alignment or disalignment (thus positioning) with other subjects.'

Biber and Finegan (1988: 1) refer to stance as 'the overt expression of an author's or speaker's attitudes, feelings, judgement, or commitment concerning the message'. Eggins and Slade (1997), talk of *appraisal*. They use the term to 'refer [...] to the attitudinal colouring of talk along a range of dimensions including: certainty, emotional response, social evaluation, and intensity' (p. 124). Interestingly, they include social evaluation among the dimensions addressed by *appraisal*. Consequently, *appraisal* is seen as not only the locus for individual evaluations, but also for the expression and negotiation of social ones.

Huntston and Thompson (2000: 5), who as seen prefer the term *evaluation*, concede that it is 'as slippery as any of the others in [the] field [of research of speaker/writer's attitudes]'. They point out that among the wide variety of terms in use 'some are in effect synonymous, while others cover slightly

different overlapping areas' (*ibid* p. 2). Martin (2000), Martin and Rose (2003), and Martin and White (2005) talk of *appraisal*.

Because the framework of analysis that I adopt for the investigation of subjectivity is the one developed by Martin and his colleagues, I shall speak of *APPRAISAL*³¹. This is a superordinate term referring generally to the expression of evaluation and personal position in discourse and, more specifically, to its analysis within the specific framework used in this chapter.

This is consistent with how Martin and White (2005: 2) define *APPRAISAL*:

[A] cover-all term to encompass all evaluative uses of language, including those by which speakers/writers adopt particular value positions or stances and by which they negotiate [them] with either actual or potential respondents'.

4.5 Overview of AT

In this section, I shall give an overview of the theoretical framework adopted in the present chapter and explain the reasons for its selection.

AT has been developing within SFG over a period of 17 years and has received contributions from, and has been applied by, a number of researchers (e.g. Adendorff, De Klerk, and Van Genechten, 2009). Just like its 'mother theory' (SFG), *AT* has aimed from the beginning to be both a theory and a practical tool for analysing texts.

AT emerged out of what was initially a model for analysing interpersonal meaning which 'could handle AFFECT alongside *modality* and *mood*' (Martin

³¹ In AT (Appraisal Theory), it is customary to capitalise this label, as well as those identifying types of attitudes (see below), such as AFFECT, APPRECIATION, and JUDGEMENT. I shall follow this convention here.

and White, (2005: xi). In the process, the focus of research broadened beyond AFFECT and began considering lexical resources for judging behaviour as well as appreciating the value of things. Significantly, it also recognised the existence of 'syndromes of appraisal' (Martin and Rose, 2003) in different types of texts and discourses. What this means is that evaluation develops dynamically and unfolds prosodically in discourse and in texts, hence the need for a more global approach to its study. *AT* is still evolving and being added to. Of all the different but related strands of *AT* in existence, the one that I am following more closely in my analysis is the one developed principally by Martin and which has resulted in a number of published works, often co-authored. Of these, the main ones that form the basis for this work are: Martin (2000a), Martin and Rose (2003 and 2007), and Martin and White (2005).

As previously mentioned, *AT* is overtly discourse-based and user-oriented, as well as firmly grounded within a specific, easily recognizable theoretical framework (SFG). The framework captures well the dynamic nature of interpersonal meaning, bringing it nicely together under one label. *AT* acknowledges that the task of evaluation is performed in language through a number of lexicogrammatical devices and across whole texts. Usefully, it introduces the concept of 'prosody of attitudes' (Martin and Rose, 2003: 27). *Attitudes* and interpersonal meanings in general 'are often realized not just locally [e.g. at clause level], but tend to sprawl out and colour a passage of discourse, forming a 'prosody' of attitude.' Therefore, through *AT* one can look at evaluation as a more global phenomenon and therefore pick up traces of it

that might be overlooked under other, more 'local' and lexically-based approaches.

A question then can be asked, in relation to this section of the present research: In a personal story of suffering and pain, which elements are foregrounded, what becomes the object of a speaker's evaluation? Are such evaluations mainly positive or negative?

One of the starting assumptions with which this project began was that – on the whole – pain and illness would be overwhelmingly evaluated negatively. Surprisingly, this – as will be shown – turned out not to be always the case. The evaluations expressed by the ALOMAR Plus speakers are manifold and variously nuanced. This is made possible by the lexicogrammatical choices afforded by the system. A 'holistic' analytical approach – such as that offered by *AT* – helps the researcher to better identify these phenomena. *AT* looks not only at the linguistic means used by speakers to encode and present their feelings and evaluations; it also considers 'those means by which they more indirectly activate evaluative stances and position readers/listeners to supply their own assessments.' (Martin and White, 2005: 2). These evaluations - the authors argue – are relevant not only because of what they reveal about the speaker's stance but also because they 'operate rhetorically to construct relations of alignment and rapport between the writer/speaker and actual or potential respondents' (p. 2). This is apparent in the language of my informants where one can detect a preoccupation with, and attention to, the possible responses of not only the interviewer, but also of 'possible audiences', whether present, past, or future.

4.6 *The linguistic realization of APPRAISAL*

When looking at the linguistic instantiation of APPRAISAL, one soon notices that it is realised lexicographically through adjectives, adverbials, nouns, and verbs, as well as whole clauses. This is not surprising; just as a musical composition relies on overall structure and tempo to build a coherent, yet complex, piece that is able to evoke a number of emotional responses, so language spreads the burden of the representation and communication of the self over a number of loci and uses a variety of means³². *AT* is also concerned with the linguistic phenomena that have been studied traditionally under headings such as ‘modality’ (especially, ‘epistemic modality’) and ‘evidentiality’: if one is to be believed when she tells a personal story, then she must present evidence (linguistic and, where possible, extra-linguistic) to support her claims.

Martin and White (2005: 2) extend traditional accounts ‘by attending not only to issues of speaker/writer certainty, commitment and knowledge but also to questions of how the textual voice positions itself with respect to other voices and other positions’.

³² The task of attitudinal positioning is carried out by para- and extra-linguistic, as well as linguistic means: body posture, intonation, voice pitch and gaze should be taken into consideration as well. Obviously, the scope of this work does not allow such multimodal analysis; hopefully, future studies will.

4.7 The functions of APPRAISAL in AT

In the APPRAISAL system, evaluation as a whole (i.e. APPRAISAL) achieves three main, overall functions: *attitudinal, dialogistic, and intertextual* positioning. Of these, the most relevant for the discussion in this chapter is *attitudinal positioning*. This function is used by authors (speakers and writers, as noted) to provide gradable positive or negative assessments of people, places, things, happenings, and states of affairs: the 'entities' which populate the world around us. Perhaps this is the most familiar of the functions of APPRAISAL under the various labels with which it is studied.

4.8. The three Attitudes encoded by APPRAISAL

Attitudes constitute, within APPRAISAL, a sub-system for the expression of what one can generally term 'feelings'; these include emotional reactions, judgements of behaviour and evaluation of things (Martin & White, 2005: 35).

Figure 4.1 shows the three *attitudes* identified by AT:

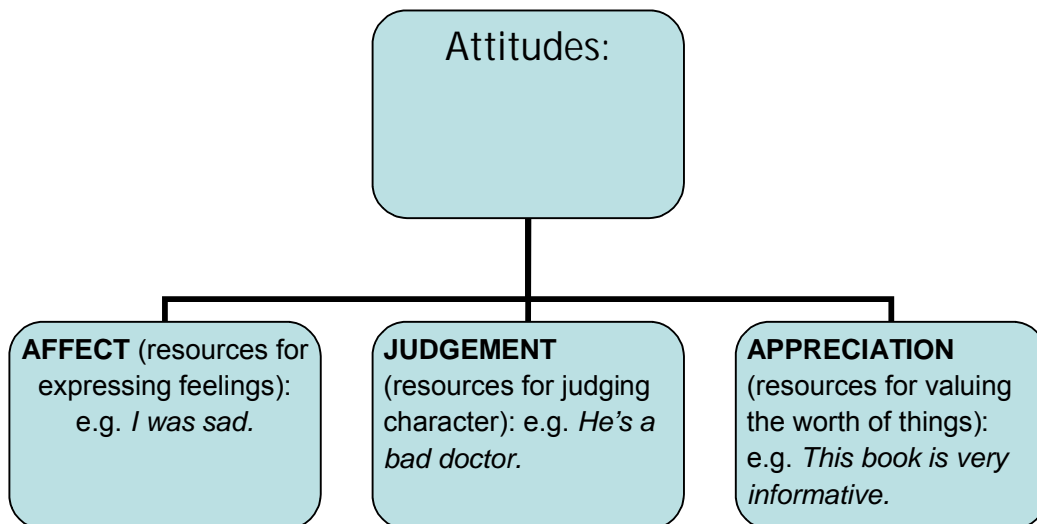


Figure 4.1. Attitudes encoded by the APPRAISAL system.

When operating within the system, a speaker selects one of the attitudes to be encoded. It is worth remembering that, in SFG, a *system* entails the possibility of making choices. Once the author chooses to resort to it, he or she has to select the *attitude/s* to encode and the lexicogrammatical means with which to do it.

4.8.1 AFFECT

Consider the extract (4.1). Fabio, who, as seen, suffers severe pain due to a protrusion of one of the spinal discs, is talking of the effects that the constant, intense pain had on him. Underlined in the passage is the expression of AFFECT:

Extract (4.1) (F I: 3-4)

Fabio: [The pain] was always there. So it, it wasn't enough to say, well, I shall go to bed and rest, no. It was, I'd fall asleep and this pain was there, I'd wake up and it would be there again. So the nights were

really bad; I repeat, it was more, an unnerving thing, stressful,
more than the pain itself [the fact that the pain was constant].

The extract is interesting because it shows this speaker using APPRAISAL to do, typically, more than one thing at once. He generally *evaluates* his experience of living with pain (which, as we shall see, constitutes APPRECIATION) and to encode AFFECT. In so doing, he voices, in this instance, his feelings about having to live with pain constantly, day and night. As mentioned, what transpires here is Fabio's exasperation at never being left alone by his pain. What the passage foregrounds is neither the *quality* of the pain (its type), nor its *intensity*. What the speaker wants us to "see" is the *effect* that pain had on him, especially because of its persistence. To this end, he uses a number of relational clauses where qualities (*stressante* 'stressful', *snervante* 'unnerving') are attributed to nominalised events: *falling asleep* and *waking up*, in both cases with the attendant circumstance of being in pain. Pain itself, in this passage, is not evaluated at all: its effects are. By so doing the speaker lets us know, obliquely, how he felt. The underlined parts neatly illustrate one of the two ways in which AFFECT can be codified: as *evoked* (i.e. *implicit*) rather than *inscribed* (i.e. *direct*³³). Martin (2000: 155) argues that APPRAISAL markers may be 'directly construed in the text, or implicated through the selection of ideational meaning.' As we shall see, the latter is something that speakers in this corpus do quite often. Especially when expressing affective meanings, speakers appear to favour the *inscribed* (i.e. direct; explicit) mode. This, as will be argued, has the advantage of positioning

³³ In the first edition (2003) of their book, Martin and Rose use the terms *evoked* and *inscribed*. In the latest edition (2007), they use *direct* and *implicit*.

the speaker's statement as factual, whilst simultaneously a disavouring an 'emotional' persona.

Using *evoked* (implicit) AFFECT is also an effective strategy for aligning the interlocutor. One cannot really 'access' or understand another's pain, but it is certainly easier to sympathise with the condition of having to go to sleep in pain and having to wake up still in pain. It is through a number of existential clauses (e.g. '*the pain was always there; well, it was there, it was there; I'd fall asleep and this pain was there*', as Fabio in extract (4.1) says) that the speaker invites the hearer into his world of constant pain. Here he relies on his interlocutor's cooperation and shared world-knowledge to provide an accurate depiction of his inner world and his lived experience.

As Martin and White (2005: 6) note, '[r]eports of one's own emotional reactions are highly personalising. They invite the addressee to respond on a personal level, to empathise, sympathise or at least see the emotion as warranted and understandable.' It is easy to see, then, how the three functions of APPRAISAL mentioned above cannot easily be separated from one another. The implicit request for sympathy, for example, involves a degree of dialogistic positioning. AFFECT, then, is 'concerned with emotions, with positive and negative emotional responses and dispositions' (Martin, 2008: 12). It is a lexicogrammatical window on the individual's inner-world and can be expressed through a variety of lexicogrammatical means. A synopsis of the lexicogrammatical means used to encode AFFECT is shown in Figure 4.2.

Lexicogrammatical means which can be used to encode AFFECT	
verbs of emotion (mental processes)	<i>love/hate</i>
adverbials	<i>happily, sadly</i>
adjectives denoting emotion	<i>happy, sad, pleased</i>
nominalisations	<i>joy despair ('his <u>fear</u> was obvious to us all')</i>
whole clauses	<i>the sadness was there</i>

Figure 4.2. The lexicogrammatical encoding of AFFECT.

It is not surprising that, given the great variety and complexity of the 'inner-life', language resorts to a variety of lexicogrammatical resources to encode it. Of course, the identification and study of AFFECT as a relevant linguistic phenomenon does not begin with AT. Ochs and Schieffelin (1989) published a now-famous article whose epigrammatic has rightly become a classic: *Language has a heart*. For the two authors, *affect* has a broad meaning. It includes 'feelings, moods, dispositions, and attitudes associated with persons and/or situations' (p. 7). They then go on to define their research agenda as the 'conventional displaying of *affect* through linguistic means.'

4.8.2 JUDGEMENT

Within AT, this label refers to the following (Martin, 2008: 30, 31):

[An] attitudinal evaluation in which human behaviour is negatively or positively assessed by reference to some set of social norms. [...] Under JUDGEMENT, we are concerned with language which criticises or praises, which condemns

or applauds behaviour – the actions, deeds, sayings, beliefs, motivations etc. of human individuals and groups.

Like AFFECT, JUDGEMENT can be *implicit* ('evoked') or *explicit* ('inscribed'). When overtly expressed, 'the evaluation is explicitly presented by means of a lexical item carrying the JUDGEMENT value, thus *skillfully*, *corruptly*, *lazily*, etc.' (p. 33). JUDGEMENT values can be 'triggered' by elements presented as simple 'facts', which apparently are only unevaluated statements of events or states of affairs. But the important, often-overlooked fact is that "these apparently 'factual' or informational meanings nevertheless have the capacity *in the culture* to evoke JUDGEMENT responses (depending upon the reader's social/cultural/ideological reading position)" (my emphasis).

This again shows the construction of the pain and illness story (or any story, for that matter) as a 'cooperative' effort. It shows how the interlocutor may appear to be a passive receiver of a narrative whereas instead s/he is actively involved – albeit often unconsciously – recruited into the building of the emerging story, because the author relies on his/her world view to sustain a particular 'reading' of events. In the following analysis, I shall look at these judgements (when present), explicit and implicit, and the function(s) they may serve within the emerging narrative.

4.8.3 APPRECIATION

This last subcategory of attitude deals with:

[E]valuations which are concerned with positive and negative assessments of objects, artefacts, processes and states of affairs rather than human

behaviour. In some cases, however, human participants may also be 'APPRECIATED' – in cases where the assessment does not directly focus on the correctness or incorrectness of their behaviour (Martin, 2008: 44).

Along the subjectivity spectrum, APPRECIATION, together with JUDGEMENT, is at the lower end. At the top of the spectrum is AFFECT. This is because it is in the expression of what might be generally referred to as 'feelings' that a speaker has the highest degree of 'involvement'. Of all the *attitudes*, AFFECT is the one which allows for the highest degree of subjective involvement and exposure. As will be seen, this affectual colouring (*evoked* more than *inscribed*) is prominent in the interviews that constitute the ALOMAR Plus corpus and, as will be shown, this is in large part responsible for their personal, subjective tone.

4.9 Previous application of AT in the study of health communication

The use of AT to analyse health communication is not new. Adendorff, De Klerk, and Van Genechten (2009) have adopted it to describe and analyse the use of evaluative language in a corpus of transcribed interviews collected over a period of four years with Xhosa English speakers. Informants varied in gender and age; they were all of direct Xhosa descent; their exposure to and proficiency in standard South African English varied and all belonged to disadvantaged socio-economic backgrounds.

The recorded conversations did not specifically aim at eliciting evaluations about HIV/AIDS. However, given the high levels of infection in South Africa and considering that the socially disadvantaged, such as the informants, tend

to experience a higher prevalence of HIV/AIDS infection, the topic appeared often.

Like pain and chronic illness (which — thanks to current treatment with antiretroviral drugs — HIV infection now is), HIV/AIDS were seen as triggers for emotive speech. In addition, the importance of language in raising awareness about crucial health issues was seen by Adendorff et al. (*ibid*). This — notwithstanding the important differences between HIV/AIDS and the conditions that affect the participants in the present study — is also true for the issues raised in the ALOMAR Plus corpus.

Adendorff et al.'s research clearly illustrates the usefulness of AT in uncovering linguistic features and patterns related to emotion in health communication. Health is a central matter in the individual's perception of his/her own identity and sense of self. Ill-health causes a breakdown not only in the biological functioning of the body but also — crucially — in overall emotive well-being. This latter aspect is often overlooked in biomedically-informed encounters with health professional and others. Crucially, a patient's distress cannot be picked up even by the most sophisticated diagnostic tools and — as previously noted — may only be visible in language. To this end, AT can be usefully used as a linguistic 'diagnostic tool'. It is perhaps in this linguistic environment (i.e. evaluation) the traditional distinction between bodily and mental pain loses most of its meaning.

Adendorff et al. also look at the different effects — in terms of interlocutor's alignment, that *evoked (indirect)* and *inscribed (explicit)* attitudes (in particular AFFECT) *have on interlocutor alignment*. They convincingly argue that evoked options, which are less 'precise', allow for greater 'interpretative

latitude' (p. 143), as opposed to *inscribed* options which, being more explicit, are 'less open to such negotiations [...]. [They] make[...] resistance or non-compliance with one's interlocutor invitation to accept a specific listening position much more difficult' (p. 143).

This chapter addresses this issues and it takes up Adendorff et al.'s invitation to utilise *AT* beyond the realm of SFG because of the precious insights it can offer in understanding the illness experience and in particular, as I shall argue, the experience of pain.

4.10 Attitudinal positioning in the ALOMAR Plus corpus

One of the first questions one asks when told by somebody that they are in pain is: 'How do you feel?' Not uniquely among human experiences, illness and pain generate in the experiencer various responses. Asked how she or he is feeling, the afflicted person might offer a report of the particular pain or condition afflicting her/him. However, soon enough the interlocutor is likely to be informed about how the sufferer *feels* about it; about the emotional response that pain engenders.

In the remainder of this chapter, I shall be looking at the encoding of APPRAISAL in the corpus, usually beginning with AFFECT and then moving on to the other *attitudes*. As the analysis will show, identifying a particular token as a representative of a single *attitude* is not always as straightforward as might be expected. With regards to AFFECT, I shall be focussing on its type (e.g. positive or negative), and function.

Unlike for the previous chapter, the analysis will consider each informant separately, becoming in effect a series of smaller-scale 'case-studies'. This choice will allow a better appreciation of the evaluative richness of each speaker's contribution. All the single sub-sections will then be considered together in the concluding section of the chapter, which will offer a kind of 'panoramic' view of APPRAISAL choices in the ALOMAR Plus corpus.

For the classification of AFFECT, I shall follow Martin and White (2005: 42-52). What they offer is 'a framework for mapping feelings' (p. 42). For the two authors, *attitude* is viewed as a 'discourse semantic system' whose realisations 'diversify across a range of grammatical structures' (p. 45). As noted, similarly to what happens with the construal of pain by the lexicogrammar, the encoding and construal of AFFECT is a task shared by various elements of the lexicogrammar. So, for example, AFFECT too can be construed as a 'quality' that describes participants (*a **happy** doctor*. Epithet), attributed to participants (*the doctor was **happy***. Attribute), or as a manner or process and realised as a Circumstance (*the doctor smiled **happily***).

Different types of 'processes' are also used, like affective-mental: *her words **saddened** him*; affective-behavioural: *the patient **laughed***. Also, in narratives AFFECT can and often does appear as a 'comment' and is realised through a Modal Adjunct: ***sadly**, she didn't stay*. Other means include grammatical metaphors, nominalised realisations of qualities (*joy, sadness, sorrow*) and processes (*grief, sobs, constriction in his throat*) (p. 46). To begin the analysis, the interviews were scanned to identify 'tokens' of APPRAISAL, which were then identified as being examples of AFFECT, JUDGEMENT, or APPRECIATION.

4.10.1 Anna

Anna's interview, although not particularly long, stands out for its high number of tokens of AFFECT (19). The term 'token' is meant to refer to any lexicogrammatical item or items encoding — in this case — AFFECT. As previously mentioned, 'tokens' of any *attitude* can vary in complexity: from a single lexical item to a whole clause.

Of all the informants, Anna appears to be the one least 'adjusted' to her condition. The impression one forms when listening to her account is one of a highly emotive response to her current predicament, as demonstrated, for example, by the frequent use of emotionally charged lexical items, such as *lancinante* 'lancinating'. The number of AFFECT tokens clearly contributes to rendering this account highly personal, both offering and eliciting personal involvement.

As Table 4.1 below shows, in the majority of cases, the tokens of AFFECT are example of *negative* AFFECT (13 out of 19, only one of which is ambiguous). Martin and White (2005: 49) provide a further, finer classification of affect. This 'variable' in the classification of affect 'groups emotions into three major sets' (p. 49), which have to do with 'un/happiness', 'in/security', and 'dis/satisfaction'. Each token of AFFECT can be, according to the theory, classified as pertaining to one of these categories. Martin and white (*ibid*) go on to explain that the un/happiness variable is concerned with 'affairs of the heart': sadness, happiness, and love. The in/security variable pertains to 'ecosocial well-being': anxiety, fear, confidence, and trust. Finally, the dis/satisfaction variable refers to emotions 'concerned with telos (the pursuit of

goals)', such as *ennui*, *displeasure*, *curiosity*, and *respect*. In Anna's case, most tokens are representative of the *insecurity* subset of feelings classified by Martin and White.

Number of tokens of AFFECT <i>Total: 19</i>	Type of AFFECT encoded	Type of subset
13	Negative	insecurity
5	Positive	confidence
1	ambiguous	?

Table 4.1. AFFECT in Anna's interview.

As will be remembered, at the time of the interview Anna was in her sixties and suffering from an acute form of RA. Her experience is characterised by a series of wrong diagnoses and extreme pain resulting in great disruption to everyday life and also disruptive of her sense of self.

As she admits, she has a long experience of telling about her experience, especially to medical professionals. During the interview, punctuated by highly factual statements, it takes some time before her feelings are given voice. Extract (4.2) shows a passage where tokens of AFFECT in her account have been identified and underlined:

Extract (4.2) (A I: 1)

Anna: Almost immediately the pain: [inaudible] strong and, by and by it grows, and in my case at least, then it becomes really lancinating, so much so that. There have been moments, before, and even during therapy that it would get so intense, that at the thought that it would come back this pain, after a few minutes, after a few hours, I really thought that I couldn't, I wouldn't be able to continue living like this. I

would tell my husband, “look [here, at me], I can't do it, I feel like throwing myself out of the window, it's not possible.”

This passage appears at the beginning of the interview. It is rather striking that, after some factual statements about the quality and quantity of her pain (instances of APPRECIATION), which give an objective tone to her account, she offers these two tokens of AFFECT (underlined in extract (4.2) above), encoded by a succession of clauses. Both are quotative: the first of what we might term an inner dialogue (*I thought that ...*); the second of a past conversation with her husband. In both instances Anna's hopelessness is triggered by the thought of the future as a continuous repetition of her painful present.

First, she tells herself that she feels she cannot cope with the pain. Then she actually voices her desperation and her belief that she might not be able to continue living under such conditions to her husband: ‘I can't do it, I feel like throwing myself out of the window, it's not possible.’ The quoted passage is a relatively lengthy one and is particularly useful in illustrating Anna's ‘style’, her ‘linguistic self’. It is also exemplary in that it shows characteristics that will reappear throughout her account which include an attempt at ‘factuality’ and the indirect, or *evoked*, expression of AFFECT. The latter can be seen in her evaluation of her pains as *lancinanti* (‘lancinating’). On the surface, this is a case of APPRECIATION, as noted above, but, sharing her cultural world, it can also be read as evoked AFFECT and one that would normally elicit sympathy from a listener. The interlocutor becomes co-author in that he/she, faced with this factual token of APPRECIATION can easily read its true import

in term of AFFECT. He/she will 'know' how Anna must have *felt* because of the lancinating pain.

Another noticeable characteristic of extract (4.2) is its 'fragmented' syntax. By this, I do not mean that it is in any way ungrammatical (Anna is a perfectly competent speaker of Italian). It is 'fragmented' in that it consists of a series of false starts and abrupt changes of grammatical constructions. In addition, from a textual point of view it clearly favours parataxis. Chafe (1982) identifies all of these traits as typical of spoken discourse. This is certainly true but in this passage, they also contribute to endowing the passage with a more 'dramatic' tone.

As mentioned, in this passage (which is typical of the interview) of all the *attitudes* encoded by Anna APPRECIATION appears to be prominent. In it, various types of bodily pain are the entities which are evaluated the most. We are given pain's quality, quantity, and temporal attributes (how long it would last, how sudden its onset might be). Importantly, the lexical items employed to describe the pain are 'charged', meaning that they convey a strong emotional response and are likely to generate an equally intense reaction in the interlocutor: (*proprio*) *lancinante* '(really) lancinating', (*talmente*) *acuto* '(so) intense', (*molto*) *forte* '(very) strong'.

The other entity to be evaluated in extract (4.2) is the period of time in which these strong pains were occurring: it lasted three years and is described as *un bel periodo* where *bel* ('beautiful') actually means both 'bad' and 'long'. As noted, this passage too is quite typical of this speaker's style and the way she manages to convey AFFECT while not being entirely overt about it and to elicit sympathy. The passage in particular and her account in general is fairly

factual: it is about entities, like pain, and how negative they are for her. The interlocutor is bound to draw conclusions on how she must have *felt*, to identify, to an extent, with her and to offer sympathy. As mentioned, Anna resorts to emotionally charged lexicon to convey the character of her experience. Pain is represented mainly as an entity (nominally) to which descriptors such as ‘lancinating’ *lancinante*, ‘tremendous/terrible’ *tremendo*, ‘terrible’ *terribile* are attached. It is interesting to observe the semantic field from which many of the pain descriptors she employs are drawn. In extract (4.3) the pains experienced are described in the following terms:

Extract (4.3) (A I: 3)

Anna: Those [pains] in the foot are quite tremendous they too, because they are just like, you know, when the blacksmith hits the hot iron?

Further on, as shown in extract (4.4), commenting on the frequency, quality, quantity, and intensity of the pains experienced in her fingers she says:

Extract (4.4) (A I: 5)

Anna: There are moments, suddenly, that I can count tens, tens at a time [...]. it’s really like lightning [tchin, tchin] in my feet [...] intense, yes, very intense.

Hot, fast, bright; temperature, speed, light. These are some of the adjectives Anna resorts to in order to characterize her pains. ‘Like lightning’ and ‘like an explosion’ are two striking similes which can be seen as pertaining to the lexicon of war. In this speaker’s account, pain is represented like (or described in terms of) an entity waging war against the individual; its consequences and

its effects on the sufferer are described in ways that would not be out of place in a journalistic account of a conflict, as extracts (4.5-4.7) shows:

Extracts (4.5-4.7) (A I: 7-8)

Anna: (4.5) after the pain was gone [after having taking immunosuppressant drugs] without the pain, afterwards there was only the pain of the disaster.

(4.6) and afterwards the illness would do the damage.

(4.7) in October I had at night a pain here, by the sternum, right in between the breasts here, which started slowly from here [she points to her left side], and grew stronger and stronger. When it arrived here there was an explosion, as if you saw a bomb go off.

For this speaker, then, the experience of pain is obviously terrible and terrifying. With words she paints a very effective picture of what it must have been like. Interestingly, she does not say that her pain was or felt like an explosion; with an existential clause she says that 'there was an explosion', and it was as 'if you saw a bomb go off'. These images convey at once the sensory experience of pain, both its quality, and quantity. They are also particularly effective in eliciting empathy from the listener who is likely to have recalled visual images of bodies damaged by explosions.

Avenati and Agliotti (2006) claim that witnessing other people's pain has very real effects. These two cognitive scientists report how in people who witness the pain (presumed or real) of others, neurological investigative techniques show the activation of the same areas of the brain that become activated in the individual experiencing the original noxious stimulus. Although the experiments conducted by the aforementioned authors involved subjects being shown images of people experiencing painful experiences, it is plausible

to assume that through language sufferers can achieve very similar, perhaps identical, results.

Summary

This speaker's account is rich in evaluative language. Among the attitudes, AFFECT has a prominent place, especially negative of the insecurity type. 'Charged' lexical items are often used as are metaphors reminiscent of the language of war and destruction. These devices, together with syntax typical of spoken language contribute to painting the image of a highly distressed individual and are witness to the multi-dimensional nature of the pain experience.

Unsurprisingly, pain is evaluated negatively, as shown by the emotionally charged adjectives used, but even more so are the pharmacological treatments received. It is interesting to note that, in this speaker's account, the true impact of RA and the pain it causes is almost entirely communicated through AFFECT.

4.10.2 Annamaria

Annamaria has been living with Lupus for decades. Her interview was the first to take place and is the lengthiest in the corpus. She gives the impression of being well-adjusted to her condition, demonstrated, among other things, by her involvement with the support-group, which she values highly, her very active life-style, and her willingness to talk of her experience and to offer

support to other people in the same predicament. AFFECT, is displayed in several places throughout her account: the feelings and innermost sensations triggered by the experience of living and coping with a disruptive and potentially life-threatening condition. Interestingly, however, contrary to Anna's, one would not label her account as 'emotional', in the colloquial sense of the word: she is in control of her feelings, which are presented for the most part as positive or leading to a positive outcome. Through her words, Annamaria comes across as someone consciously displaying a positive attitude *vis-à-vis* her condition and, more generally, life.

The apparent effort to paint a positive picture of her experience and, ultimately, of herself, is not undermining of her sincerity. Through a skilful use of language she offers the overall impression of a balanced personality, of a woman who has successfully been coping with a chronic disease for a number of years without succumbing to it.

It is in large part through evoked AFFECT that this balance is achieved and presented discursively. Through it, the speaker informs her interlocutor of her unique point of view, her feelings and perceptions as she tries to make sense of what she has been experiencing. The skilful combination of evoked and inscribed AFFECT and, more generally, of Appraisal allows her to achieve the equilibrium that obviously matters so much to her.

As noted, APPRECIATION rests along a spectrum of involvement/subjectivity. Together with JUDGEMENT it stands at the lower end of the spectrum, while at the top we find AFFECT. An account rich in AFFECT will be read as highly subjective, as showing more involvement on the speaker's part and also, one might argue, it will engender more empathy in the interlocutor.

APPRECIATION and JUDGEMENT, on the other hand, can contribute to a more 'detached', more objective, less 'emotional' reading. Obviously, one's evaluation of an entity or of someone's character are highly subjective but they can be presented in more objective terms. One 'infers' or 'reads' the speaker's stance by paying attention to what is said about a person, an entity, an event, and so forth. With AFFECT, however, the evaluation and the evaluator are more 'fused' together and more difficult to disentangle.

There is also – it can be argued – a degree of 'iconicity' in the lexicogrammar of Attitude which fuses the evaluator more with her judgements in AFFECT than in JUDGEMENT and APPRECIATION. When a speaker says, of an entity, that it *was/looked/etc. horrible/interesting/etc.*, one can imagine the speaker standing outside of the scene and doing the evaluating. Lexicogramatically, the 'evaluator' is separated from the judgements. This, I believe, enhances objectivity, or the appearance of it. However, with AFFECT evaluation and evaluator are more difficult to disentangle. Compare, for example, an utterance such as *I felt sad* or, even more so, *I cried/smiled, etc.*; here the Attitude and its *Experiencer* are closer together. The feeling expressed and the person expressing it are more entwined, even in terms of lexicogrammar and therefore the account appears 'more involved'.

Perhaps surprisingly, of all tokens of Appraisal in Annamaria's account only a small number can be classified straightforwardly as instances of inscribed AFFECT. An example of this is extract (6), where she is talking about a period before she was given an exact diagnosis and her symptoms were thought to be indicative of a rheumatic disease but her blood tests would show no confirmation for it. For a period of about ten years, she lived in this kind of

limbo with her condition more or less stable. This all changed when she entered a period of psychological as well as physical distress which, in her view, caused her condition to deteriorate:

Extract (4.8) (Am I: 3)

Annamaria: And then I did indeed get worse, in the sense that, it's not something one just says but I've experienced on my own skin, that when one's not well psychologically, in moments of crisis these illnesses take over. And in fact, I was going through a moment of crisis, I put myself under a remarkable physical and moral [psychological] stress and I began to have bigger problems.

Stavo passando un momento di crisi ... uno stress sia fisico che morale 'I was going through a moment of crisis ... a remarkable physical and moral [psychological] stress'. These clauses clearly give voice to Annamaria's feelings, mainly through lexical choices: *crisi* 'crisis', and *stress*. This is an obvious example of negative AFFECT, triggered by some unspecified circumstance, which opens a window on her inner-world. Yet, as Table 4.2 shows, of the total 23 tokens of Appraisal in Annamaria's account less than 50% (eleven) are clearly identifiable as straightforward instances of AFFECT. Of these, five are examples of positive AFFECT.

Total number of tokens of APPRAISAL	Type of attitude encoded	Positive	Negative
23	AFFECT	5	6

Table 4.2. AFFECT in Annamaria's interview.

However, it is interesting to note that apart from these instances of explicit or inscribed AFFECT, Annamaria informs the interlocutor of her emotions more ambiguously (or indirectly), through expressions that need interpreting because of the potential for multiple readings. One of the ways in which this is achieved grammatically is through the use of expressions that have a 'double' reading: clauses that can be construed as referring to her physical as well as her psychological state. For example extract (4.9):

Extract (4.9) (Am I: 1)

Annamaria: I was [doing; feeling] very well, with cortisone I was [doing] very well.

Here this speaker begins painting an image of well-being notwithstanding her illness (the extract is from early in the interview), thanks to the medication that she was first prescribed (cortisone) that eased some of her symptoms. Although a 'physical' reading is obvious, one that refers to her mental state (one that, in other words, could be seen as an instance of AFFECT) is also plausible. 'To do/feel well' *sentirsi bene*, in Italian as in English, can refer to both physical and psychological well-being. Here, the co-text helps to disambiguate and reveals that in this case the well-being that Annamaria is referring to is pre-eminently physical. The passage comes from the opening

part of the interview; immediately prior to it, Annamaria has been listing all the physical symptoms that characterised the initial phase of her illness and the prescription of cortisone following the diagnosis. In addition, the quoted passage is in reply to the interviewer's specific question as to whether cortisone made her feel physically better. As Eggins and Slade point out (1997: 125-126), in analysing Appraisal the co-text is often crucial: 'it is often not possible to state whether a lexical item [or clause, for that matter] has attitudinal meaning until it is used in context.' Similarly, the kind of attitude encoded can only be interpreted successfully once the linguistic and cultural context is considered. However, even this unambiguous example carries, it can be argued, the possibility of more than one reading. The sympathetic listener is bound to discern traces of AFFECT in this statement of physical well-being. Being culturally positioned as sharing Annamaria's assumptions about health and illness, and the desirability of being free from pain, one can infer that her physical well-being also meant mental well-being. Eggins and Slade (*ibid* p. 126) stress the importance of taking into account 'the sociocultural background and positioning of the interactants' in interpreting utterances. In their view, '[a]ppraisal analysis must [...] be sensitive to the potential for different readings [...] of attitudinal meanings' (p. 126). Annamaria's use of sentences that allow a "double reading" is clear in extract (4.10):

Extract (4.10) (Am I: 1)

Annamaria: [Referring to her doctor's suggestion to wait until the symptoms got worse before making a more precise

diagnosis] 'I was only 21, the thing [waiting until the symptoms got worse], I didn't like it very much.'

Obviously, here the speaker is evaluating (appreciating) negatively a nominalised proposition (*la cosa 'the thing'*: having to wait longer before receiving a surer diagnosis). However, what transpires from this utterance is also a general, *negative emotion* of dissatisfaction with a state of affairs: her doctor's proposed course of action and, more broadly, being left in the dark as to the true nature of her condition.

So, although an instance of APPRECIATION on the surface, the statement can also be classified as belonging to the insecurity group of Martin and White's typology of AFFECT (see above). The speaker resorts to a mental process (*piacere*: 'to like') which lends itself to a double reading, one more 'emotive' than the other. In the less emotive reading, Annamaria is evaluating a proposition negatively (*la cosa*); however, a second reading also offers an insight into her inner world, her emotive state. And these are clearly feelings of dissatisfaction and insecurity. It is quite easy to sympathise with this informant's state of mind: in the realm of pain and illness uncertainty is particularly distressing and likely to cause anxiety.

To complicate (or to enrich) things even further, a reading of the passage above as an instantiation of JUDGEMENT could also be suggested: the doctor's behaviour is evaluated negatively, albeit in a rather "veiled" manner. Annamaria here (as throughout her account) positions herself as an active individual who challenges both the ability of pain to paralyse her and her clinician's inability to name her illness and thus somehow control it. It is interesting to note that she could have chosen to express AFFECT and

APPRECIATION separately, using distinct clauses. This, however, would have contributed to a less 'restrained', more emphatic or emotive reading. By being less explicit, Annamaria has the listener 'do more work', while simultaneously maintaining more equilibrium. In addition it should be noted that the clause in question is an example of what Martin and White (2005) refer to as 'mental processes/states' in opposition to 'behavioural surges' (the captain *disliked* leaving/the captain felt *sad* vs. the captain *wept*). Behavioural surges 'involv[e] some kind of embodied paralinguistic or extralinguistic manifestation' (p. 47), and certainly make for more 'dramatic' reading.

Later on, when mentioning the time when she suffered from pericarditis, and experienced severe, debilitating pains because of it, Annamaria says:

Extract (4.11) (Am I: 7)

Annamaria: It was a really hard period ...it was hard.

We are again faced with two instances of APPRECIATION (the evaluation of things, events, and so on) which can also be read as examples of *evoked* (implicit) AFFECT. Here 'period (of time)' is being evaluated through two clauses representing relational processes where *periodo* is a participant role to which the Attribute *hard* has been assigned. But crucially, through this evaluative stance we are also informed of how the speaker *felt* during that time. The period of time was hard *for her*. This reading is reinforced by the prosody of the two clauses. In between the two, the speaker inserts a pause, as if the mere mention of this difficult period had brought back a vivid memory of it. This is confirmed by the second clause which simply states that 'it was

hard', but for whom? For the speaker, whether a time-period is more or less hard depends a lot on the person's frame of mind.

As previously, one can detect two strands of meaning. The use of clauses that can be interpreted as expressing mainly, or primarily, APPRECIATION but which also offer an affectual reading contribute to a balanced, not over-emotional rendering and reception of the account. The grammar of these two clauses does not show a human *Emoter* (Annamaria) but an inanimate, abstract *Carrier* (time) which is a participant in a relational process. The speaker has thus transferred the 'harshness' of having a heart condition to a particular period of time, of which it is a quality; it is an 'objective' observation, rather than a 'felt' emotion. However, the experiential, subjective import of the clause is apparent to any native speaker of the language sharing in the same cultural values.

As Scheibman (2002: 120) observes, in conversation the prototypical function of relational clauses 'is evaluative and not descriptive.' She goes on to say that '[e]ven the more objective locutions are not without subjective import'; this is because simply 'choosing what to say [...] is the most basic expression of subjectivity in language' (p. 168). Included in Scheibman's use of the term 'subjectivity' are 'mental states, AFFECT, preference and evaluation' (p. 7). We are therefore presented with clauses that on the surface are instances of APPRECIATION (in itself a subjective endeavour) but that a closer reading will reveal as expressing also, or primarily, AFFECT: the speaker's feelings, broadly speaking. Evoked AFFECT incorporated in APPRECIATION clauses, can also be seen in extract (4.12):

Extract (4.12) (A I: 3)

Annamaria: And consequently if it [the illness] takes [attacks] vital organs, it goes without saying that...it isn't very easy.

Here Annamaria is talking of one of the effects of lupus which she has experienced, namely, its ability to attack the body's vital organs (like the heart, in her case). After a long pause, she uses again a negative relational clause (*non e' molto facile* 'it isn't very easy'). Typically for Italian, the grammatical subject (*it*) is unexpressed. We can interpret the *Carrier of the Attribute* (*facile* 'easy') to be the situation of having one's vital organs attacked by the disease. But by using this particular wording, she indirectly informs the listener of her feelings about this (for her very real) possibility. Similarly to what was seen previously, by resorting to APPRECIATION through this relational clause she achieves two effects. First, the account is more detached (it is, in fact, a major understatement): there is no *Emoter*, so the feeling is distanced from the speaker. Secondly, the proposition is presented as a general truth with which it is difficult to disagree. This reading is reinforced by her premising it with the evidential clause, *va da sé* 'it goes without saying.' These general statements, by virtue of their appeal to a common, uncontested understanding, align the listener as well as presenting the speaker's reactions and emotions as 'normal' and perfectly understandable, given the situation. It is interesting to note, in passing, the rhetorical effects of the juxtaposition of the evidential *va da sé* to the clause *non è molto facile* 'it isn't very easy', which frames the whole sentence as an understatement. Thus, the use of these relational

clauses allows the speaker to express AFFECT (albeit ambiguously) while simultaneously establishing her reliability.

In her study of mood and modality in Spanish history textbooks, McCabe (2004: 3) speaks of the clause as an 'interactive event between writers and readers'. Of course the same can be said of speaker and interlocutor. Citing the frequent use of unmodalised declaratives in the texts she examines, McCabe highlights how these help to build consensus around propositions. Particularly relevant is the use of the present tense which, cross-linguistically, is used to make generic statements and enhance factuality. The use of these 'generic statements' in the present tense abounds in the ALOMAR Plus corpus. It is testimony to the resourcefulness of language how they can be used to convey simultaneously factuality, subjectivity and, as I argue, AFFECT. Further on in the interview, Annamaria mentions a period when she would experience brief spells of mental confusion, probably due to minor vascular constrictions caused by lupus. She describes how, for example, she would attend her clinic and, on leaving, would not – for a brief moment – know where she was. Understandably, this was the cause of major distress. Extract (4.13) is how she describes it:

Extract (4.13) (Am I: 8)

Annamaria: Oh well, it was ... unpleasant. A sensation of...insecurity. And then well, it's clear that any physical pain, I think one can...one can deal with it, but a mental thing...I think that that is what scares the most.

Annamaria is talking about the clouding of one's mental faculties ('but a mental thing') and says that, in her opinion, that is 'what scares the most'. It is interesting to note that, in reality, she is talking about *her own* lived experience; but again she does so in general, rather impersonal terms. When she says that this temporary mental clouding is 'what scares the most', she is making a general statement which, however, is also an indication of her personal state of mind at the time. The verb *spaventare* 'to frighten' has obvious connotations of AFFECT (*somebody* is frightened; an *Emoter* is needed) but here it is not tied to any particular *Emoter*. Instead, it is presented as a mental process with an unspecified *Experiencer*.

Although not actually voiced, what the hearer understands is that Annamaria herself must have been quite frightened. The 'toning down' is also achieved through the use of 'uncharged' lexical items. The sensation is described euphemistically as *antipatica* which could be translated as 'not very nice or pleasant'; it was, Annamaria informs us, *una sensazione di insicurezza* 'a sensation of insecurity.' Both descriptors, which again allow Annamaria not to position herself overtly as an *Emoter*, are example of lexical choices which suggest a certain detachment and that favour a reading which is not too 'emotive', in the common sense of the term.

Again, we see a tendency on Annamaria's part to 'distance' emotional responses from herself and to present them as general propositions that are generally valid, even commonsensical. The view discussed here is not attributed to any specific individual or group, although she takes some ownership of the comment by prefacing it with 'I think (that that is what scares

the most)'. Again talking of her memory blips, she makes another of these general statements:

Extract (4.14) (Am I: 8)

Annamaria: If you are out of your head, it is hard.

The pattern is by now familiar: through a relational clause this speaker makes a general statement about being *fuori di testa* 'out of one's mind; i.e. having lost one's mental integrity and informing the listener that 'it's hard.' Yet, in light of all that has occurred so far in the conversation the sympathetic listener will know that this is not only a general (and, crucially, sharable) statement about the difficulty of living with impaired mental faculties, but also an instance of AFFECT: an expression of the speaker's own feelings at having to endure such difficulties.

One last example, extract (4.15), of this strategy occurs shortly after the one just discussed. Still reminiscing about the time when she experienced respiratory problems, she makes the following general statement:

Extract (4.15) (AM I: 9)

Annamaria: It is a dreadful thing.

Understandably, the interlocutor will sympathise with the evaluation of having respiratory problems as 'a dreadful thing', yet by now he or she will know that s/he has been listening to a woman who has had that very same experience;

the listener will know the terrible nature of Annamaria's emotions and sensations while experiencing pleurisy. He/she will also know that this general statement is also a very personal one; it is a statement of the speaker's own lived feelings. Notice also the lexically charged adjective 'dreadful'.

Throughout her account, Annamaria uses the lexicogrammar of Italian to inform the listener of her experience as a lupus sufferer. Through the resources of Appraisal she expresses her point of view. In her account, one finds numerous instances of AFFECT but these require a degree of interpretation and disambiguation, for they convey more than one strand of meaning.

The examples discussed above can be read as instances of APPRECIATION as well as of AFFECT. Annamaria favours the use of relational clauses, which allow her to present her inner states as general statements with which the listener can sympathise; as attributive relational processes, often with an impersonal *Carrier* rather than with overt instances of AFFECT with herself as the *Emoter*.

This recontextualisation of both JUDGEMENT and APPRECIATION as AFFECT has also been noted by Adendorff et al. (2009) in their analysis of HIV/AIDS talk. This might be a tendency of health communication in general, especially by patients. Further analysis of this type of communication using AT is therefore necessary to establish whether this is actually the case. The 'recontextualisation' of AFFECT in terms of APPRECIATION might derive — at least in part — from a desire on the part of the informants to appear as 'rational', believable, and not overly emotive. As Macken-Horarik (2003: 314) notes, 'it is implicitly evaluative meanings that are most coercive of the reader

[or speaker] simply because they appear to pass beneath the threshold of conscious awareness.'

Summary

Probably owing to its length (as stated, Annamaria's interview is the lengthiest in the corpus), this speaker's account is 'rich', from an Appraisal point of view. AFFECT appears often, both of the negative and positive type. Interestingly, for the expression of negative AFFECT, this speaker often resorts to relational clauses which, it has been argued, can also be read (on the surface) as instances of APPRECIATION or JUDGEMENT. This allows her to present her story as more 'balanced' and less 'emotive'. AFFECT is more often evoked, i.e. indirectly expressed, that inscribed. When it comes to APPRECIATION, this speaker evaluates pain mostly negatively, especially for its life-fragmenting consequences. However, on the whole, she resists evaluating SLE in an overtly negative way. As will be argued in chapter five, this is because following her diagnosis she was able (not without effort) to style a new self, more in tune with what she feels is her true personality. This too contributes to presenting a positive, rather balanced persona. Like other speakers in the corpus, Annamaria appears to leave her more negative evaluations for the treatments she has received over the years.

4.10.3 Veronica

To fully appreciate Veronica's story, one has to be reminded of the circumstances in which the interview took place. I interviewed her while she was in hospital following her 18th surgical procedure which, this particular time, was required to adjust her badly deformed knee.

Veronica's account is remarkable because, notwithstanding the severity of her condition (as well as its temporal extension) for the most part she refrains from the overt expression of feelings, with the result that it comes across as particularly 'factual'. Appraisal is present and among the attitudes expressed APPRECIATION is prominent. Of the entities this speaker evaluates pain is foremost. JUDGEMENT is present too, but in only one case.

As stated, pain features prominently in the account. This is not particularly surprising, given that she was asked specifically to talk about it and her condition. Interestingly, Veronica overwhelmingly construes her pain as 'thing', nominally; it is an entity to which particular characteristics are then ascribed. These are: *quality* (*erano come dei bruciori* 'they were like burnings'), *intensity* (*erano tutti dolori acuti* 'they were all acute pains') and *temporal characteristics* (*come e' venuto se n'e' andato* 'as it came it left [suddenly]'). In a few cases, she establishes a relationship of ownership with her pain through the possessive 'to have', where pain is again an entity that she possesses (albeit unwillingly). However, she never construes it as a 'quality', through adjectives, and only once as 'happening', through a verb. Interestingly, in the latter case, pain does not occupy the whole of her self but only a part of her body:

Extract (4.16) (V I: 2)

Veronica: At times I fall asleep on pain, because it makes me focus. Yes if it isn't a really strong pain, but if it's a pain typical of my illness, which is there, still, I focus on the point where it hurts [me], the limb, and afterward if I'm isolated, calm with/by myself, I even manage to go to sleep on the pain.

Construing pain as an entity allows this informant to place it outside of the self, or on the periphery of it. Pain is thus discussed objectively as something coexisting with the speaker but not coterminous with her. 'Pain as Entity' can be spoken of, described, possessed but, crucially, it remains separate. It is as if, by nominalising it, Veronica managed to 'contain' and, somewhat, tame it. Indeed, the image of her 'going to sleep on it' does not lack a sort of poetic beauty.

Obviously, one could also construe pain as an entity, objectifying it linguistically as a noun ('thing'), while at the same time giving a representation of it as entirely negative, evil and ferocious (a pain that devours you and kills you, for example). Yet this is not what this speaker chooses to do. The clauses in which pain appears are existential and relational ones.

Even when probed explicitly as to whether she is experiencing any pains during the interview, Veronica resorts to relational clauses of *being* and of *having*, as in extract (4.17):

Extract (4.17) (V I: 4)

Veronica: I have it [the pain] at the knee, where they operated me; I have it going up [it moves upwards]; if it happens to have a pain in a foot, in a hand; I've had strong pain, strong rather than constant, in the cervical [vertebra].

Veronica's pain is an entity that *is* rather than *does*. If one keeps in mind Halliday's description of grammar as a 'theory of experience', it is easy to see how this speaker, through specific lexicogrammatical choices, has chosen to construe and encode her lived experience. Lexically, the account is also noticeable for the limited presence of emotionally-charged lexicon, a feature which, together with the aforementioned lexicogrammatical choices, contributes to presenting the speaker as calm and in control. It is this serene self that the interlocutor is asked, successfully, to align with. One does feel for Veronica, and the difficult reality of her situation is all too real; yet the picture she paints is one that inspires admiration and optimism, rather than dread and pity.

Summary

Veronica's experience has been a particularly hard one: it began early in her life and changed the course of it by, among other things, putting an end to her athletic ambitions. She has been experiencing a particularly aggressive form of RA, which has resulted in frequent hospitalisations and numerous surgical interventions. Pain figures prominently in this speaker's experience, taking various forms and degrees of intensity.

The resources of Appraisal are used by this speaker for the representation of mainly one *attitude*: APPRECIATION. Of all the possible entities, it is pain that is most often evaluated, through relational and existential clauses. The result is one of objectivity and apparent detachment, akin to that of medical and scientific literature about pain. This does not mean that Veronica's story is

devoid of AFFECT. AFFECT is recontextualised mainly as APPRECIATION and has to be 'interpreted' by the interlocutor, who is skilfully and gently enlisted as co-author in this speaker's story.

4.10.4 Sandra

Sandra's account is quite rich and detailed as to the genesis of her illness, the type of pain she experiences, and the kind of treatments received. She also relates information about her private life, like her marriage, voluntary activities, and work. Of the attitudes encoded, several are examples of APPRECIATION. The vast majority of examples of those concern her pain, in its various guises. Unsurprisingly, the totality of evaluations it receives are negative. However, they all group towards the lower end of the emotional spectrum. Thus, her pain(s) is *molto acuto* 'very acute', *molto forte* 'very strong', but at times also *molto gestibili* 'very manageable', *molto relativi* 'very relative'. Since Sandra's illness is characterised by what she defines as *fasi acute* 'acute phases', so her pains, during those times are 'acute', 'really strong', as well as 'dull'. They are also localised (in the joints, for example) and distinguishable (*distinti*) from each other. None of the descriptors used to characterise her pain can be considered as emotionally charged. Yet, Sandra's story does not appear cold or somehow 'technical', in spite of the 'matter-of-fact tone'.

On more than one occasion, APPRECIATION is communicated by this speaker by nominalising pain and placing it in the grammatical role of *Actor*,

thus endowing it with a degree of volition, or in relational clauses, as in extract (4.18):

Extract (4.18) (S I: 2)

Simone: What type of pains are they? how do you describe them?

Sandra: What I experience, It's really an acute pain, really dull, of a really dull type. I can't even find an appropriate term [to describe them]. Pains that don't allow you to...to do, let's say...to lead a life, normally. But even the most trivial things, like writing, or wash oneself, or get dressed...It's really a strong pain that doesn't allow you to lead a normal life, yes, the daily activities one engages in, yes.

Here pain is introduced as an entity that *does* something: it impedes, when present, the leading of a normal life, making even the simplest activities, like washing oneself, getting dressed or writing, almost impossible. What the speaker foregrounds is the evaluation of her pains; yet those evaluations can also, as is the case with other speakers, be read as instances of evoked AFFECT, recontextualised as APPRECIATION.

Further on, while narrating an episode when, while on holiday and after years of remission, she started to experience intense pains in her knees, she quotes an unnamed source who informed her that there was nothing she could do about it because the pain 'would leave when it felt like it':

Extract (4.19) (S I: 3)

Sandra: They explained to me that the only thing [that might help] was rest. When it felt like it, it would go away. There were no tablets, there were no creams.

Although AFFECT is not expressed overtly, like other speakers Sandra implies it. For example, in a revealing passage, she relates how when she is experiencing a relapse, especially if acute, her condition (with its associated pain) is lived as 'other', psychologically and lexicogrammatically away from self:

Extract (4.20) (S I: 3-4)

Sandra: When I'm not unwell I talk positively of my experience of being ill. When I'm in an acute phase [of the illness], don't talk to me about my illness. Because it's a thing that doesn't belong to me, really, I tend to dissociate [from it].

It is interesting how in extract (4.20) she lexicalises her illness as *una cosa* 'a thing' with which she has no formal relationship: *non mi appartiene* 'it doesn't belong to me'. Behind this simple declarative, the attentive interlocutor can read Sandra's inner state of profound distress. Again, AFFECT is just below the surface.

Before joining the support group, Sandra would rarely, if ever, discuss her condition, thus experiencing that 'loss of voice' so common among chronic sufferers. This, she informs us, is not 'for a desire to hide, rather for a feeling of inferiority'. Illness and pain thus build a wall between her and the world of the healthy; an invisible one, but a wall nonetheless. And although here she is ostensibly talking about her illness in general, it is clearly pain which achieves this silencing effect, albeit temporarily. The 'flare-ups', in fact, are announced and characterised throughout by intense pain.

When experiencing a relapse, she retreats to an inner space. Through silence she shows her rejection of her illness (*è un rifiuto* 'it's a refusal or a rejection'). The effects of pain, coupled with the strong medication to combat it, is addressed in extract (4.21):

Extract (4.21) (S I: 4)

- Sandra:** [they] really entail mood swings, changes in physiognomy, and that is something that's really heavy [to bear], that's very heavy, really heavy. There I truly feel very different.
- Simone:** From what you normally are like?
- Sandra:** yes, I'm not like myself anymore, I truly change, my personality changes, yes.

The passage above is particularly revealing because it is representative of how this speaker skilfully weaves the emotional tapestry that finally allows us to glimpse, however partially, her inner world; a world of resilience but also of intense suffering. She moves from the general to the particular by reporting first that the pains and medications 'cause mood swings, changes of physiognomy'. After this general statement, whose truth-value is reinforced by the main verb (*comportano* 'entail') in the indicative, present-tense, she informs us that 'that is a thing that's heavy, that really weighs, really does'. The statement is still expressed as a general truth but through repetition, and the epistemic stance expressed twice by the intensifying adverb *proprio* 'truly, really', Sandra's feelings have now made their way to the surface. In the tapestry metaphor, these moments can be considered spots of brighter colour. And now that the gates have been opened, emotions pass through; not uncontrollably but certainly more distinctly: 'there I truly feel very different [...]

I'm not like myself anymore, I truly change, my personality changes. Yes'. One can detect a shift from general, impersonal statements to personal ones, as indicated by the use of verbs in the first-person singular (*mi sento* 'I feel', *cambio* 'I change'), by the superlative *diversissima* 'very different', which has a clearly *emotive* (AFFECT) value and the repeated use, again, of the epistemic evidential *proprio* 'truly' and, finally, by that peremptory *si*, 'yes' made even more prominent by the fact that it is spoken as a single, separate intonational unit.

AFFECT, then, is always in the background and at times is brought to the fore. Generally it is evoked rather than overtly mentioned. But even when noticeable for its supposed absence, it is provided by the interlocutor who correctly decodes the instances where, for example, the speaker has recontextualised it as APPRECIATION, as in the above extract. One could go as far as suggesting that upon hearing this kind of story, the absence of overtly expressed AFFECT generates a sort of implicature (almost in the Gricean sense) and it is then provided by the interlocutor. Sharing a common humanity he/she 'fills in the gaps', verbally or non-verbally, and becomes co-author of the story, having been enlisted as a sympathetic listener.

In extract (4.22), where she describes the consequences of her treatment (mainly, as for the other informants, with cortisone) the emotive 'volume' is turned up. Resorting to lexically charged lexicon she says:

Extract (4.22) (S I 4)

Sandra: My body has been ravaged, consequently I don't have a good relationship with my body [...]. The doses of cortisone that I've

taken, unfortunately on my young body, it really has ravaged it. Luckily, there aren't very many of who have been so ravaged. But it's happened, amen, what can one do? I don't look at myself a lot.

Cortisone, we are informed, has 'ravaged' (in the sense of: 'laid waste to') Sandra's body. She states that, fortunately, not many other patients have been so 'ravaged' (notice the repetition). Yet, she, though on the surface is accepting of the situation, does not like to look at her own body which, in a way, has become alien to her. When probed on the latter point she explains that she does have a husband who loves her but tellingly concludes with one of those declaratives that are on the surface just a statement of fact but that represent truly implicit AFFECT:

Extract (4.23) (S I: 5)

Sandra: If I really have to dig deep inside of me ... it really is all very difficult.

Sandra, then, offers an account rich in factual detail which, upon a first reading, is not as rich in AFFECT. Yet, closer reading shows this not to be the case: AFFECT is indeed present but in a rather understated manner. In this, this speaker is not atypical among the other informants.

Summary

This speaker's account is quite rich in factual detail. Like Veronica, Sandra appears to favour construing pain nominally, which – in turn – allows her to objectify and evaluate it. The speaker tells us about its quality and quantity and, unsurprisingly, provides negative evaluations of it. All of this contributes to the image of the account as objective and factual, and of the narrator as reliable. However, 'objectivity' and 'factuality' are not an impediment to the encoding of AFFECT. More or less overtly, we are informed of how Sandra *felt* through her various encounters with pain and illness. Fear and insecurity are never too far from the surface (e.g. the feeling of being very different from other women, *healthy* women). In common with other speakers, Sandra's emotional reactions are often triggered by pharmacological treatment. It is when speaking of the usual culprit, cortisone, that the listener witnesses the use of emotionally-charged lexicon and metaphors of war and disaster.

4.10.5 Marta

Marta's experience did not begin dramatically. Her pain and related problems were initially mild; only with time did they grow, until the illness, finally, took over. When it comes to APPRECIATION, it is interesting to note that pain is the first and almost the only entity to be evaluated in this speaker's account. For her, pain is always encoded as 'thing' and is always spatially situated. This can be seen in extract (4.24), where she succinctly relates the genesis of her illness:

Extract (4.24) (M I: 1)

Marta: Suddenly, from a small pain, from a finger.

Pain appears suddenly. It is 'small' and its initial location minute: a finger. With time this apparently inconsequential event evolves: the pains multiply, growing in number, location, and intensity. Marta informs us that she then began experiencing *dolori fortissimi* 'very strong pains' in her hands, which especially at night became *insopportabili* 'unbearable'. Interestingly, these are almost the only instances not only of pain-appreciation but of APPRECIATION in general.

However, like other informants, in evaluating the pains (which were 'unbearable'), Marta also encodes, indirectly, her emotional state. Thus, APPRECIATION and AFFECT coalesce into one. As for the other speakers, APPRECIATION here can be read as 'evoked AFFECT'. Elsewhere, Marta qualifies her pain in terms of quality. She tells us that her pains became *bruciori* 'burnings', *rigonfiamenti* 'swellings', *indurimenti* 'hardenings/rigidities' but although more specific, these definitions do not receive further evaluation. The other entity to be evaluated, shortly afterwards, is the initial (wrong) diagnosis she received: *una semplicissima tendinite* 'a very simple/mere tendonitis'. Keeping in mind that both speaker and interlocutor know what the real diagnosis and the consequences will be, the minimizing statements about the initial pains and the first diagnosis are obviously in stark contrast and only intensify one's amazement at the final outcome. In addition, pain is given pride

of place by being almost the only entity to be explicitly and directly evaluated by this speaker.

With regards to AFFECT, the picture Marta paints is characterised by light brushstrokes. In her life, there is definitely a 'before' and an 'after'. Before the onset of the illness, she felt she was lucky (*mi consideravo fortunata* 'I considered myself lucky') for never having been ill, a situation obviously modified by the onset of RA. This, in Martin and Withe's (2005) typology of affect can be considered as a token of the satisfaction subgroup, which — as the past tense used indicates — contrasts with the present situation. It is therefore interesting to note how an alternation of tokens of affect (positive vs. negative) help the speaker characterise the transition from health to illness. Although we are not explicitly told about how she feels about developing RA, we can infer it: her luck ended and she is now one of the 'unlucky'. Although the issue of agency will be addressed in more detail in the following chapter, suffice it to mention here that whenever an individual is faced with pain and illness, the precarious nature of health and the vulnerability of the embodied self are suddenly revealed to her. Attention to the way AFFECT colours and gives voice to the speaker's inner states — his/her emotions — in relation to the onset of illness, helps illustrate how — to use Sontag's (1978) metaphor — the healthy and the ill inhabit different worlds.

Crucially, this is also revealed to the attentive listener who, upon hearing of the ill person's predicament, immediately has a glimpse of his or her own vulnerability. AFFECT, then, is present in a broader sense, whether linguistically instantiated or not. Although this may pertain more to psychology

than linguistics, one wonders whether it might be appropriate to investigate it in the decoding, as well as the encoding, of linguistic messages.

Similarly to other speakers, Marta limits the expression of her inner states more in relation to the treatments received and the overall experience of living with a chronic illness than to the experience of pain itself. Referring to the by now familiar cortisone, she says: (4.25) '*sono stata bastonata di antiinfiammatori: cortisone*' 'I've been bludgeoned/clubbed with anti-inflammatory drugs: cortisone' (M I: 5).

The expression is interesting because it depicts both a state of affairs as well as letting the hearer infer the *feelings* of this individual. The metaphor *treatment = weapon* which is used *against* the person before it affects the disease is particularly powerful. It invites sympathy while simultaneously communicating the psychological and physical state of the patient. Like Sandra, Marta resorts to emotive metaphors of violence where the treatment is a weapon intended to subdue the disease but, ultimately, ends up harming the entire embodied self. Bearing in mind that our perception and appreciation of the world is always an embodied experience, it is easier to see how a pharmacological treatment can arouse such negative emotions and elicit such negative evaluations, before and even more than the disease itself. This is even clearer (and more widely appreciated) with other diseases, such as cancer. There the mention of the treatment — chemotherapy — elicits responses and evaluations that at times compete in harshness with cancer itself. Indeed, Marta's interview illustrates an interesting trend in the ALOMAR Plus corpus which will have become apparent by now: the tendency to evaluate the treatments more negatively than the disease and disease-related

pain themselves. For Marta, for example, the metaphor used to describe the effects of cortisone is the *only* instance of emotionally charged lexicon.

Negative AFFECT is expressed again in a passage where Marta talks of the way she felt for being housebound following a flare-up of the disease. She felt like a *malata grave* 'one seriously ill' but could not behave otherwise, since she felt 'scared' to use public transport, due to her weakness. On the contrary, whenever she feels well enough to be independent she feels *realizzata* 'fulfilled'.

Between the two extreme poles of *positive* and *negative* AFFECT, there exists a fluid space occupied by a feeling that can be more or less negative: insecurity. This is the result of not knowing how the disease will develop in the future, as extract (4.26) shows:

Extract (4.26) (M I: 6)

Marta: From a physical point of view [...] an ache passes, therefore one overcomes it. But there comes a point, this kind of disease has no return, well also, you always think well, if I'm like this, will I still be able to drive? Will I?

Here too, Marta hints at her inner states, rather than declare them openly. The interlocutor is 'transported' into her inner space and left to draw his or her conclusions. 'Opening up' exposes one to the risk of not being understood or of being misunderstood. Worse: the ill person may be disbelieved. This might account for a speaker's (this one's, for example) apparent reluctance to 'share all'; paucity of words may therefore be a 'strategy' and their scarcity is not evidence of absence of feelings, rather it is an awareness of the possible different 'uptakes' of one's emotions in relation to illness.

Summary

In the encoding of *attitudes*, this speaker resorts to mainly direct APPRECIATION of pain, which, unsurprisingly, is evaluated negatively. This, however, is not done in emotionally-charged ways, resulting in a balanced, 'matter-of-fact' account. The telling of her experience is also an opportunity for displaying AFFECT. This mainly relates to feelings of insecurity and apprehension and the 'volume', to use Martin and Rose's metaphor (2003) is only 'turned up' in relation to the effects of the pharmacological treatment, through emotionally-charged metaphors of violence and war. As seen, this is a common, and by now familiar, trope in the ALOMAR Pluscorpus. It is worth noting how this speaker expresses, among her attitudes, no JUDGEMENT: no one is blamed, no one is praised but this is not because other characters are not present in Marta's story: they do exist, yet she chooses to focus on herself.

4.10.6 Gina

In common with other RA sufferers, Gina began developing symptoms over a long time. Initially, they were relatively mild. Paralleling this development, throughout her account her emotional responses develop in a similar fashion: from milder to more intense, in response to particular symptoms. So, when she first began experiencing stiffness in her legs accompanied by mild pain, she was 'not very worried.' As time went on and the increasingly frequent pains in her hands, legs, and joints became began to have a limiting effect on

her daily activities, such as looking after the house and the children, her emotional responses intensified too:

Extract (4.27) (G I: 2)

Gina: At first it was hard, because my children were still young, consequently they were traumatised too.

Like other speakers, Gina uses relational clauses to recontextualise AFFECT as APPRECIATION, on the surface attributing the quality of being ‘hard’ to a period of time. But of course such encoding also reveals her state of mind. Interestingly, she then goes on to talk of her children’s feelings with a lexically-charged adjective such as ‘traumatised.’ Yet, by saying that the children were ‘traumatised *too*’ the implication is that that is how she felt. It is again elliptically that, later on in the interview, the listener is informed that all the pains and other symptoms that this speaker experienced made Gina feel ‘not normal’ anymore:

Extract (4.28) (G I: 2)

Gina: Now I feel like a normal person, if I don’t look at my [deformed] hands, I feel normal. I’ll tell you the truth, at times I feel embarrassed, with these hands. But you get over it.

It is only ‘now’, at the time of speaking, that Gina feels normal, and then *only if* she refrains from looking at her own deformed hands. Inscribed in the body, her pain and illness act as a reminder that, in pain or not, Gina is no longer a member of the ‘realm of the healthy’. Emotional states are thus once again

revealed as being embodied, in the sense of 'passing through' the body and — in good part — dependent on it.

The effect that physical deformity, or visible disability, has on onlookers is itself interesting. Often, it acts as a validation of the sufferer's claim to be in pain, or to have a disability. Speakers in this corpus (Annamaria, for example) and elsewhere (Heshusius, 2009 and Frank, 1995, *inter alia*) often comment on the frustration of not being able to *show* doctors and other people visible, tangible signs of their suffering.

However, visible signs of disease can often be over-interpreted, as confirmed by Gina herself later on in the account. She relates an incident when she met up with her sister and some former work-colleagues to catch up (Gina is now permanently off work). After Gina left, these women, who had noticed her deformed hands, told the sister that they could see Gina was 'really in a bad way'. Extract (4.39), however, shows her comment on this paradox:

Extract (4.29) (G I: 4)

Gina: They must have imagined God knows what; just because they saw these hands. But this is nothing, for me it's nothing; they would not have guessed how I felt before, when there were no deformities. Yes, at times I would feel terribly, but there was nothing to see.

Physical signs, it appears, are not always sure indicators of an individual's inner states; words, however scarce, are more reliable.

For Gina, with time came a degree of acceptance. Yet, there is the fear that the future might be bleaker, as she readily acknowledges in extract (4.30):

Extract (4.30) (G I: 3)

Gina: I think I'm ok now about my illness, the pain and all that [laughs] even if now the big problems start, maybe. The liver, kidneys, eyes and now there is [laughs] there's the other thing, the drugs. I've been taking them for twenty-two years.

In common with most speakers in the corpus, Gina expresses negative AFFECT of the in/security type triggered by uncertainty about the future. However, in places her experience of illness and pain are the source of positive AFFECT too. This is the case in relation to activities gravitating around the support-group, with the opportunity they afford for the sharing of experiences, feelings, and talents through volunteering.

Unsurprisingly, pain and RA are evaluated negatively but in rather mild tones. The 'volume' is never turned up in Gina's narrative. Unlike other speakers in the corpus, Gina refrains from giving very negative evaluations of the pharmacological treatments she has undergone; her criticism of them is toned down, albeit not entirely absent, as the following example illustrates:

Extract (4.31) (G I: 4)

Gina: Well, the drugs, they're good in one way but they're bad in another.

Gina's account is mainly about herself. When other characters appear, they are either not evaluated (her children and, husband, sister), praised (medical

professionals), or very mildly and obliquely criticised (her former work-colleagues).

Summary

For this speaker, the experiences of illness and pain have entailed a series of changes and adjustments, at times difficult ones. Overall, the pre-eminent attitude encoded in her account is negative AFFECT, mainly of the insecurity type. However, the expressions of negative AFFECT are always rather 'mild' as is the one, indirect criticism (JUDGEMENT) of other characters in her story (her former colleagues). Again, in what seems to be a common trope of the ALOMAR Plus pain and illness narratives, here too we find negative evaluation (APPRECIATION) of the pharmacological treatment. Again, this type of evaluation too is expressed mildly and rather obliquely. This is probably due to Gina's 'personal style' than to the mildness of either her symptoms or the treatments received.

4.10.7 Fabio

As noted, Fabio is the only male in the corpus and the only interviewee not to suffer from an autoimmune disease. In addition, he is the only informant with a background as a medical professional, being a registered nurse with several years of experience.

In common with the scientific literature about pain (and possibly because of his training and familiarity with medical language), this speaker tends to

construe pain nominally as a 'thing'. This allows him to conceptualise it as a circumscribed and circumscribable entity that can be talked of as, among other things, having spatial and temporal characteristics, as well as quality (i.e. type of pain) and quantity (i.e. intensity). As an entity, pain thus displays a number of qualities; in other words, it receives, or is the object of, APPRECIATION.

Evaluative relational clauses abound in Fabio's account, with his pain being described as, *fastidious*, *strong*, *intense*, *massive* and *shocking*. The adjectives are in ascending order of intensity; this is the order in which they appear in the speaker's narrative and they trace the evolution of his condition, right up to the point when he had to undergo surgery to try to rectify the problem but achieving only partial success. At that point the pains were *shocking*; this is the only instance of an emotionally-charged adjective. This type of overall balanced APPRECIATION contributes to the image of the speaker as competent and able to provide detached evaluations. This kind of evaluative language is reminiscent of the language of medical case-histories which focus on the symptom (in this case pain) but seem to obliterate the sufferer. However, under the surface one can detect AFFECT being encoded as well as APPRECIATION, a pattern that — as seen — is typical of this corpus.

As well as pain, both the pharmacological treatment to control the pain and the surgery he underwent are the objects of APPRECIATION. The latter is evaluated in mildly negative terms (*'it didn't work'*), mainly as a consequence of the speaker's failure to comply with his physician's instructions to fully rest over a certain period of time. However, in contrast to the other participants the

pharmacological treatments, only partly based on cortisone, do not receive a strongly negative evaluation. This negative evaluation has more to do with what the treatment *failed to do* than with what it *did*:

Extract (4.32) (F I: 2)

Fabio: I did take painkillers, very many, and they didn't give me any respite. Well, I never, I never received any relief from painkillers. I, I followed a therapy for a certain period of time, prescribed by the doctor, with painkillers, cortisone, and other things, but never got any relief. Absolutely zero.

This is in stark contrast with the views of more or less all the women in the ALOMAR Plus corpus. Unfortunately, given the composition of the corpus, it is not possible to determine whether the difference has to do with the gender of the informants, the nature of the medical problems experienced (autoimmune vs. non-autoimmune diseases), or a combination of the two.

As stated, Fabio's evaluation of his pain comes across as mostly precise and factual. As shown, and possibly because of his medical training, pain APPRECIATION in this speaker's account resonates with the language of medical reports and case-histories. However, this degree of apparent impersonality (one might speak of detachment) dissipates somewhat once Fabio is probed further on the nature, its quality and quantity, of his pain. Then he resorts to vivid similes and metaphors which, again, indicate a difference between this informant and the others. Examples of some of these are reproduced hereafter (4.33-4.38):

Extracts (4.33-4.38) (F I: 5-6, 8)

(4.33) It was like pins, from inside, pins pricking you from the inside.

(4.34) It is like something that blocks you, which stops you from doing the things you want.

(4.35) It was like something that would take its place inside of you, and annoy you.

(4.36) Then it becomes pain, but pain that would still annoy you, remain a nuisance, psychologically more than physically.

(4.37) And this problem, well the pain, the problem was more the stress that the pain caused than the pain itself.

(4.38) If I had to give an image of my pain, well, it's a workman, on the road, you know when they're doing road works, and this workman uses a pneumatic drill ... well, I'm the person near this drill and I hear the noise, this deafening noise, continuous, that causes you problems. Something that reaches a maximum level, right? Because it's like this drill, this noise, always there, which goes on and on. Yes, that's how I see my pain, like that, rather than something utterly catastrophic.

The similes and metaphors employed by Fabio have some common characteristics. First, they highlight the persistence of pain through time: the tap dripping, the pins that keep pricking, and finally the continuous noise from the drill. Although, as the speaker himself points out, none of these events is tragic per se, their relentlessness is a major cause of stress and, ultimately, suffering.

It is interesting to note that when the speaker shifts from using simple adjectives to metaphors and similes to describe his pain, the narrative immediately becomes more vivid and personal. Figurative language also allows the speaker to communicate another attitude effectively: AFFECT.

He does so by telling us explicitly how the continuous presence of pain makes him feel (namely, *stressed*). This stress also derives from the fact that continuous pain interferes with the ability to carry on 'normal' activities.

Talking of the experience of serious illness, Charteris-Black and Seale (2010: 17) note that it "necessarily entails a break in the life story, since it interferes with the 'normal performance of social roles.'" This statement can certainly be extended to include life with constant pain.

The kind of figurative language used by this informant is very effective in eliciting an emotive response in the hearer, who becomes co-author of the narrative by providing AFFECT in his/her responses to what he/she hears. It does so whilst preserving the informant's chosen *persona*: factual, resilient, and — ultimately — truthful. Figurative language also allows this speaker to simultaneously encode APPRECIATION and AFFECT, to encode involvement whilst, at the same time, maintain credibility through descriptive accuracy. This is why, in linguistics encoding of pain, figurative language is almost always present. Figurative language combines the referential power of language with the evocative potency of images (albeit linguistically evoked). The interlinked nature of metaphors with our thought-processes has been famously discussed by Lakoff (1981).

Sontag (1978, 1988) pointed out how, in some cases, the type of metaphors used to talk of illness and pain can be criticised for the way in which they

direct, even constrain, our way of thinking about these phenomena. However, their ubiquity is, as noted by Gwynn (2001), testament to their usefulness. The fact that, in talking of physical pain, we so often resort to figurative language is not, as hinted by Scarry (1985), a 'limitation' of language. On the contrary, it is testament to its resourcefulness.

Before concluding, it is worth making some remarks on the nature of the figurative language used by this speaker, especially in comparison with that of other speakers in the corpus. Whereas some of the other informants resort to metaphors of war (e.g. explosions, intense heat), violence (e.g. tearing apart, conquering, devastating), and violent natural phenomena (e.g. lightning), Fabio favours images of malfunction (e.g. the dripping tap), and annoying remedial activity (e.g. road works). In addition, the fastidious nature of these events resides mainly in their *auditory* qualities; these *interfere* more than totally *disrupt* one's life (as, for example, a war-related event would do). It is likely that there is a correlation between type of illness and the kind of figurative language used; it is also possible that gender plays a role in such differences (see Charteris-Black and Seale, 2010).

Among the *attitudes* expressed by this speaker, JUDGEMENT is entirely absent. As seen, it is rather peripheral among the *attitudes* expressed in the corpus in general. However, for this particular speaker this might be the case because of the rather more straightforward manner in which his illness developed, and the symptoms it entails, as opposed to the autoimmune diseases experienced by all the other informants.

Summary

This speaker differs from the others because of his gender and the nature of his illness. Analysed for *appraisal*, his account reveals that the *attitudes* expressed are APPRECIATION and AFFECT. Through relational and existential clauses we are informed of the type of pain experienced (quality and quantity). Pain is mainly construed nominally and qualified adjectivally; the choice of descriptors is reminiscent of medical language (probably because of the informant's professional background but also the nature of the illness). However, some of his adjectival choices point to a recontextualisation of AFFECT as APPRECIATION (e.g. when pain is described as 'shocking'), which — as seen — is common in the corpus. Fabio also resorts frequently to figurative language (metaphors and similes). This has the advantage of simultaneously allowing readings in terms of both AFFECT and APPRECIATION, especially because they allow the interlocutor to derive affective meanings from the evoked images. The nature of the figurative language is noticeably different from that of the other informants. It is possible that this is because of personal differences (such as gender) and the nature of the illness experienced.

4.11 Concluding remarks

Pain does not subsist in a vacuum. It exists (and persists) in a world that gives it cultural meanings and is experienced by individuals that are also culturally-situated.

Pain is always experienced subjectively: no two pains are alike. This is a principle that, as previously mentioned, has been recognised by science and is increasingly acknowledged in medical practice. When language re-emerges from the silence, from that 'pre-language' that Scarry (1985) refers to where pain has banished it, it is a language rich in 'subjectivity'.

The aim of this chapter has been to uncover and systematically analyse this subjectivity as it appears in the ALOMAR Plus corpus of interviews. To do this, it has adopted *Appraisal Theory* as its analytical tool. Each interview has been individually 'scanned' for tokens of APPRAISAL and the aim of these concluding remarks is to summarise what the analysis reveals about the way (or ways) in which the experience of bodily pain and chronic illness is assessed by the speakers in the corpus, especially from the point of view of the emotional responses these experiences engender.

As the preceding analysis has shown, chronic pain and illness 'personalise' language. Their experience is highly salient for the individual. Their overall impact is different, and often far greater, than the mere quality and quantity of the pain experienced. Chronic illness, with its attendant circumstances of bodily pain and various degrees of discomfort, alters the person's life-course — often irrevocably — and this disruption is often only discernible in the language used by the chronically ill to encode their experiences. APPRAISAL analysis of the collected interviews has revealed a number of things, summarised below.

Perhaps unsurprisingly, most speakers in the corpus evaluate the experience of bodily pain and of chronic illness in negative terms. However, the majority

of speakers do so without resorting to 'emotionally charged lexicon'. This is surprising; to the external observer the majority of the narrated experiences appear to be objectively 'extreme' both in their nature and for the consequences they have entailed for the participants. Such consequences include (but are not limited to) repeated hospitalisations, multiple surgeries, and the need to redesign one's life-course, often abandoning cherished careers, such as professional athletics as in Veronica's case.

In order to understand this phenomenon, one has to fully appreciate both the situational context of the interviews and the informants' personal life-stories. In terms of situational context, one has to keep in mind that all the speakers in the corpus have been living with their respective conditions for a number of years. Although for some of them, Anna and Veronica for instance, aspects of their conditions were still very much present when the interviews took place, a degree of 'habituation' had occurred. Perhaps an individual experiencing an episode of acute pain related to an accident or to a non-chronic condition (such as myocardial infarction), or the first acute manifestation of a hitherto absent chronic condition, would make the degree of fear and distress more 'visible' in the language used.

With regards to the informants' personal histories, one has to keep in mind the numerous times when they have had to "rehearse" their stories, in both medical and non-medical encounters. Each of the informants in the ALOMAR Plus corpus is acutely aware of the possibility that their account will be met with doubt or even disbelieved. One of the accusations that chronic sufferers encounter often, especially when their conditions do not show outward signs, is that they are exaggerating their symptoms or, in some cases, faking them.

This has an impact on the structure and 'texture' of their accounts; whilst the more emotive aspects get backgrounded, speakers tend to present their accounts, and thus themselves, as less emotive, more factual and, by implication, more credible. By using the resources of APPRAISAL skilfully, the ALOMAR Plus informants demonstrate a desire, albeit an unconscious one, to appear as 'credible' witnesses to their own condition. They often express the desire not to 'exaggerate' their experiences, seemingly equating an emotive (or emotionally-charged account with lack of, or minor, credibility).

Of all the *attitudes* encoded, AFFECT is the most common. However, speakers in the corpus appear to favour *evoked* (i.e. implicit), rather than *inscribed* (explicit) AFFECT. I have suggested that this is probably in order not to detract from the 'factuality' of the experiences described; having had their pain and suffering doubted before, these speakers want to make sure that the factual nature of their experiences is not questioned. Therefore, the second most frequent expressed *attitude* is APPRECIATION. By using it, the speakers are able to voice factual statements that, especially when expressed as declaratives in the indicative, can also be read as instances of evoked AFFECT. AFFECT, to put it differently, tends to be recontextualised as APPRECIATION which, as noted, also has the advantage of presenting a more objective, truthful persona.

Expressing emotive states in this manner, below the surface as it were, highlights the dialogic nature of much health communication. What is meant with this statement is that, not uniquely in human communication, in health communication there is a relevant role to play for the interlocutor in the

meaning-making of the speaker who chooses (or has to) tell of her troubles. By adopting a more 'detached' stance, the speaker is thus able to protect herself from a degree of emotive exposure that, based on previous encounters, might be face-threatening. Thus, when AFFECT is not inscribed into the speaker's language, it is provided by the interlocutor. He or she inhabits the same cultural space as the sufferer and although not privy to their innermost feelings is very likely to provide a degree of empathy. Not offering a degree of empathy, as some of the medical professional in our speakers' stories appear to do, is – to adopt a sociolinguistic label – marked.

Surprisingly, although the experiences of body pain and of the chronic condition that has caused it elicit mainly negative evaluations, it is the pharmacological treatments used to control it that act as a catalyst for the most overtly negative evaluations. Treatment, especially when cortisone-based, is construed discursively and lexicogrammatically, as an entity that *does* unpleasant things to the sufferer. Often, it appears in the role of *Actor* in material processes with the speaker occupying the role of *Goal*. This, I suggest, is something that medical professionals ought to give more consideration to if they are to gain a more accurate understanding of the chronic illness experience. Speakers are obviously fully aware that the treatment is necessary and, ultimately, beneficial. Yet they perceive it and evaluate it in consistently negative terms.

Although this may be due to the type of communicative-encounter (the semi-structured interview), the speakers in the corpus do not, in their accounts,

often evaluate other individuals and their behaviour. JUDGEMENT is used rather sparingly and mainly to appraise the behaviour of medical professional and family members. Criticism of the former is mainly mild and relating to their inability to provide a prompt and precise diagnosis. Positive JUDGEMENT is used to appraise the behaviour of family members, especially for their support and desire to help. Negative JUDGEMENT for family members is present too but is much milder, indirect or 'veiled' and mainly relates to their perceived inability to fully understand the sufferers' predicament.

This chapter has shown the advantages of using *Appraisal Theory* for the analysis of health communication. It has shown how a theoretical tool that fully appreciates the way in which the subjective import of communication is spread across the entire communicative act and – crucially – relies on an array of lexicogrammatical features can be useful in obtaining a fuller appreciation of the impact of pain and chronic illness on the experiencing individual. Such impact is much more nuanced than originally expected and requires attentive listening (or reading) in order to be fully decoded. The approach shows that evaluating the impact of pain and chronic illness by only relying — for instance — on questionnaires is unlikely to reveal the patient's point of view and unique experience.

Chapter 5: The (re)shaping of identity in the experience of bodily pain and chronic illness through language and narrative

Chapter 3 dealt with the encoding of the experience of bodily pain caused by chronic illness through the lexicogrammar of Italian by the speakers in the ALOMAR Plus corpus. The subsequent section, chapter 4, widened the scope of analysis by considering the use of evaluative language, and the function it achieves, by the ALOMAR Plus interviewees.

Here, the aim is to broaden further still the scope of analysis by investigating the informants' understanding of their own situation. This overall aim will be pursued by looking at how, through narrative activity (see section 5.2 below for an explanation of the way the term is employed here) embedded in their accounts, they present and structure their experiences. Attention will also be paid to how, in turn, these shape their sense of self as the normal life course is interrupted by chronic illness and the capricious nature of the accompanying bodily pain. Here 'self' and 'identity' are used as more or less synonymous. Following McAdams (1993), what is meant here by 'self' is the individual's sense of what constitutes the 'real me'. This is what persists 'behind the many roles [one] play[s]'; it is what continues and exists 'in space and time as a causal, continuous, and independent agent' (p. 44).

The main questions that the analysis will ask are the following:

1. What type of self, or identities, emerges from the accounts of the participants in the present study?
2. Who are the 'actors' in their narratives and what roles do they play?

Question 2 will be addressed by paying particular attention to the notion of *personal agency* (to be defined below). It will be argued that an appreciation of the individual and of their integrity as an agentive being is crucial for a full understanding of the individual's experience of both pain and illness.

5.1 The understanding of the experience of illness through narrative

Riessman (2008: 14) traces the 'flowering' of 'the practice of treating narrative as an object for careful study' to the mid-1980s. However, as she points out, attention to and an appreciation of the importance of narratives in structuring personal experience can be seen as early as the 1960s and 1970s. She also notes (pp. 14-15) that the study of narrative is not the prerogative of any scholarly field and that 'the narrative-turn is part of larger moves in the social sciences *away from discipline-specific and investigator-controlled practices*' (my emphasis). In sociolinguistics, the work of Labov (Labov and Waletzky, 1967; Labov, 1972, 1982; Labov and Fanshel, 1977) was crucial in highlighting the frequency, structure, and functions of narrative in everyday talk in structuring, understanding, and presenting experience.

Since the so-called 'narrative turn', various researchers have turned to narrative in order to shed light on the ways in which individuals and groups use narrative to make sense of their experiences, to present a preferred sense of self, and to create — or re-create — coherence in lives disrupted by traumatic events such as divorce (Riessman, 1989, 1990) and illness. The latter, as noted by Frank (1997; 2002), is especially prominent in its ability to fracture the individual's sense of self and to create what he terms 'incoherence'. Therefore, it is perhaps unsurprising that through narrative,

affected individuals attempt to re-establish a degree of wholeness. Williams (1984) makes a similar point; it is to his work that we owe the concept of 'narrative reconstruction'. Williams' study is of particular interest for the present research. Using a thematic approach, he investigates how individuals affected by rheumatoid arthritis explain the biographical disruptions they have to endure. Furthermore, a number of researchers with different backgrounds have looked at patients' narratives to investigate their use of 'narrative power' to reconstruct and present to the wider society a new, still coherent self. Such researchers include Williams (*op cit*), Kleinmann (1989), Riessman (2000a) and, more recently, Cheshire and Ziebland (2005). In discussing the story of a patient affected by chronic pain, Kleinmann (*op cit*: pp. 96-97) states that attention to the patient's narrative allows the clinician (and, it can be argued, his/her interlocutor generally) to simultaneously attend to both the noxious/pathological event and to the illness and pain as a 'personal crisis'. Crucially, she states (p 97) that '[a]ttention to either bodily or personal pain alone distorts the psychosomatic integrity of the problem. Illness (especially chronic) is a dynamic entity.' Although, from a scientific point of view, it may be possible to circumscribe it to a set of biological malfunctions with their resulting symptoms, from the point of view of the sufferer the symptom(s) and the experience of it do not make sense. It is through narratives that affected individuals attend to and — hopefully — cope with both.

Georgakopoulou (2007: 31-32) points out that the belief in the therapeutic functions of sharing events from one's life has become 'a guiding assumption within the framework of the narrative-interviewing method in biographical research [...]', resulting in the method being 'often seen as offering chances

for a healing process for the informants involved.’ Undoubtedly, in social research the belief in the therapeutic value of narrative, however loosely defined, is widespread. In good part this is related to the notion that the ordering of one’s life events in narrative form, and especially in the strict Labovian manner, is somewhat mirrored by a re-orderings of one’s life following a disruptive event, such as illness.

This can be true but is not always so. Narrative can just as well reproduce chaos, disruption, disorder, paradox and contradictions. In my view, what is of value is primarily the *verbalisation* of one’s experiences and mental activity, not necessarily its reproduction in ‘strict’ narrative form in the sense mentioned above. Verbalisation is often the only way of making visible the hitherto inaccessible. It is this principle that, fundamentally, lies at the root of Freudian psychoanalyses, Jungian analytical psychology, and their ‘descendants’. It is within this process that, for the linguist, the linguistic product – in whatever form it occurs – is of interest and especially Halliday’s concept of grammar as a ‘theory of experience’. Recently, Ramanathan (2010) has written of the need to investigate the language of the ‘ailing bodies’ she advocates the use of a variety of data, gathered in a variety of ways. Whilst acknowledging the contributions to the study of the experience of illness by applied sociolinguistics and narrative studies, she advocates approaching the embodied experience of the ailing body by investigating ‘the language by which experiences around bodily breakdowns and ailments occur’ (p. 2), without limiting oneself to ‘narratives’ – whether strictly defined, à la Labov – or even more loosely understood. Her opinion, which I share here, is that ‘the language of ailments / disability experiences and body breakdowns

matters' (p. 15). This language includes narrative forms but is not limited to them. Ramanathan's invitation has been successfully pursued in McPherron and Ramanathan (2011), which explores the ways in which ailing bodies get 'languaged'. This endeavour has practical and political implications. This is because it can show how often 'patients' voices and experiences with their bodies run counter to those held by the medical world' (McPherron and Ramanathan, 2011: 4).

5.2 What is a narrative?

The term 'narrative' has been thus far used without providing a definition of what is meant by it. Since several disciplines have appropriated the term, it is inevitable that its definition should have acquired a degree of heterogeneity. Intuitively, it can be said that a 'narrative' has something in common with a 'story'. Indeed, the terms are often employed interchangeably, as more or less synonyms. From a narrative point of view, a story must contain a minimum of two events, which are connected sequentially and temporally.

In sociolinguistics (Labov and Waletzky, 1967; Labov, 1972), what constitutes a narrative is its structure. There has to be a sequence of narrative clauses. These are clauses that contain a verb in the simple past tense or in the historic present tense. The order of the narrative clauses in the narrative has to mirror the order in which the events they describe occurred in the real world. A second criterion is that to be defined as such, a narrative must be tripartite; it must contain a beginning, middle, and an end. This, as observed by Riessman (2008: 4), goes back to Aristotle's examination of the Greek tragedy.

The Labovian model stipulates that a narrative contains the following elements: *Abstract*, *Orientation*, *Complicating Action*, *Evaluation*, *Resolution*, *Coda*. The *Abstract* consists of a brief summary, normally to be found at the beginning of a story. The *Orientation* contains background information: who; where; when. The *Complicating Action* refers to the key events of the story as encapsulated by narrative clauses. The *Resolution* tells what happened in the end. The *Evaluation* is — in a way — the point of the story; the reason that prompted the narrator to tell it in the first place (e.g. ‘it was so scary’). Finally, the *Coda* is a final comment appearing after the resolution. For a narrative to count as such, the only two essential elements are *Complicating Action* and *Resolution*. As noted, the idea of narrative has been adopted as an analytical tool by various disciplines. As Riessman (2008) notes, not all traditions adhere to the Labovian model for identifying a narrative.

The work of Labov and his colleagues has been particularly influential and has given rise to a sort of ‘prescriptivism’ in the understanding of what constitutes a narrative and how to analyse it. Georgakopoulou (2007) points out that narrative research within linguistics, and indeed in many social science disciplines, tends to employ ‘specific kind of data and methodologies that in turn generate a specific analytic vocabulary’ (p. 31). She then goes on to suggest that ‘it is not an exaggeration’ to suggest that this process of canonisation is directly traceable to Labov. As Georgakopoulou points out, the typical ‘Labovian narrative’ (or ‘prototype’, to use her definition) is ‘invariably about non-shared, personal experience past events’ (p. 31) and is produced in response to the researcher’s elicitation. In this sense, the interviews

presented in this thesis are 'canonical', being the product of elicitation by the researcher. The second 'prototype' identified by Georgakopoulou (and directly ascribed to Labov) is 'a short-range narrative that gives an account of a certain landmark or key-event or experience that is considered to be pivotal in the formation of the interviewee's sense of self' (p. 31). Some of the 'narratives' identified as such here are 'prototypical' in this second sense too. Among them, I identify the telling of the onset of symptoms as well as the moment when a correct diagnosis was first obtained.

In this chapter, some of the stories that my informants tell do indeed conform, in terms of structure, to the Labovian model. When this is the case, such model is mentioned and commented upon. However, even during a researcher-led semi-structured interview, less polished forms of telling can and do emerge in ways that are similar to what occurs in casual conversation. To refer to the less polished, less coherent, 'non-canonical' stories that emerge, for example, in casual conversation (i.e. departing from the canonical form in structure and momentous nature of the content), Georgakopoulou (2007) uses the phrase 'small stories'. These stories are not only literally 'small', i.e. short; they are also metaphorically so, i.e. less 'momentous' and life-defining in a grand sense. For Georgakopoulou, 'small stories' range from literally 'small and fragmented tellings to refusals to tell and deferrals of telling' (p. 148). Whilst warning against the substituting of one set of hegemonic criteria for another in the definition of narrative, Georgakopoulou (*ibid*) proposes a set of features that identify a narrative. However, the prototypical characteristics she suggests are – crucially – 'part of a more or less rather than as an either or approach' (p. 37). These are: 'temporality' – the temporal

organisation of narrative events, then matched onto a sequence of clauses – ‘disruption’ – the transition from one state of affairs to another, more or less ‘problematic’ one (an alteration of an existing equilibrium) – ‘consciousness’ – the presence of a ‘filtering consciousness (normally human) that makes sense of the events, interprets them, is emotively and psychologically affected, develops more or less strategic and rational responses’ (p. 38). In this chapter, the two elements of disruption and the presence of a filtering consciousness are certainly criteria for the inclusion of a particular stretch of language in the analysis.

It should be noted that in illness interviews and more generally in social science studies, ‘narratives’ are defined in somewhat looser terms. The term is often employed simply to individuals (patients, in the case of illness research) telling their experiences. In this sense, a ‘narrative’ is therefore more akin to the relating of an experience, including inner states. Here, in order to address the research questions mentioned above, I tend to use the term ‘narrative’ in this looser sense. By ‘narrative’ (unless otherwise specified), I mean the (elicited or spontaneous) re-telling of relevant (from the informant’s point of view) events which have either occurred in the past or the relating of events which are ongoing and convey, among other things, inner states. My use of the term ‘narrative’ also refers in general to the linguistic organisation of experience in tellable form. The ‘tellability’ of the narratives or stories here refers both to their being suited to linguistic encoding as well as their being emotively relevant to the filtering consciousness of the speaker.

Like Ramanathan (2010), my focus here is on the ‘linguaging’ of the ailing body, whether in strictly narrative form or not.

5.3 Pain, illness, and the loss of agency

A very common view of illness and especially bodily pain (at least in contemporary Western culture) is that it reduces its host to a passive *experiencer*; pain – in other words – is the active partner in an unequal relationship: it *acts* and the individual experiencing it *is acted upon*.

Linguistically, this view is reflected in the very lexicons that several languages use to talk of both illness and, in particular, pain. In English, the individual who is ill and/or in pain is often a ‘patient’ (especially when in the care of the medical profession), a word that has its etymology in the Latin for “to suffer” and “to endure”. To remain with English, the word *pain* ultimately derives from *Lat. poena*, “punishment” or “penalty”; both are commonly understood as phenomena normally inflicted or administered by an entity (human or institutional) on an individual (or group), originating outside the self and therefore possessing varying degrees of ‘otherness’.

Obviously, words change their meanings and we should not expect any lexical item to carry its entire semantic weight over time. Nevertheless, it is interesting to reflect on the etymological origin and semantic development of words such as *pain* and *patient* and their implications for our understanding of such experiences. It is also true that pain can be self-inflicted, as is the case

in self-harm³⁴ (Faber, 2000; Strong, 2000). In some cases, it may even be welcomed, or yearned for (one only has to refer to the vast corpus of Christian martyrology to get an idea of willingly sought pain). Yet, even in such cases, the idea of “being acted upon” persists. However, is it always appropriate to think of the chronically ill and in pain as being inevitably “victims”? Are they invariably the passive partners in their encounters with pain and, more generally, illness? If so, to what degree?

In what follows, I resort to the notion of ‘agency’ to problematise the notion of the chronic patient as passive ‘experiencer’ of both pain and illness. It will become apparent that my informants’ representations of their respective relationships to pain are rather more nuanced than might be expected.

An analysis of agency (defined below) in the narratives of individuals affected by chronic pain can prove fruitful for more than one reason. Among other things, it can contribute to a better understanding, and a more accurate appreciation, of the pain/illness experience. Although pain can undoubtedly be, and very often is, *isolating* it is not *isolated*: pain is an embodied experience lived by a socially situated individual. As mentioned, pain does not only affect bodies, it also affects lives; one of the most severe ways that it

³⁴ The issue of self-harm is a complex one and a proper discussion of it is well beyond the scope of this work. Suffice to say that the position of self-harmers is ambiguous: they are both victims and perpetrators. In addition, more than the physical pain derived from it, it is the physical evidence of self wounding that self-harmers ‘seek’. Self-harming highlights the complex interrelatedness of so-called psychological and physical pain and the problematic nature of expressing pain (psychological or otherwise). In a sense, self-harming might be considered a consequence of the failure to capture one’s pain linguistically: words are taken over by scars. Interestingly, Strong’s study on the topic (2000) bears the title, “A Bright Red Scream: Self-mutilation and the language of pain.”

does so is by eroding personal freedom: the freedom to operate in the world as a free *agent*.

In their study of the gendered experience of illness (which includes pain), Chateris-Black and Seale (2010) point out that such experience 'often entails a break in the life story' (p. 17). This is often the case because it makes the person 'dependent – to a greater or lesser degree – on carers, whether family or friends, on health support workers and professionals' (p. 17). Illness and pain entail, in other words, a reduction of agency. The focus on agency can also help highlight the multiplicity of roles that chronic sufferers experience, often simultaneously, (victim, hero, sufferer, and so on) as parts of their different personas. All this is captured, construed and simultaneously constructed, by language.

Consequently, attention to the lexicogrammar (without losing sight of the wider discursive context) is again an important tool to achieve the aforementioned aims, especially if one agrees with the already-mentioned Hallidayan view of grammar as 'a theory of experience' and with the view that speakers' 'cognition of agency and the extent to which [they] invest an entity [...] with agency influence various levels of human language a great deal' (Yamamoto, 2006: 6). Indeed, Yamamoto's observation, in line with Halliday, that, through the concept of agency we 'observe and interpret the world around us' (2006:2) is particularly pertinent and, as I aim to show, can be fruitfully employed to examine how speakers in the Alomar Plus corpus view their relationship with pain and their illness.

5.4 Agency: definitions

To proceed with the discussion, it is first necessary to find a satisfactory working definition of “agency”, albeit a rather general one. The concept can be (and indeed has been) approached from a number of perspectives: linguistic and philosophical for example. Any discussion of agency requires the mention of what Yamamoto (2006) refers to as its ‘satellite concepts’: *intentionality*, or *volition* (the two terms often used interchangeably), *awareness of action*, *control*, *causality* and *responsibility* attributed to an entity. It is quite common for agency to be attributed to, and associated with, humans; perhaps humans are (from our anthropocentric perspective) the quintessentially agentic beings precisely because they are seen as being capable of both intentionality and volition. Humans can and do initiate actions willingly, more or less appreciating their consequences (they claim responsibility and establish a causal link between their actions and certain results). However, non-human and even inanimate and intangible entities are often invested (by us agentic humans) with varying degrees of agency and its corollaries of volition and intentionality. It would be beyond the scope of the present work to examine in any detail all the cognitive and philosophical issues surrounding the concept of agency³⁵. From the perspective of this thesis, what matters is which entities, if any, speakers in the corpus treat,

³⁵ The literature on agency is vast and the concept, as mentioned, has been approached from a variety of perspectives. A good overview of philosophical discussions on the matter can be found in Yamamoto (2006, especially chapter 2); the same work also discusses concepts pertaining to agency from the point of view of various Case Grammarians and Functional Linguists.

linguistically and – arguably – cognitively, *as if* they possessed their own volition and acted in what could be termed an ‘agentive manner’.

As Osterman et al. (1999: 128) note, it is often the case that people who are affected by chronic pain experience feelings of ‘frustration, hopelessness, despair, anger, anxiety, and depression’. In the case of SLE, Danoff-Burg and Friedberg (2009) identify stress, anxiety and depression as accompanying symptoms. Similar observations have been made by Spanwick³⁶ (2008). Disempowerment and loss of control were found to be part of the experience of women in RA-related chronic pain by Skuladottir and Halldorsottir (2008). All these states can reasonably be correlated, or be expected to co-occur, with a general sentiment of loss of agency and freedom to act; the sensation of being somewhat constrained and imposed upon. It is with these findings in mind that I shall therefore look at the degree of agency speakers attribute to themselves *vis-à-vis* their illness and pain. How disempowered or, perhaps, how empowered do the speakers in the corpus see and, consequently, represent themselves? I shall adopt a working definition of agency as provided by Duranti (2004: 453):

Agency is [...] understood as the property of those entities (i) that have some degree of control over their own behavior, (ii) whose actions in the world affect other entities’ (and sometimes their own), and (iii) whose actions are the object of evaluation (e.g. in terms of their responsibility for a given outcome).

³⁶ Spanwick, in his study of patients referred to a specialty pain-clinic, reports that patients affected by conditions characterised by chronic pain present ‘high levels of distress’ (p. 94). The emotions they display include (but are not limited to): worry, anxiety, sadness, depression, anger, frustration, exhaustion, fatigue, various sleep disorders which result in (and in turn are generated by) reduced or impaired physical and social functioning.

In discussing agentive behaviour, Ostermann et al. (1991: 143-145) talk of *non-accomplished agency* and *real agency*. Under the label of *non-accomplished agency*, they include *negated actions* (e.g. *I couldn't sleep anymore*), intended actions and *wishful thinking* (e.g. *I'm trying to get back to my normal routine, before the RA I mean; I wish I didn't have to do this*). Both are indexical of diminished agency. On the other hand, the label *real agency* refers to those actions, activities, or 'moves' that social actors engage in when they are 'actual agents' (Ostermann et al., *ibid* p. 144) in their own life-stories. These 'moves' obviously have grammatical encodings, but the labels themselves also refer to 'extra-linguistic' behaviours.

5.5 Analysis

As in the preceding chapter, each of the interviews will be addressed separately and will be followed by a summary of the findings relating to that particular interview. The chapter will conclude with final remarks relating to the entire corpus.

5.5.1 Annamaria

From a thematic point of view, two macro sequences can be discerned in Annamaria's account. The first is relative to the appearance of the symptoms; this phase lasts until shortly after her first diagnosis. During this initial period (narrative and actual time here coincide), Annamaria appears as relatively passive: 'things' happen to her and she simply takes notice. Subsequently, she follows advice and visits a doctor (therefore not as a result of her own

initiative). He gives her a diagnosis and prescribes pharmacological treatment (cortisone). In a narrative passage at the beginning of the interview, Annamaria starts to present herself as 'active':

Extract (5.1) (A, I: 1)³⁷

Simone: And initially the doctor, well, did you go to see a doctor right away, to...when the pains began...did you see someone right away or did they...what were they saying to you?

Annamaria: I went to, went to an orthopaedist, who gave me cortisone. Without doing any tests, he told me right away I had rheumatoid arthritis and he gave me cortisone, er, just looking at my hands, er, I...well for a month I took this cortisone but then I could see that without a diagnosis, in spite of only being twenty-one...I was still young but I was telling myself: "without a diagnosis I'm taking cortisone...and then? What happens?" So after a month I stopped taking it.

As noted, this passage is found early in the interview. It also refers back to an early stage in Annamaria's illness. However, it is already revealing of this informant's mental attitude towards her illness. It also illustrates how she portrays herself as unwilling to succumb to the disease and, crucially, unwilling to passively follow her doctor's orders and to accept his diagnosis. In fact, her comments juxtapose her own sound judgement with that of the doctor, which is implicitly criticised ("*without* doing any tests"; "*just* looking at my hands"). Even this relatively short extract already problematises the idea of the patient as powerless vis-à-vis the medical establishment, which is often repeated in the literature. Annamaria paints a picture of a woman whose cognitive and critical functions are intact and who is clearly able to act

³⁷ The codes following each extract refer to the participant, type of date, and page where the extract appears in the original version of the transcript. So, here A=Annamaria; I=interview; 1=page one in the original Italian transcript)

following her own better judgement, even if this means acting against medical advice. The kind of behaviour displayed by this speaker is indexical of *real agency* (see above); it is antithetical to ideas of patient passivity and the power imbalance in the doctor-patient relationship. However, the narrative passage exemplifies an 'evolution' of the speaker. In it, Annamaria portrays herself as transitioning from one role, that of the compliant patient, to another, more 'active' one. McAdams (1993) uses the term 'imago' to refer to the personified and idealised concept of the self. He argues that our 'imagos' are part of our 'personal myths':

Each of us consciously and unconsciously fashions many characters for our life stories. These characters function in our myths as if they were persons; hence, they are "personified." And each has a somewhat exaggerated and one-dimensional form; hence, they are "idealized." Our life stories may have one dominant imago or many (1997: 122).

This 'active' stance contributes directly to forming Annamaria's 'imago' (and each of the informants in the ALOMAR Plus corpus works toward presenting and sustaining one or more preferred imagos) and also appears in a subsequent passage: Extract (5.2), which appears further on in the interview and refers to a time when, having stopped taking cortisone, her symptoms reappeared and once again she sought medical help:

Extract (5.2) (A I: 1-2)

Simone: And, the symptoms were...during the therapy with cortisone was...did you feel any better?

Annamaria: Yes, I felt much better, with cortisone I felt much better but after a month, when I stopped taking it, I began experiencing pains again. My GP wasn't saying anything [to me] and my son's paediatrician realised I wasn't feeling very well because I brought him the child for a check-up and he saw I found it hard to move, so he asked what was the matter and I told him. So he advised I come to the [name of hospital], where there was a rheumatology centre. I did come to the [name of hospital] and did the first tests and the doctor who saw me, since all tests were negative, said that...that for him it could be something...but he thought it was only...only psychosomatic.

Simone: So...he thought it was...

Annamaria: A psychological factor. He told me that according to him it was only a psychological factor because...each time that I came for tests, I never had anything to show to him, because my hands would swell up and then get normal again and the same my knees and each time I came to see him I had nothing...to show him.

Simone: And the pain was always there, was it there only when it was swollen?

Annamaria: The pain was there mainly when [the hands and knees] would swell, and so, he told me to come again once I had something swollen, without making an appointment and after two days I arrived with a swollen knee and he goes "well, then it's not a psychological problem because otherwise the knee wouldn't have become swollen." So he tested the liquid [from the knee] and...he told me I had rheumatoid arthritis, but that from the blood tests it didn't show. So he didn't give me strong medicines, only anti-inflammatories...and he told me to go on...well, he told me: "*signora*, I don't know what to tell you anymore, come back when you feel worse." I was only 21, I didn't like what he said but that's exactly how it went, to tell the truth, I only took anti-inflammatories...when I needed them, which was often [...] then these knees would swell up and swell up, they would stay swollen for a week. I had quite a heavy job, I was a weaver, so, with the walking and all, but I always kept on doing it [working], in spite of everything, me, with my swollen knees, I would still go to work but well, even staying at home wouldn't have changed my life. No, I managed to keep on working in spite of it all.

This rather lengthy extract is interesting because it reiterates three themes which are paramount in Annamaria's story. First, the encounter, especially in the first part of her illness, with a number of well-meaning but, ultimately, ineffectual clinicians. Secondly, Annamaria's portrayal of herself as affected but 'unbroken' by SLE. Thirdly, the problem of living with an 'invisible' chronic condition. SLE often results in reddening of the skin of the face; it is from this

'wolf-like' feature which it derives its name. However, the visibility of the illness is intermittent and often not present for long periods of time.

The doctors she consults first cannot make a diagnosis, then dismiss the symptoms and attribute them to 'psychosomatic factors', and finally give a diagnosis which is the result of 'guessing', albeit – one might argue – 'educated' guessing. It is interesting to note that Annamaria does not openly criticise the doctors. Her criticism is implicit; it can be inferred from the surrounding text and, ultimately, its interpretation as such is left to the interlocutor.

Her encounter with the hospital doctor highlights one of the recurrent themes in the interviews of the ALOMAR Plus corpus: the 'invisibility' of the illness which often results in the *de facto* delegitimization of the patient and of her suffering. As Okada (2011: 161-162) notes, the 'invisibility' of one's illness is a mixed blessing; although it allows the affected person to conceal the extent of their pain and suffering, it also results in the illness not receiving social recognition. The problem is particularly acute when, like for Annamaria, there is a 'double invisibility' (Okada, *ibid* p. 162), where the illness is 'invisible not only to lay people but also to (most) medical practitioners.'

Paradoxically, the situation is made worse by Annamaria's attempts to portray herself as an active person and her showing a high degree of agentivity. This is the second of the themes apparent in her account: her self-portrayal, through narrative, as active and 'unbroken'. She goes on to effectively paint a picture of a resilient woman; although her job is heavy, she carries on doing it. However, to carry on 'working in spite of it all' is precisely the type of behaviour that, although it allows her to keep playing an active role in society,

impedes her chronic illness and her suffering to receive full social and, crucially, medical validation. In the quoted extract, Annamaria uses 'habitual narrative'. This type of narrative, which uses the auxiliaries *used* or *would* (or their equivalent in other languages), is – as noted by Cheshire and Ziebland (2005) – less 'dramatic' than one where the simple past tense or historical present is used. In the latter, the 'blow-by-blow effect of a story about a single occasion' (Cheshire and Ziebland, 2005, pp. 23-24) is effectively conveyed. Habitual narratives – on the other hand – are better at conveying repetition and routines. Interviews in the ALOMAR Plus corpus seem to lend credibility to Cheshire and Ziebland's (2005) observation that habitual narratives:

are likely to occur in talk about the experience of chronic illness because that experience inevitably includes a series of repeated events and everyday small decisions about the management of the illness (pp 24-25).

This particular example of habitual narrative is also very effective as a tool for building a particular type of identity for this speaker: resilient and unwilling to let chronic illness have too heavy an impact on her life. It is through narratives like these that Annamaria is able to 'reclaim' her life and her identity as a wilful, active, 'agentive' operator in the real world.

In extract (5.2), Annamaria challenges again the view of the patient as somehow 'passive'. Once again, she challenges her doctor's proposed course of action, (although not by directly confronting him) with her decision to take anti-inflammatories only when needed. Again paradoxically, it might well be that this 'act of resistance' resulted in the deterioration of her condition.

Speakers often construct their identities by comparing their behaviours with those of others. Annamaria employs this strategy, although – typically for her – she does so in a rather oblique and understated manner. Extract (5.3) shows her doing so in a non-narrative passage produced in answer to a request to describe her experience of pain:

Extract (5.3) (A I: 9)

Annamaria <DEEP BREATH> it isn't easy, to describe pain <LAUGHS> it isn't easy. Well, then there are different kinds because, pain, erm...I'd like to say a burning but it isn't a burning, it's really something intense. In some cases, it seems like, well, often one hears these phrases, that appear exaggerated, but it feels like somebody is twisting a knife inside of you, isn't it? Well, truly, often it is like that, even if these are things that I never say because I don't...just hearing them bothers me; to me it feels like, like you're emphasising, isn't it?

Simone: mhm mhm...

Annamaria: Yes, to make them [things] even heavier that they are but in truth it's like that, at times pain just as if a knife was piercing you.

Extract (5.3) is interesting for more than one reason. First, it reveals Annamaria's difficulty in encoding the precise nature of her pain. As noted, in works about bodily pain as well as in lay people's observations about it, this difficulty is often commented upon. However, Annamaria does offer some characterisations of her pain. The fact that the most appropriate descriptor she can find is a simile is not, as Scarry (1985) claims, a limitation of language but a clear example of its resourcefulness. The evocative power of the image used by this speaker conveys well the type of sensation, its emotional impact, and the sense of powerlessness felt. The agent causing the pain is encoded

as a generic 'somebody' and the 'patient' (in the grammatical sense) as a generic 'you'. Then Annamaria provides a configuration where the 'actor' is 'a knife' and the 'patient' still a generic 'you'. However, the interlocutor knows that this 'you' is really the speaker, Annamaria.

Discursively, as noted in previous sections, by utilising generic statements in the indicative and generic pronouns Annamaria is able to convey the emotive impact of her experience effectively. Yet because of the absence of emotive language, the image which is projected is that of an individual who is 'in control' and whose account has therefore credibility. Simultaneously, the interlocutor is enlisted as a sympathetic listener (a 'believing' listener, one might say). It is interesting to note Annamaria's use of tag questions. Not only do they ensure that the interlocutor is still following but as discourse markers they also work to align the listener to the speaker's position.

Related to the point that has just been made is that in extract (5.3), Annamaria presents her identity by indirectly comparing and contrasting her behaviour (in experiencing and reacting to bodily pain) with that of other lupus sufferers. She attributes the encoding of the pain experience in terms of a knife piercing the body as something that 'one hears'. She skilfully pre-empts the interlocutor's possible disbelief by saying that this might appear 'exaggerated'. Her stoical identity is thus put forward but without realising the contradiction, she states that 'these are things [she] never say[s]' (she is, in fact, saying them now). She is 'bothered' just hearing them; she fears that speaking in these terms might reduce her credibility. Annamaria is thus performing the role of the 'good patient', comparing her behaviour (albeit indirectly) with that of the 'bad patient', with whom she wishes not to be identified. Undoubtedly,

this behaviour is the result of previous encounters with medical professionals and lay people. It reacts to and pre-empts possible objections as to the veracity of the account. Encountering disbelief of one's condition and suffering (both by medical professional and lay people) is evident in Annamaria's account as well as in other of the participants' interviews. As noted (Okada, 2010), it is particularly common in the experience of patients with chronic, 'invisible' illnesses.

As stated at the beginning, Annamaria's experience can be subdivided into two macro-sequences: the initial phase of her illness and her experience after certain diagnoses and 'fully-blown' lupus. In spite of her effort and of her desire to continue her life as before the onset of illness, ultimately she has to adapt to this new reality. However, as the following passage (extract 5.4) illustrates, she is able to maintain coherence in her life-story, and to remain the principal 'actor' in it.

Extract (5.4) (A, I: 12-13)

Simone: Can you remember what life was like for you, before this all began?

Annamaria: Yes, I've always been a very active person, erm, I've always very much enjoyed working, even toiling has never been a problem for me. I've always done it willingly, I must always move [be physically active], always feel useful, do something and I must say that in spite of everything I'm still able to do it today, even with the pains. Clearly, I'm a bit limited compared to before; I can't bend down anymore, kneel down, do these things, I have difficulties, now I have nephews and nieces, my brother's children, I'd love to go for a run [with them]. Sometimes the younger one says: "come on auntie, catch me", Well, it's easier said than done <LAUGHS>.

In spite of her efforts and resilience, ultimately Annamaria has to acknowledge that her life cannot remain the same. There are adjustments she has to make

(in another passage she tells that after some time she had to leave employment). Extract (5.4) is important because in it Annamaria presents her 'new', post-illness identity. This identity is not diametrically opposed to her previous one. The continuity is illustrated by the passage referring to the 'before', immediately followed by the depiction of her current self. Pain in particular, Annamaria tells us, has not been able to change her. In her resilience there is continuity; hers is a coherent, unbroken identity. What changes there *have* been, like – for example – diminished physical strength, are downplayed.

Finally, what is the overall image of her illness that Annamaria gives? Extract (5.5) illustrates this very well. In it, I asked her to elaborate further on an image of lupus provided earlier in the interview:

Extract (5.5) (A, I: 14)

Simone: Finally, just one thing, I was struck by the image you used earlier of lupus as, as an illness, this kind of monster, something inside of you...

Annamaria: No, it's not a monster!

Simone: A...

Annamaria: A little wolf.

Simone: A wolf, a small friendly thing...the illness but...lupus...but if you had to picture, well I don't know, picture the pain, independently from...well pain in itself, what kind of image would you think of?

Annamaria: Not a bad one.

Simone: Not a bad one?

Annamaria: No...no, something that's part of my life, then...I have to say that I don't know if I'd really like to be cured of this illness.

Simone: Oh?

Annamaria: Because it's taught me many things. And...I was able, in my life, to do something I really like, which is taking care of other people. And I was able to do it thanks to lupus, because I wouldn't have been able not to have a job [...] so this allows me to come to Milano and do voluntary work and be close to the ill. It's something I truly enjoy.

In extract (5.5), Annamaria displays an integral, reconstituted identity. The 'breakages' in her life story are repaired and this is presented as a coherent whole, where even illness and pain have an ultimately positive role. This can be seen as an example of what Frank (1997) calls a "restoration narrative" but also has elements of the "quest narrative". In spite of the illness's disruptions and the ruptures it caused, the integrity of Annamaria's life-narrative has been restored. Indeed, illness has been instrumental in 'unveiling' this speaker's true identity, which had remained hidden underneath the burdens and the constraints of the life of an ordinary, healthy, working woman. Paradoxically, for Annamaria, the arrival of lupus has strengthened her role as 'actor', as an agentive force in her own life.

Summary

For this speaker, the arrival of chronic illness and the related bodily pain have obviously been disruptive. However, in her account – through both typically narrative as well as non-narrative passages – she presents an identity which is fundamentally unaltered. Before the onset of lupus, through the initial stages and thereafter, she remains a highly volitional individual. Her sense of self may have been temporarily disrupted but she was soon able to recover a coherent life-story and an intact – indeed strengthened – sense of self. Although powerful forces have intruded on her life, Annamaria remains a

powerful actor in her life. Perhaps paradoxically, chronic illness and even her experience of pain are invested by this speaker with positive, often 'liberating' attributes. The narrative truth here is one of 'reconstitution', rather than fatal disruption.

5.5.2 *Sandra*

Sandra's interview covers a long period of biographical time since, as stated previously, she is the one who began experiencing symptoms at the earliest age amongst the participants in this study. Indeed, the topic of age is a recurrent theme in her account. Thematically, it develops in ways analogous to those of the other participants: onset of symptoms, first referrals to various practitioners, prescription of pharmacological treatments and their side-effects, and subsequent life with the condition (lupus).

As mentioned, the theme of the very young age at which Sandra began to experience the symptoms of lupus is prominent in her story. Extract (5.6) – which opens the interview – immediately brings this to the fore.

Extract (5.6) (S, I: 1)

Simone: So, would you like to begin by telling me a bit of...of your experience, in general...of when you began...?

Sandra: Well, I am 32 years old. I became ill in 1983. I was 11 years old. I've been ill for 21 years. So, I began...I was at 'scuola media'³⁸ and I had...I was listless, you could say. I began to have temperatures,

³⁸ Part of the compulsory cycle of state education, scuola media ('middle school') is for pupils aged 11 to 13.

pains, but my temperatures were not continuous. I just had a low temperature, it would come and go, so I wouldn't always show I wasn't feeling well, then once my arm would hurt, another time the bottom of my foot would, and the pains would move about until one day I went to the doctor's and that day my temperature was actually 39 [degrees Celsius]. It was very high. From that time, well, practically I kept getting worse.

The first clauses of Sandra's turn – which were spoken as three distinct, clearly separate intonational units – are highly indicative of the temporal value in this speaker's story. These introductory lines signpost Sandra's experience and – for the interlocutor – provide the emotive interpretative key for all that follows.

To begin with, there is Sandra's age at the time of speaking is 32, which in the western world, is very young. Then there is the date of the appearance of the first symptoms, 1983. Significantly, this is followed by the statement of Sandra's pre-pubescent age at the time: 11 years and by the length of her life as a chronically ill person: 21 years. As noted, each piece of information is spoken in a clearly distinct intonational unit; this – together with the fact that it appears at the beginning of the account – foregrounds the information and signals its importance for the speaker. For this speaker, what is significant is not only that she became ill but that she did so at such a young age. In Sandra's case, it is not so much that there is a 'before' and an 'after' the onset of chronic illness; the latter and her life have been running an almost entirely parallel course. The significance and the impact of this fact are apparent in a subsequent non-narrative (in the Labovian sense) passage (extract 5.7), which – in a way – functions as a *Coda* to the entire interview (although it actually appears in the middle of it):

Extract (5.7) (S, I: 3)

Simone: How would you say that, that you were influenced...what's the effect that on you, that having this illness and the pain has had on you?

Sandra: The illness? Not that much, because, because apart from the acute phases, then one can live with it. So after having stopped it with drugs, one can...how can I say...to...to go about one's business, it's not like you aren't able to...however, as far as...the fact of being...well...oh God. I am...how can I say it...explain it. Every choice I've made...let's say that every choice that I've had to...that I've made in my life has always been influenced by the illness, because it's always been present, since I was a child and everything has always been...a problem; a problem going to the seaside; going out with friends; a problem...everything. And still, and I'm married, there are problems. Every choice has...I mean a consequence, because the illness developed when I was a little girl and I grew up with it. Consequently...a parallel journey.

Interestingly, bodily pain does not play a crucial role; it does not appear as a main actor in the story. Lupus, or chronic illness in its entirety, does. In Sandra's life, chronic illness exerts a definite, altogether malign influence. This is not so much in the physical symptoms it causes (e.g. fevers, various pains, and so on), but rather in its power to limit freedom of choice and the leading of an ordinary existence, especially for a young woman.

Particularly problematic for Sandra is the fact that lupus has – *de facto* – always been with her. In other words, practically, there has not been a time when its influence has not been felt. Hurwitz (2004: 422-423) notes that patients' narratives often differ from medical histories in the role time plays in them. In the former, although accounts are frequently 'segmented into medico-biographical eras, such as "before", "at the start", "during", and "at the end" of an illness', the biological factors around which the events of the illness evolve are organised around an 'inner time', which often stands still and

distorts 'real time'. Sandra's perception of her life's (and her own) timeline is certainly influenced by her having become ill so young.

It is interesting to note that, from a grammatical point of view, in extract 5.7 *illness* appears as grammatical subject only once. Initially, the role of illness is presented through a passive sentence ('every choice that I've had to...that I've made in my life has always been influenced by the illness'). By thematising the phrase 'every choice', the *active* role plaid by the illness is somewhat muted. What are foregrounded are the *consequences*, the '*results*' of having lived with lupus for such a long time. Lupus, in other words, more than in the role of potent, negative actor (in the sense of an entity with the visible, obvious power to impede the exercise of free will), is cast in the role of *eminence grise*, a force operating from behind the scenes.

Although, as discussed above, Sandra appears to attribute more importance (and more negative value) to the fact of having been chronically ill for such a long time than to bodily pain *per se*, the latter cannot be entirely ignored. However, as a coping mechanism Sandra differentiates sharply between the 'woman in pain' and the woman who may be chronically ill but is not in pain. In so doing, effectively she creates and sustains two distinct identities. This is not to suggest that she suffers from some kind of dissociative disorder (although 'dissociation' is a term she uses), but that she distances the self-in-pain as much as possible from her everyday self. This can be seen quite clearly in extract (5.8):

Extract (5.8) (S, I: 1)

Simone: These pains you were talking about, at the foot or in the arm, what type of pains were they? Can you remember them?

Sandra: Well, I have a difficult time remembering them because as soon as I'm well I delete them from my memory the pain I've felt. But then when I hurt, when even just a finger hurts the memory of pain re-emerges [...]. When I'm not unwell I speak positively of my experience of illness. When I'm in an acute phase [when experiencing a relapse] don't talk to me about my illness because it's something that doesn't belong to me, really. I tend to disassociate.

In (5.8), Sandra very effectively conveys her rejection of at least one aspect of her illness: bodily pain. This is in spite of having stated before that bodily pain is not much of a problem for her.

The separating of the 'hurting self' from the 'not-hurting self' might result in an apparent fracture of the self. However, Sandra's effort to present a coherent, unbroken identity is successfully achieved in extract 5.8, thanks in good part to her skilful use of *because narratives*. As Cheshire and Ziebland point out (2005: 27-28), '[b]ecause clauses occur frequently in conversation, presumably because of their semantic role of explaining the speaker's thoughts, feelings or actions' (p. 28). In (5.8), Sandra states that she has a difficult time remembering her experiences of pain. She explains why this is: she forgets the experience as soon as it is over. She does so with a wilful act that exemplifies her agentive power, her status as an *actor*: 'I delete them from my memory, the pain I've felt.' Following Osterman et al. (1999: 144), I refer to these wilful actions on the speaker's part as examples of *real agency*. The label indicates actions, activities, or 'moves' that speakers engage in when they are 'actual agents' (*ibid* p. 144) in their own life-stories. These 'moves' obviously have grammatical encodings, but the label also includes

(and refers to) extra-linguistic moves represented discursively. These 'moves' include 'deleting' painful memories, as well as – for example - deciding to see a particular specialist or stopping a treatment, as in Annamaria's case (see above). Interestingly, from the point of view of the clause as representation in SFG, the clause 'I delete them [the memories of the pains] from my memory' looks like a 'material' clause (it could also be thought as a *mental* process, since it entirely occurs in the speaker's mind), with Sandra as the *Actor* and the memories in the role of *Goal*. For Frawley (1992), in this clause Sandra is the stereotypical *agent*: a semantic category with corresponding grammatical manifestations. He defines the *agent* as, 'the deliberate, potent, active instigator of the predicate: the primary, involved doer' (p. 203). To return to Sandra, this 'deletion' is an act of resistance, as well as a coping mechanism. However, when she experiences a relapse – with its attendant pain – Sandra does not want to hear about her illness. The *because* clause explains the reason in no uncertain terms: 'because it doesn't belong to me'. Therefore, thanks to these *because* clauses embedded in a 'descriptive' (i.e. non-narrative, in the traditional sense) sequence, Sandra is able to provide a rationale for what – on the surface – might look like contradictory statements (and behaviour) regarding her acceptance of her illness. Thus the separation of the 'self-in-pain' from the 'non-suffering self' appears entirely understandable to the interlocutor and a coherent identity is preserved and presented.

The 'strategy' used by Sandra to maintain coherence and to cope with the harsher aspects of her illness may come at a cost. In chronic illness – and especially where pain is present – lack of communication about any aspect of

one's illness can make "invisible illnesses *even more invisible*, as language is 'the medium through which... [the] collective notions of disabilities and 'able' bodies get discourses into place" (emphasis in the original). In extract (5.9), which follows immediately extract (5.8) in the interview, Sandra explains how being a member of ALOMAR helped her to regain a voice that was partly lost:

Extract (5.9) (S I: 4)

Simone: When you're experiencing a relapse?

Sandra: Yes, yes, right. I...it's only since I began coming to the group that I can talk of my illness...otherwise...if you saw me...you wouldn't see I am ill because it doesn't show and I would never have told you. Not out of a desire to hide, more because of a sense of inferiority in relation to others, yes. Whether it's right or wrong I don't know, maybe it's because of my personality...I'm very sensitive, yes, that's the truth but let's say that I'm trying to overcome it...to become more confident.

Extract (5.9) exemplifies Sandra's re-empowerment through membership in the support group and the re-emergence of – quite literally – her voice. In other words, being a member of ALOMAR has allowed Sandra to forge a new identity. Whereas before joining the group, her sensitivity and shyness resulted in insecurity (and silence), she now feels more confident. It is important to note that, for Sandra, this is an ongoing process; she uses the present continuous (*stare+gerund*, in Italian) to indicate her efforts to change. Being a member of the group, in other words, has allowed Sandra to find a voice and construct new narratives – where before there were none – that, as Ramanathan (2010) points out, have enabled her to move away from an undesired positioning. This is what Ramanathan (2010) and McPherron and Ramanathan (2011) have termed 'linguaging' of the body; through

'linguaging', the ill are able to engage again with other human beings, with themselves, and with their bodies.

Extract (5.9) shows the reconstitutive power of language and the emerging of a new identity. Chronic illness (and lupus in particular) is a complex, multifaceted experience. It would be inaccurate not to point out some of the challenges that – for people like Sandra – persist. In extract (5.10), Sandra talks about the effects of pharmacological therapies on her body and – crucially – on her sense of self as a person and, more specifically, as a woman.

Extract (5.10) (S, I: 4)

Sandra: Because the drugs they give you are really strong, and they really entail [cause] mood changes, changes in physiognomy, and that's something that's really heavy [to bear], really heavy. There I truly feel very different.

Simone: From what you normally are like?

Sandra: Yes, I'm not myself anymore. I really change, my personality changes, yes.

Simone: Would you say that...if it has changed, how's your relationship with your own body changed?

Sandra: Mhm, what a tricky little question...

Simone: <LAUGHS>

Sandra: Well, my body, my body has been ravaged so consequently I don't have a good relationship with my body. Because maybe you can find out, yes, from doctors, the doses of cortisone that I took, unfortunately, on my still young body, it really ravaged it. Luckily we're not many to be so ravaged...but it happened, amen. What can one do? I don't look at myself a lot <LAUGHS>.

Extract (5.10) is of crucial importance because it illustrates very effectively how the experience of chronic illness is extremely complex. In it, it is entirely

possible to come across as strong and resilient – forging new identities – whilst acknowledging weaker areas. It is not rare, in reading the existing literature on the experience of illness, to form the impression that the shaping of new identities through narrative (and experientially), the shifting from dispreferred positions to newer, preferred ones, is a coherent process which takes the patient from older positions to a new, altogether better place. Sandra's experience, and that of the other informants in the present research, shows that the shaping of a new identity is fluid; and so are the experiences of illness and pain. It is precisely to keep the whole picture together that the individual has to strive continually, to re-adjust her narrative, to take this fact into account. The result is that she does not look at her own body very much. Extract (5.10) is also interesting because it highlights an often underestimated factor in discussions on chronic illness: the impact of therapies. It is only in discussing this topic that Sandra utilises emotionally charged lexicon ('ravaged'). She says that the drugs cause mood and personality changes; using a *because* clause, she explains that the drugs used to treat lupus are 'really strong'. So much so that at times, whilst taking the drugs, she doesn't feel like herself anymore. Furthermore, the drugs have also caused body changes. As mentioned, she reports that her body has been 'ravaged' (It: *devastato*) by the therapies, which is the most emotionally charged lexical item in the entire interview. However, it is interesting to note that Sandra portrays her behaviour and her responses to treatment as entirely reasonable, and in line with that of other patients. With another *because* clause, she invites the interviewer to make his own enquiries and seek confirmation from medical professionals that what Sandra is saying is accurate. This again

portrays her reactions as reasonable and justified, given the situation; it also aligns her with other sufferers in the same condition. Thus, not only is it important to build and present a coherent – perhaps new – identity; it must also be a believable one.

Summary

For this speaker, the experience of illness and pain has been a long one. She has literally grown up with it. By choice and necessity, she has had to show resilience in order to carry on with her life as normally as possible. In terms of agency, there is a contrast between the severity and duration of her condition and the reluctance in portraying herself anything other than a full agent. Interestingly – and consistently with what other speakers in the corpus do – the entity endowed with negative agency (agency whose effects are evaluated negatively) is the pharmacological therapy, rather than the overall experience of living with lupus. One should not underestimate the negative effects (physical and psychological) that such treatments often have.

The identity that emerges from this speaker's narratives is one of resilience and adaptation. However, it is a 'fluid' identity in the sense that it has weaker areas and requires constant attention. If, on the one hand, Sandra has been able – perhaps *because of* her illness and, even more, thanks to the support group – to draw on sources of strength that she did not know she possessed, on the other hand her embodied self remains a problematic area. Her illness and pain are, therefore, both an opportunity and an impediment. It is on the

balancing of these contradictions that her stability and well-being ultimately depend.

5.5.3 *Anna*

As noted (see biographical notes, chapter 2), Anna comes across as the most distressed of all the interviewees. The memory of the onset of her condition (RA), its fast progression and the often devastating effects endured are still vivid in her memory and come through vividly in her account. The distressing nature of Anna's experience, and the role that physical pain plays in it, is apparent from the inception of the interview. Asked to talk in general terms about her experience, she immediately discusses pain. Anna knew that part of the interest of the research was the experience of bodily pain; this may have influenced her choice of opening topic. However, so did the other participants. The topic of bodily pain is decidedly prominent in this speaker's account. Extract (5.11) – which opens the interview and, as stated, was given in answer to an invitation to tell me about her experience – immediately takes the interlocutor into this speaker's world of pain and suffering. It is in the form of a habitual narrative:

Extract (5.11) (A, I: 1)

Anna: So, the fact of the illness, clearly, because, even before but, maybe it isn't connected to the illness, clearly, almost suddenly the pain [INAUDIBLE], strong, and...by and by it grows, so much so that...there have been moments, before, mmm, and even during the therapy, that...it would become so intense that...just at the thought that it would come back, this pain.....after a few minutes, a few hours, erm, I would really think I couldn't go on with a life like this. I would tell my husband:

“look here, I can’t take it, I feel like jumping out of the window, it’s not possible.” My heart would beat very fast, so much so that, that I would pass out. So this lasted for a period of at least three years and then, finally, some treatment, let’s say that it eased a bit, these periods were not as frequent and when it would come this pain was still very intense but, it would last less...

As stated, Anna produced this narrative section in response to a general question on the nature of her experience. What is immediately striking, from a linguistic point of view, is the fragmented nature of extract (5.11). It is characterised by false starts and self-repairs. The immediacy of the onset of pain is rendered by a nominal clause, where the verb is absent. All this is clearly indexical of the disruptive effect of the arrival of pain in Anna’s life. Unlike other speakers in the corpus, she is unique in the apparent lack of gradualness of the inception of the symptoms. The experience of this kind of pain is clearly devastating for Anna. In general, it is instructive to analyse how patients report their interactions with health care professionals and people around them. First of all, in this passage, quoting herself using direct speech, the immediate effect is of heightened drama. This foregrounds her sensations and immediately and effectively draws the interlocutor into her world of pain. For this speaker – and especially in this passage – bodily pain is clearly a potent *actor*, it appears suddenly, obviously uninvited, and causes disruption. Anna is at the mercy of it. It is interesting to note that in extract (5.11), Anna does not appear in any material process (processes of *doing*, in SFG), only twice in mental process (expressed circumstantially), and once in a *verbal* process (a process of *saying*). It is only pain that *does*: it comes; it goes; it increases in intensity, while Anna is reduced to a passive, powerless host. It is common for people affected by chronic conditions to have to wait a considerable amount of time before receiving a sure diagnosis. This

uncertainty, as noted, is a common experience for the people in the Alomar Plus corpus. It was the case for Anna and this is undoubtedly a contributing factor to the distress and overall uncertainty felt. Extract (5.12) illustrates the progression of Anna's symptoms (i.e. pain) in the absence of a sure diagnosis:

Extract (5.12) (A I: 1-2)

Simone: Where would you get the pains?

Anna: Well, I began with the hands.

Simone: The hands.

Anna: It would starts from here [POINTS TO OWN WRIST].

Simone: From, from the wrist?

Anna: Yes, or here.

Simone: Okay.

Anna: It would become inflamed lightly, it would take me [i.e. affect] all the tendons up to here, to arrive here.

Simone: Up to the armpit?

Anna: Yes, yes, yes, and then regularly, it would take here, my back.

Simone: Your back?

Anna: And it seemed I had something nasty...nasty precisely because...the doctors still could not understand...at the beginning...this went on for, always going on with the drugs, trying, that's it.

Simone: After how long did you finally receive a diagnosis?

Anna: The diagnosis, let's say, I got it ... because first I had been followed by an orthopaedist, let's say, and the orthopaedist hadn't really understood well himself then, when he saw the tests, and the rheumatest kept getting higher and higher and well, he couldn't assist me anymore and the illness, it was [another] orthopaedist who understood it, on holiday.

Simone: Mm...

Anna: It was on holiday, in the building where I was staying, and so he saw me, holding the little girl who was screaming because she'd hurt herself and he saw my hands like this and...he asked me, he says: "but you [INAUDIBLE] have RA? I said: "yes", well I said: "yes..but" "excuse me, but you, have you got RA?" I said: "I don't know, I know I have pains". He said: "well, in Milano there is the [name of hospital] since you live there", I didn't even know where it was.

Prompted by my questions, Anna relates the various pains experienced and their progression. In a brief passage, she relates the inability of a doctor to arrive at a diagnosis. This resulted in increased worry. Anna believed it could be something very serious ('nasty', It: *qualcosa di brutto* 'something ugly') precisely because the doctor could not arrive at a diagnosis, as the conjunction *because* indicates. Therefore, this *because* clause casts Anna in a positive light; she is acting rationally and her conclusion (that it is something nasty) is justified in light of the doctor's inability to properly diagnose.

It is only because of a chance encounter with (yet another) orthopaedist that Anna began to have an inkling of what her illness might be. Another passage dramatises this fortuitous encounter. The encounter is reported through direct speech. Both the location of the reported encounter and the fact that the narrator uses direct speech for herself and the doctor indicate that the encounter is de-medicalised. Although of the two interactants one is clearly the 'expert', his behaviour and diagnostic acumen are clearly, albeit implicitly, contrasted with the ability of those that came before him. In addition, both interactants are given equal amounts of direct speech, which indicates the narrator places both on an equal footing. In this apparently insignificant interaction, we can detect the re-emergence of Anna's integrity of identity; it is from here that she begins to become once again an actor in her own life-story by – for example – going to the hospital and taking steps that will help her

manage her condition. As a result of this chance encounter, Anna's illness is given a name and she begins to re-acquire a voice.

Finding a name for one's illness and beginning to find a voice do not necessarily mean that one's identity has remained unaltered. In the following extract (5.13) Anna relates the change of personality she experienced as a consequence of having RA:

Extract (5.13) (A, I: 6)

Simone: How would you say that your life has changed, because of this illness?

Anna: Because of this illness? Well, it changed a lot, in my personality especially. I was...I used to be a jester type of person...I was...erm...but...I enjoyed the things I did with my family...various things...well, it's changed a lot because now I'm irritable, really, it takes a little.

Simone: I see...

Anna: Even though...

Simone: It changed your personality...?

Anna: It changed my personality, yes. The days when I feel better...a little is enough to feel better but I go up and down. It takes a little to go up, and a little to fall back down.

Prompted by my question, Anna establishes a causal connection – through a *because* clause – between the onset of RA and a change in her personality.

Anna clearly portrays a 'before' and an 'after'; the former positive and desirable, the latter negative and unwanted. Extract (5.13) shows how – in the presence of chronic pain and illness one's emotional equilibrium is often precarious. Although in extract (5.12) we saw Anna taking on an active role (the role of *actor*) by finally going to see a specialist, here she is again a *patient* (in the grammatical sense). Significantly, illness ("it") appears as *Actor*

in a material process where “my personality” – which stands meronymically for Anna – is the *Goal*. Here, Anna portrays herself as literally *transformed* by her illness.

For Anna, a consequence of the awareness of having been changed by her illness is a sense of isolation. The healthy and the ill inhabit different worlds and often speak different languages; hence the frustration. In extract 5.14, Anna relates her sense of isolation, even when in the company of her family:

Extract (5.14) (A I: 6)

Anna: And...let's say that, like this, yes, even though...even though I have everyone around me but...sometimes I think they don't understand me because it's difficult...even always telling you...how can I put it? Always, always pampering you because that's what I need, and they do it, but it doesn't alleviate it...

In this passage, the psychological reality of chronic illness is highlighted. There is – at least for some of the time – a chasm between Anna and her loved ones. There is isolation and the belief that those around her do not really comprehend the whole impact of illness. Such a statement is ‘dangerous’, from a psychological and interpersonal point of view; it risks portraying her loved ones as somehow uncaring. Thus, understandably, Anna is quick to justify their lack of understanding using a *because* clause (‘because it's difficult’). Even if she acknowledges that her loved ones are responsive to her need for tangible signs of affection, ultimately, this does not necessarily help: ‘it [their ‘pampering’] doesn't alleviate it’. A possible consequence of this realisation is then a sort of self-imposed silence. Convinced that it is not possible to truly communicate the full impact of their situation, the chronically

ill person often retreats into isolation. This sensation is made more acute by the fact that – unlike for non-chronic conditions – there is no ‘way out’. As Anna puts it in a later passage (extract 5.15):

Extract (5.15) (A I: 8)

Anna: Always problems and therefore...you spend entire days...in the various hospitals...doctors...and...well, you never get out of it, you never get out of it...

The last clause (‘you never get out of it’), repeated, perfectly makes the point: chronic illness, at least for Anna, is like a prison where personal time does not exist anymore, having been substituted by ‘illness time’, meaning that a chronic condition of this type leads to loss of ownership of one’s most precious resource: time. The imprisoning power of this cycle is very well rendered by the repetition of the clause in line 3 (‘you never get out of it’). For Anna, and for many chronically ill persons like her, this constitutes the ultimate loss of agency.

Summary

RA has proven to be a traumatic, highly disruptive experience for Anna. Reflected in her language is a sense of powerlessness vis-à-vis her condition, with its fast onset and unpredictable course. For this speaker, what seems to be particularly relevant (relevant enough to require linguistic embodiment) are her inner states, which she sees as often inaccessible to others, even her loved ones. For Anna, RA has had a transformative power

and there is clearly a 'before' and an 'after'. Although she does appear as an actor in her life-story, illness is invested by her with considerable agentive power. Anna favours habitual narratives to blow-by-blow accounts and this might be because habitual narratives are better at capturing and transmitting the sense of 'entrapment' that she often feels. This speaker foregrounds the negative impact that illness and pain have had and continue to have on her life. Pain in particular has had a particularly distressing and disruptive impact, as the fragmented syntax exemplified by extract (5.11) vividly illustrates its 'force' is clearly encoded by the number of 'material processes' in which it appears as *Actor*.

5.5.4 *Marta*

At the time of the interview, Marta was in her 60s. She was 58 when she received a diagnosis of RA. For this speaker, there are clearly a 'before' and an 'after' and the onset of the symptoms, or – more accurately – receiving a diagnosis of RA, acts as the demarcation line. A brief narrative passage at the beginning of her interview effectively depicts Marta's identity *before* the onset of the first symptoms:

Extract (5.16) (M, I: 1)

Simone: The first question...I just wanted to ask you if...if you wanted to talk a little bit of your experience with the illness, when it started...just to give?

Marta: [INAUDIBLE] I began when I was fifty-eight and I was, I had never had any illness in my life. I was truly...I considered myself lucky because I had never had anything, and suddenly from a small pain,

from a finger...was born a whole sequence of this pathology which is RA.

Extract (5.16) neatly illustrates Marta's perception of herself before the onset of symptoms. Most importantly, she was a healthy woman, for which she considered herself lucky. The link between her sense of having been fortunate and physical health is clearly indicated in the *because* clause. However, at some point things changed. What on the surface might have appeared as a small, inconsequential event, turned out to be the beginning of life with chronic illness.

The section of the interview where Marta presents her life before the onset of illness is characterised by numerous clauses expressing 'real agency': clauses presenting a highly active self, engaged in a number of endeavours. For example, Marta the great lover of outdoors activities. A number of clauses display her agency by presenting the speakers in activities such as: driving, taking long walks, and going hiking on the Italian Apennines. Ironically, it was on one of these holidays that Marta began experiencing an almost insignificant symptom (fatigue) that signalled the imminent change in personal circumstances. This can clearly be seen in extract (5.17):

Extract (5.17) (M I: 4)

Marta: Oh well, I used to...to run...to hike like I said, before becoming ill. it was in June 1997. I...twenty days earlier...and in fact I blamed it on this hike I went on. I went on a hike on a...on a mountain on the Apennines.

Simone: Mhm.

Marta: At two-thousand metres. Well, actually from a thousand to two-thousand. I came back that it was, well at one point I had to leave it because...I left the group <LAUGHS> because I went back on my own

because I couldn't continue anymore. I made an effort. Maybe I couldn't...walking for so long...but I was feeling well...like I say...I was a healthy person and I had the desire to do things and naturally my life has changed in the sense that I can't say anymore: "tomorrow I'll go...I'll go on a trip". Tomorrow I'll have to see how I feel...if I can go...if I can do...even this morning...I had an appointment with a friend but honestly...I didn't feel like it and even if...even if it had been urgent...one thing, I can't plan my life anymore, yes...first...I can't plan my life anymore and this, obviously, changes many things.

The transition from the *before* to the *after* stage in her life is illustrated very well by the passage reproduced in extract (5.17). In the opening lines, Marta presents her pre-illness identity as that of a very active woman, exemplified here by her love for outdoor activities. This reinforces the positive self-image given previously. Having gone on a hike, she has to abandon the group and go back, on her own, because she became fatigued. Marta remembers that she initially blamed this hike for her early symptoms.

It is interesting to observe how she encodes the transition from the world of the healthy — with its possibilities and unfettered agency — to that of the chronically ill; the latter characterised by a number of impossibilities and limitations. This shift, in the story and in Marta's life, is clearly signalled by — among other things - negative clauses signalling impossibilities. It is at this point that a change in the degree of her agency can be seen. What up to that point was possible, normal, and taken for granted, suddenly becomes fraught with difficulties.

This new identity is highly embodied and is characterised by what Ostermann et al. (1999) refer to as 'non-accomplished agency'. 'Non-accomplished agency' means that the individual's freedom to operate, to move and act in the real world as a free *agent*, is progressively reduced (in which case, one might speak of *reduced* agency) and — in some cases — completely

eliminated. For Marta, as for many other affected individuals, RA, with its corollary of symptoms, results in a series of impossibilities. Quite simply, life is not the same anymore. The fact in the narrated episode may appear as relatively minor and, ultimately, inconsequential. However, it is precisely the mundane nature of the incident (the inability to attend an appointment with a friend) that starkly highlights what the transition from *before* to *after* the onset of illness has meant for this speaker. This is especially true because of the textual proximity of the highly-active self portrayed by the previous narrative. So, whereas before Marta was able to engage in physically demanding activities, now even meeting a friend can prove too taxing. This speaker, because of her illness, is no longer able to make plans, which 'obviously changes many things'. The repetition of the two forms of the verb 'to change' is indicative of the frustration deriving from this state of affairs. The diminished agency, at least initially, results in a lessened sense of ownership over one's own life, as noted by many chronic pain sufferers (Goldstein, 2000; Heshusius, 2009; *inter alia*) and in the fragmented sense of self indicated by Frank (1997).

Answering a question on whether her pain is continuous, later on in the interview, Marta recounts how, on the previous day, she had gone shopping for food and had to carry a couple of carrier-bags on her forearms. This resulted in pain that is still present during the interview:

Extract (5.18) (M I: 3)

Marta: Well, sometimes even when one is resting, sometimes there are pains that appear even when one is resting but obviously, resting allows

you...and I yesterday, yesterday I told myself I was a stupid woman because I carried a carrier bag.

Simone: Mhm.

Marta: Stupidly, I go out to do the shopping and stupidly even just from the car to, the thing, instead of picking up with my hand as one would normally do, I carried it on my forearm and this morning I feel all [INAUDIBLE]. It must be that the nerve got inflamed and so I said: “absolutely I can’t carry a bag anymore, not even on the forearm.”

What is relevant here is that although the degree of pain resulting from carrying the bags is not extraordinary, the outcome is: a housewife who cannot even buy her own groceries without assistance. Had Marta been asked to quantify her pain on one of the commonly used pain-questionnaires, it would have barely registered. Yet, the consequences in her life are at least noteworthy. This fact highlights how pain is invisible in more than one way; its power lies not only in the capacity to cause unpleasant physical sensations, but also in its often unacknowledged ability to take away or limit one’s agency.

However, for Marta, like for other sufferers, not *all* agency is lost. Her ability to act, to steer her life in the preferred direction, is displayed in activities such as seeking medical advice, taking part in ALOMAR’s activities, and – most importantly – being able to drive. The latter is especially important for Marta in maintaining a sense of independence:

Extract (5.19) (M I: 5)

Marta: Yes, I’ve had an operation on my hand...so...as I say, being able to drive has helped me a lot, truly, and this...

Simone: In order not to depend on...

Marta: Yes, yes, absolutely. Also because of the illness we have. I would always have to ask my husband to accompany me for tests, to accompany me to the doctor's, to accompany me to get all the forms.

Extract (5.19) illustrates how Marta is able to maintain a degree of continuity with her non-ill self. She achieves this by driving to places, which allows her not to have to rely entirely on others, especially her husband. Interestingly, this continuity is also illustrated by a further passage in which Marta reflects on how good it was that, in the past, she had insisted on obtaining a driving license, even in the face of her husband's opposition.

A final comment on extract (5.19) relates to the shift from the first-person singular pronoun to the inclusive first-person plural. Here Marta not only situates herself within the community of the chronically-ill (both the immediate one of the other ALOMAR informants, some of whom are present while she is being interviewed) but also to the wider group of RA sufferers. In doing so, she also compares her behaviour favourably with those of others and implicitly justifies it to her interlocutors, present and potential.

Aside from what is left of it to her, what other 'characters' in Marta's account display agentive behaviour? Pain is certainly one of them, as extract (5.20) shows:

Extract (5.20) (M I: 1)

Marta: The pain got hold of my hands, my feet, the carpal tunnel was compromised by the inflammation. It would give pains, especially at night.

Characteristically, this speaker has something to say about the pharmacological treatment she has undergone. Like other speakers in the

corpus, it is not that she does not acknowledge the necessity of drugs such as cortisone or their benefits. It is clear, though, that they too have an impact on the sufferer's life and that this is not entirely positive:

Extract (5.21) (M I: 3)

Marta: Well, I've been bludgeoned with anti-inflammatories, cortisone, at the beginning. So the burning I would feel in my hands, well, these things became less intense.

This passage is interesting in the way it configures the therapeutic experience. From a lexical point of view, 'bludgeoned' (*bastonata*) is an example of emotionally-charged lexicon (Martin and Rose, 2003), with clear connotations of violence. By resorting to a passive sentence with no visible human *Actor*, the speaker does not apportion blame (bludgeoned by whom?). Yet, interestingly, the use of the passive and the charged lexical choice conspire to present a picture where therapy equals a weapon used against the sufferer. As previously stated, this at least problematises the expectation that therapy will be viewed as unequivocally positive.

Summary

For Marta, living with a chronic illness is a relatively recent experience. In her account, its onset, with all the typical accoutrements such a pain, is a clear watershed: on one side are the possibilities, the '*I can*'; on the other, the impossibilities, the '*I can't anymore*.'

The picture she paints through her careful use of language is one of ever decreasing freedom, of limited agency, though not one of absolute powerlessness. Like other speakers in the corpus, Marta too highlights, almost *in passing*, the difficult relationship so many ill people have with their treatments.

For Marta, the onset of chronic illness has meant a transition from an identity characterised by high embodied agency (her outdoor activities) to one of reduced agency, in some cases severely so. Bodily pain has obviously been instrumental in this reduction, but so have the necessary pharmacological treatments. However, through narrative Marta manages to maintain a link and a certain sense of unity with her identity before she became ill, against which a considerable portion of her identity is defined.

5.5.5 *Veronica*

Aged 58, Veronica has RA. Unique among the informants, she is on the hospital ward when we meet, following surgery (her eighteenth). Her experience could be thought of as one of increasingly eroded agency owing to the ever-increasing severity of the problems she has been experiencing. As will become clear from the following, the situation is, once again, not as clear-cut. Veronica's condition went undiagnosed for a number of years, owing to her blood tests being negative for arthritis. In a brief passage that opens the interview, she succinctly but effectively presents her life's trajectory:

Extract (5.22) (V I: 1)

Simone: Nothing, could you maybe tell me a bit about your experience...when...how it began?

Veronica: So, I was 17. I was doing athletics professionally and distance running, 800metres. I began to experience these pains, and to sum up...instead of ending up doing the running I ended up at [name of hospital].

This opening, very brief narrative is quite interesting: it pinpoints the beginning of Veronica's experience of chronic illness. It sums up the main events in her story and it is also a window into the kind of identity she is keen to present.

Immediately, we are informed of her age and her activity at the time. The image of a young professional athlete is enough to conjure up, in the interlocutor's mind, an idea of a very determined, strong individual, characterised by dedication, self-sacrifice, and — crucially — a promising future ahead of her. However, for Veronica this was not to be.

Then we are told us of the early onset of symptoms. The sentence beginning with 'instead' is particularly interesting. In it, Veronica juxtaposes the possible to the real; instead of ending up running, she ended up in hospital. Not only back then, once, but several times afterwards, as the rest of the interview reveals.

The disruptive effect of illness and injury in the life of athletes, and the reconstitutive power of narrative, has received considerable attention (Sparkes, 2005; Stewart, Smith, and Sparkes, 2011). In Veronica's case, the appearance of RA has impacted on three distinct, yet interconnected, identities: the young person, the athlete, and the woman. In all these roles this speaker has had to make re-adjustments, as the life-course she had

envisaged failed to materialise. Yet, already from this brief passage, one can see Veronica framing her experience along the lines of the 'quest narrative' identified by Frank (1995).

In this type of narrative, the individual affected by illness or injury accepts it and tries to use it to his or her advantage. This was especially clear in Annamaria's story, where the onset of lupus was presented as the opportunity to leave work and devote her efforts to what she really enjoyed: volunteering. In embryonic form, this is already visible in extract (5.22). The speaker presents the outcome of the onset of illness in factual terms; this 'factuality' with the attendant lack of (negative) emotionally charged lexicon, are indicative of Veronica's attitude which will become apparent throughout the rest of the interview.

Paradoxically, Veronica's physical fitness may have contributed to delaying a precise diagnosis of RA, resulting in invisibility and silencing. Veronica's condition went undiagnosed for a number of years, owing to her blood tests being negative for arthritis. In common with many people suffering from chronic pain and chronic illnesses that do not show visible signs, Veronica narrates that her pain was at times doubted. On one such occasion, while training, she was the object of some rather cruel behaviour on the part of her trainer. This incident instantiates quite literally Frawley's (1992: 210) definition of *patient* as 'the primary recipient [of the *agent's* actions]':

Extract (5.23) (V I: 2)

Veronica: I remember my trainer, we were training for the relay race and he was holding the baton to tease me [following complaints about pain], I

don't think he meant any harm, he took the baton and hit me under the foot, where it hurt. It was an atrocious pain, acute, very intense, yes, he stopped teasing me, because I must have, probably I must have been transfigured by pain, because it was a very intense pain.

This passage is particularly interesting and revealing. Veronica appears as grammatical *patient* ('and he hit me') or, in SFG terms, as *Goal* in a material process where her trainer is the *Actor*. As a result of his thoughtless action, pain sets in and itself becomes the potent *agent* that 'transfigures' her; it changes her outward appearance. Here, Veronica uses emotionally charged lexicon to thus encode (in *Appraisal Theory* terms) simultaneously *Affect* and *Appreciation*. Interestingly, it is at this point, when wordless *pain-behaviour* appears that Veronica is accepted as a reliable witness of her own story. Being able to talk about one's pain, it appears, is not sufficient proof of one's suffering; words, as often pointed out by chronic pain sufferers like Heshusius (2009) can and often *are* disbelieved. It is also interesting to observe how Veronica encodes her reaction and her appraisal of what might have caused the trainer's change of attitude. In the line beginning with a *because* clause, introducing epistemic modality ('I must have'). The clause however is left hanging; later the same epistemic modality is modulated by her use of 'probably'. Veronica, in other words, is making suppositions as to the true import of her painful reaction which must have been sufficiently out of the ordinary to make her coach reconsider her previously dismissive behaviour. Extract (5.23) shows Veronica's identity as an ill individual – and one affected by great pain – emerging slowly and gradually. One gets the impression that it was the combined effect of her painful sensation *and* the observed reaction of the coach to the effect it had on Veronica that worked together to fully

awaken Veronica's consciousness to her own new condition. However, it was still some time before this speaker was finally able to receive a sure diagnosis and thus gain full visibility. This, as mentioned, was because of her athletic body, as well as the absence of visible signs.

Extract (5.24) (V I: 2)

Simone: But there were still no signs that could be seen, there weren't...

Veronica: No, also I had two very agile hands, so much so that many would say: "you've got the hands of a pianist".

Simone: <LAUGHS> yes, I was going to tell you...

Veronica: Yes, so...erm, they would tell me: "move your hands" and I would move them. I would do all they asked. Says³⁹: "no there's no arthritis here" and I've told you, I had a nice pair of legs with good muscular tone, because...being a distance runner I would run every day. I would run kilometres upon kilometres, so...mhm...it could make one think...that it was <LAUGHS> psychosomatic. But then no then it was...

In the second speaking turn in (5.24), Veronica animates some undefined third-parties (*they*) who would comment on her nice hands. Thereafter, one begins to form the idea that these *they* might in fact have been doctors who, presumably during consultations, would instruct her to move her hands. Veronica portrays herself as compliant; indeed the whole situation is presented in entirely de-medicalised language. Later, Veronica animates one of these professionals who diagnoses (wrongly, as it turns out) that it is not a case of RA. Cheshire and Ziebland point out (2005: 28-29) that for patients, interactions with clinicians may be highly charged occasions.

³⁹ This literally translates It. dice 'he or she says', a quotative frequently employed to introduce direct speech.

It is instructive to analyse how patients report their interactions with health care professionals, both in terms of what they choose to report, and in terms of how they report it.

It appears that, at least initially, Veronica deems the doctor's (or doctors') words to be more quotable than her own (of which there is no trace). Importantly, the general statement in lines 18-19 ambiguously relates a statement that may or may not have been uttered by one of the doctors; the fact that the pains might have been psychological (i.e. unjustified and unverifiable) in origin. Such statement is presented as a possible explanation for reaching this conclusion. The fact that only Veronica's interlocutor's speech is reported directly and that the conclusions it relates are presented as reasonable suggest a compliant identity, at least in the initial stages of the illness. Subsequently, she contradicts this early 'diagnosis'; however, she does not apportion any blame. Just like with the episode with the coach mentioned earlier, what might be construed as criticism is very light and indirect.

Pain in RA is present and it is often very intense. As mentioned, Okada (2011) looked at the experience of two chronically ill women, one of whom had a herniated disc. The woman whose experience Okada analysed (Mia), was compelled to hide her condition and the resulting pain from her husband. Okada argues that because Mia's pain was warranted biomedically (i.e. it had a diagnosis) but not socially, Mia was effectively silenced and her suffering increased because of it.

Silence — however — can be empowering and a weapon of choice in the fight against pain. On condition, however, that it be freely chosen. This is the case for Veronica. In extract (5.25) she explains how she does this and in the process presents a resilient identity:

Extract (5.25) (V I: 2-3)

Veronica: As time went by, I've always had a slow but aggressive form [of RA], in the sense that...I have, I have no memory. I could have suffered them [the pains] because I delete. So...if now I'm in pain, in fifteen minutes...if I'm not in pain anymore I forget...the pain. It's a form of defence of mine...I think I've never had, as many say, pains you can't stand. I have pains...for example now my hands are hurting but, I...they are bearable pains. It's rare that I've had pains so strong you couldn't talk with others and feel the need to isolate myself. Because when I've had these crises, regularly, I isolate myself. I need to curl up inside myself and get my strength back, and then it passes [...].

Simone: Is this a technique you've developed yourself...or something?

Veronica No no no, I've done all by myself, little by little...I did. I can't even say if I've made myself do it; it came natural for me to behave in this way.

Simone: So this self-imposed isolation is...to better face?

Veronica: To better isolate the pain and overcome...earlier, much earlier the crisis, because I realised...even with the operations I've had and with this one it's 18, I realised that if I stay calm and quiet, if I don't communicate with others but concentrate...the pain is less intense. If instead I have to talk, maybe because I need something, then pain gets stronger.

For Veronica silence is a better way of coping with intense pain. Through a sort of mindfulness technique, she is able to control her pain. On the contrary, speech — about pain itself or anything else — is detrimental.

Like other speakers in the ALOMAR Plus corpus, this one too constructs aspects of her identity by comparing herself with others. For example, she says that, unlike other sufferers, she has never experienced unbearable pain

and is keen to portray her condition as manageable. Her identity, in other words, is one of a woman who is not exceedingly affected by pain and, one might argue, Veronica does not entirely identify with the 'chronically-ill'. However, when pain does appear, she is able to manage it and, significantly, using a 'technique' discovered and developed by herself. Crucially, this puts her in control not only of her pain but, more generally, of her whole situation. In a later passage, she reinforces this image and goes on to paint a picture of acceptance of her pain:

Extract (5.26) (V I: 3)

Veronica: Pain is a constant, in the sense that, more or less intense it's always there [...]. It's never been the kind of pain that would make life impossible to go out, go to school, but at the same time it's always been with me, it's always been a companion, yes <LAUGHS>, of 40 years. Last year I turned 57, arthritis turned 40. I told it: "come on, make me get younger, you take the 57 years <LAUGHS>. It kept its 40 years.

Extract (5.26) suggests that, for this speaker, the experience of pain (which is an integral part of RA) has been harmoniously integrated into the self. This is not to suggest that pain (and RA, which causes it) are somehow welcomed. Nor does it signify that acceptance of pain and illness are constant and do not allow contradictory behaviours. Extract (5.26) is particularly illustrative in this sense; albeit brief and apparently insignificant, it exemplifies Veronica's effort to maintain a coherent, unbroken identity. Crucially, however, it also illustrates how this effort is fluid, rather than fixed. She presents her experience of pain in terms that indicate acceptance. She also refuses to present a 'medicalised' identity and to identify with extreme cases. This is particularly interesting

because it exemplifies how narrative truth is a subjective construction. This is not to say that Veronica is lying but rather that — through narrative and, more generally, language - she chooses to assemble and present a particular type of identity. It should be noted that to the interlocutor, who has been told of her medical history and witnesses Veronica's current situation, her statements regarding the non-extreme nature of her condition appear remarkable. Veronica also jokingly highlights how, for 40 years, her life and RA have been developing in parallel. The passage again demedicalises her situation and presents a coherent, well-adjusted identity. However, the laughter which brackets the sequence indicates the emotive import of the topic.

Summary

Although, for this speaker, RA has clearly been the source of numerous problems, it is not presented as an overpowering entity, and neither is pain. Pain is indeed seen as an agentive entity that obviously affects the speaker's life. However, this agency is primarily construed as the ability that pain has to make its entrance unannounced and to overstay its welcome.

In spite of the numerous obvious and understandable difficulties that Veronica has encountered, she retains and displays a high degree of agency. This is mainly employed to control her pain through a number of 'psychological' techniques, such as focussing. Throughout her account, Veronica is keen to present a harmonious identity, not overly affected by either RA or the physical pain it entails. Often, she does this by minimising their effects, by 'de-medicalising' her situation', and by not aligning with other

sufferers for whom pain is a major obstacle. RA and pain, at once distinct and fused, are metaphorically represented as an amicable 'companion', spoken to and cajoled, unwelcome but not feared. This, perhaps, can be thought of as the supreme expression of agency.

5.5.6 *Gina*

Gina, who is in her fifties at the time of the interview, has been living with RA for twenty-two years. Like Marta, she loves the mountains and again, like Marta, began experiencing pain (for her, the first symptom of RA) on the way back from a hike. It is in this circumstance that pain begins displaying its disruptive agentic behaviour. Like other speakers, Gina construes and represents pain's agency mainly in its capacity to persist temporally and spatially in unpredictable manners. Understandably, this is cause for concern and frustration. Interestingly, this speaker provides numerous examples of body-parts displaying agency by, for instance, swelling, stiffening, and hardening. In extract (5.27e), she relates the onset of her illness:

Extract (5.27) (G I: 1)

Simone: I wanted to ask you, to begin, if you could tell me a bit about your experience, how the illness began, the genesis of your story.

Gina: Well, I began...I kept getting pains in my knees, or feet. I would mainly realise when I went to the mountains because I love the mountains and when I had to come down my knees would swell up I would be blocked. Then maybe at home, erm, at times a hand would swell up, at times an arm, but, erm...with a temperature also but I wasn't exceedingly concerned because they would tell me: "if the pains move it means it's nothing serious."

In the above passage, Gina relates how her first symptoms (swellings of body parts and pain) first appeared, over a period of time. Significantly, she does so whilst also informing us of a passion of hers: the mountains. This love for a particular activity represents a persistent and enduring trait of her identity, as the shift to the present tense in the *because* clause indicates. As with other speakers in the ALOMAR Plus corpus, the onset of symptoms represented, for Gina, the beginning of a period of uncertainty marked by wrong diagnosis and visits to a number of physicians. Initially, encounters with medical professionals are represented impersonally. This can be seen, for example, in the latter portion of the quoted passage, where an unspecified ‘*they*’ makes her think that the fact that the pains are not fixed is a good sign, thus downplaying them. Gina’s journey towards a diagnosis of RA is encoded in the following extract:

Extract (5.28) (G I: 1)

Simone: And what types of pains were the ones you experienced initially?

Gina: They were very strong pains, at the knees. They would really block me...my joints and the same would happen with the hands and wrists, high temperature and strong pains because then the joint would swell up, the joint would become blocked but initially I repeat I didn’t think too much of it. Instead, there was one morning that I couldn’t even get up from my bed and I called the family doctor and he said to come here, to the [name of hospital] but it was far, so I let it go. Then I began doing some tests, blood tests...and once I went to a doctor’s, then he sent me to another doctor’s, and first they treated me for my teeth. It looked like I might have some abscesses in my teeth and then they’d say that it was an inflammation so...and meanwhile almost two years passed. When the illness was finally discovered, that I really couldn’t resist any more, I went to a cardiologist who was a family friend, a friend’s friend, and as he saw my hands he said I had RA. He sent me to do some tests and there everything really started. I began feeling a bit better but logically it’s been kind of harsh, especially at the beginning.

Through habitual narrative clauses, Gina gives the background to what led to a degeneration of her overall condition and, finally, to a diagnosis. This sort of prologue was characterised by debilitating symptoms: pains, swelling, and fever. It is interesting that these events are represented rather impersonally, simply as a list of “happenings”. This changes in a series of clauses where she appears as an *Actor* by going to see a number of doctors.

Like most of the other speakers in the corpus, Gina avoids emotive descriptions of her inner states. In extract (5.28), there is only one instance where her inner states come to the surface, albeit in a rather muted way: “Logically it’s been kind of harsh” (*It. Logicamente è stata un po’ durezza*). This clause accomplishes two things simultaneously. First, by opening with the stance adverbial ‘logically’, Gina presents her emotive reaction as justified and as a position that the interlocutor can easily align with. Yet, this emotive stance (encoding *affect*) is clearly toned down. It represents a trend which, as noted, is common in the ALOMAR Plus corpus: the tendency to avoid linguistic encodings of the individual’s emotional responses that might characterise her or him as somehow unreasonable or, to use a term that some of the informants use, a ‘complainer’. The imperatives to appear reasonable and as much in control as possible therefore seem, for Gina as well as for other informants, overarching preoccupation.

With the progression of RA, life becomes increasingly complicated. Living with a chronic condition characterised by intense pain and body changes is a challenge not only for the ill person but also for those living around her. Often, this can be made worse by the fact the chronically ill person hides or minimises the true impact of the illness in order not to cause distress. In the

following extract (5.29), Gina talks about this in response to a question asking her to explain how RA has influenced her life:

Extract (5.29) (G I: 2)

Gina: Initially, it's been hard because my children were still very young, and so...they were a bit...I'm not saying traumatised but kind of, because I was often blocked [It.: *bloccata*] and they would help their dad...doing house chores and consequently...well my life did change, little by little, but I got used to it and now I feel almost like a normal person, as long as I don't look at my hands...

Extract (5.29) illustrates well the fluidity of the chronically ill person's identity. For Gina, her response to RA and its attendant pain is not only determined by her own reaction to them. It is also greatly affected by having to observe their effect on her family. The harshness of the initial period is causally related to the young age of her children (through the *because* 'because I was often blocked...'). Her inability to fully perform her role as a mother and wife is presented as the cause of a gradual change in her life and, presumably, her identity. The 'impossibilities' – or reductions in agentic power – caused by illness and pain force the experiencer to face an emerging 'mismatch' between the self they've become accustomed to and aspect of a new, emerging self that still hasn't been integrated (and might never be) into the existing personality structure. In Gina's case, the initial disruption, however, was followed by a degree of adjustment. However, she gives the impression that the newly found equilibrium is somewhat precarious. Revealingly, she says that now she feels *almost* like a normal person. The impediment to feeling completely normal seems to lie in the physical deformities caused by RA, so that her hands are a constant reminder of the disruptive and altering

power of this illness. For Gina, the alterity caused by RA is visible and inscribed in the body. This point is reiterated later during the interview. Extract (5.30) is given in response to a question asking about the influence of RA on her activities and whether she has ever had to be involved in activities that she found hard to the point of having to opt out:

Extract (5.30) (G I: 3)

Gina I refuse...because...even in church, I used to be the secretary, so... there were some jobs...easily, I never hid my illness. Also because you can see it. And I say: “no, this job I can’t do because my illness doesn’t allow it.” Yes, I tell the truth, even if...there are times that...one...mhm...I feel a bit embarrassed with these hands, but one does overcome them.

In the opening sentence, Gina shows agency by telling how she openly refuses to take on jobs she feels unable to perform because of her illness. What on the surface might look like a fully volitional action that shows her openly and willingly taking ownership (and acceptance of) her condition is partly ambiguous. As she says, it is not possible for her to keep it hidden; her hands speak for her. Interestingly, she does not feel embarrassed by having RA; it is the fact that a highly visible part of her body is clearly and visibly deformed. However, Gina tries to re-establish the integrity of her self-image, and thus her identity, by making a general ‘programmatic’ statement: one has to overcome. This can be read both as a statement of fact and as guiding principle.

As for other speakers in the corpus, one of the main problems for Gina lies in the fact that having a chronic illness entails fluctuations in well-being. RA can result in a highly paradoxical situation, a dissonance between the externally

visible and the internally invisible. The absence of outward, visible signs of discomfort can undermine legitimacy and lead to the doubting of one's suffering. However, when RA does project outwardly and leaves signs on the body, it can mislead the onlooker as to where the real suffering is and how intense it is. This paradox is well illustrated by the exchange in (5.31):

Extract (5.31) (G I: 3)

Simone: Do you feel, maybe, more understood by people who...who suffer like you?

Gina: Yes, undoubtedly. Especially at the beginning people who are near you, apart from my husband and my children, but people on the outside wouldn't understand, the illness because maybe I, I was in pain and one day I was on the floor. On the phone: "how are you?" "I'm not well, like this." But the following day they'd see me, as if nothing had happened, and so they say: "well but this one is taking us for a ride." They're really, truly rheumatic diseases are something unclear, that today you feel bad and tomorrow instead you've nothing.

Simone: It's a bit the stereotype that people have of the illness, that should be, in the collective imagination something...that blocks you in a way, constantly, in bed, for months.

Gina: Yes it's true and...look, I found myself, no in November, with some former colleagues, that it was a long time I hadn't seen them, I had stopped working when I had nothing. I had stopped working because I had had my second child and, afterwards they spoke with my sister because we both used to work for the same firm and they said to her: "oh but Gina is in a bad way, with those hands." But I have nothing in comparison. I mean they imagined who knows what because they saw the deformed hands, isn't it? And on the spot they hadn't said anything but they had this impact, whereas at the beginning the deformities still weren't there, and then maybe you felt bad today and tomorrow you had nothing. It looks like today you have nothing but instead...it entails taking drugs that are quite heavy in order to be able to function every day.

Although this is by no means universal, it is often the case that people with a health condition feel more understood by those in the situation and, often, by those closest to them. This is true for Gina. Glucklich (2001) talks of

communities of suffering and it is precisely the sharing of a common problem that encourages the formation of and attendance at support groups, such as ALOMAR.

However, for people 'on the outside' understanding might be more problematic; misunderstandings and breakdowns in communication are an ever-present danger. In the above extract, Gina very effectively draws her interlocutor into one of these situations where her suffering is doubted because of the fluctuation of the illness. Through the shift to the present tense in reported speech, we are effectively drawn into what it feels like to have one's illness and discomfort doubted. Gina's animating her former colleagues' is a very effective way of bringing the interlocutor into her world and conveying other people's inaccurate — and, potentially, hurtful judgements — without explicitly apportioning blame. These judgements are more openly voiced (whilst being attributed to third parties) later on, where the same 'technique' is used.

Finally, the episode told in Gina's second turn, relates an incident where the confusion as to the true extent of her suffering is brought to the fore. This ambiguity and the ensuing suffering are caused by the misreading of visible signs and the non-perception of real, but invisible to the eye, signs. Gina's former colleagues comment to her sister that she must be in real pain, because of the state of her hand. Yet, this visible deformity (which at the time is, Gina informed us earlier, a source of embarrassment) does not necessarily cause suffering or indicate the presence of pain. It is often the case that the more intense the suffering, the less visible the signs.

I have already pointed out some of the specific limitations imposed by the onset and the progression of RA and pain on Gina. Life-sustaining activities such as breathing become extremely difficult when pain is at its peak. Other simple, quotidian activities become difficult too and result in diminished agency, or 'freedom to act': buying groceries, doing the housework, participating fully in the activities of her parish church. Most of all, RA's complications (of which pain is, as seen, a major one) have made it impossible for this speaker to continue with full-employment. However, after an initial period of adaptation to her condition as RA sufferer, she once again takes ownership of at least part of her life. As much as she can, she becomes again 'an actual agent in her life story' (Ostemann et al., 1999: 144):

Extract (5.32) (5.33) (G I: 4, 5)

Gina: I don't hide my illness. If people ask I tell them. I went to see a psychologist, because I was feeling down.

[...]

Gina: I come here to the Group, I like it, I like being with the other women.

Summary

In common with the other women in the corpus, Gina has experience of diminished agency. This is reflected mainly in the impossibility to carry on activities that were once normal and taken for granted. However, like the other women, Gina presents an image of self which is not entirely passive,

and certainly not that of a 'victim'. She remains an active protagonist in her own life-story, although each move has to be negotiated against the difficulties and the impossibilities imposed by her pain and her status as a chronic-sufferer.

Her identity is one of re-established coherence although exposed to the contradictions forced upon her by RA. One such contradiction is the paradox that often her suffering is acknowledged and legitimised in the presence of externally visible signs, whereas it may be most acute and disabling in ways which are invisible to the inattentive onlooker. Credibility — and the integrity of the individual's identity — has to be continually negotiated and reaffirmed in order for suffering to be legitimised. Interestingly, Gina does not openly apportion blame and her criticism of others is veiled and oblique.

5.5.7 Fabio

As noted, Fabio is the only male speaker in the corpus; unlike the other interviewees he does not suffer from an autoimmune disease but from SDH (see biographical notes above). SDH (more commonly referred to as "herniated disk") does not have the same degree of recognition as a disabling condition that RA and lupus have.

First, it is not an autoimmune disease and — unlike lupus — is not life-threatening. Secondly, it can be revealed by imaging technologies and is normally quite easily diagnosed. However, SDH often has devastating consequences. The pain it causes can severely limit daily activities but, unlike RA, does not result in *visible* deformities.

This interview is also unique in that it took place in the privacy of his home; unlike the other participants, he is a medical professional,(a nurse) as well as a patient. This fact should be kept in mind as it might account, at least in part, for some peculiarities of his narrative, such as the degree of accuracy and detachment that seems to transpire from his words.

As mentioned, and possibly because of his professional background, Fabio is very precise when communicating his experience. The first narrative in the interview appears very early, when he answers a question asking him to relate how his symptoms first appeared:

Extract (5.34) (F I: 1)

Simone: And how did [the problem] first appear?

Fabio: Well, I have to say that, this kind of problem...before the surgery, it had happened already, circa seven or eight years before and that miraculously it had disappeared as it had appeared. It lasted a few months, well no...maybe a year, with which I lived, not comfortably but since that was a particular time in my life so I didn't...I put up with it, so to speak, the pain. And then, miraculously, it disappeared, miraculously and luckily. Years later, probably because of a change, of job...of a different kind of ward...with different workloads, the pain reappeared, initially more like an ache...an ache...a something, like the drop from a dripping tap.

Simone: mhm mhm...

Fabio: something...like this that you'd feel...continuously...fastidiously...but that wouldn't, erm, wouldn't...when I say fastidious I mean...that wouldn't allow me to make movements that until then, that time had been normal, but let's say it would cause me handicaps and then, by and by, as well as the ache, pain began to take hold.

The 'blow by blow' narrative passage is very effective in conveying the appearance and development of symptoms. As noted, the precision with which the events are related could be due (at least in part) to Fabio's

professional background. However, this is also indicative of the relevance — in this speaker’s mind and life — of the onset of illness which, as will be seen in more detail later, had and still has a profound impact on his life and identity. Fabio very effectively communicates the appearance, disappearance, and then again appearance of pain and its transformation (in the second episode) from an ache⁴⁰ to proper pain.

Bodily pain is represented as an entity endowed with its own volition. Fabio clearly depicts himself as totally powerless in this respect, except that — at least initially — he chose and was able ‘to put up with it’. However, Fabio’s evaluations vis-à-vis bodily pain are well encoded by the adverbials *miraculously* and *luckily*. As well as encoding *affect* (his relief at the disappearance of pain), they also encode his powerlessness towards it and, by implication, a view of bodily pain as ‘maximally agentive’, that is conceptualised and beyond the experiencing subject’s control. In this narrative by Fabio, pain is clearly encoded as an agentive entity, endowed with volitionality.

As mentioned, strictly speaking, only volitional beings can be agents. However, in everyday speech we routinely endow entities that are inanimate or that exist at the lower end of the biological spectrum with varying degrees

⁴⁰ The translation of this passage is not straightforward and poses some problems. The original Italian says: “Una cosa, così, che avvertivi, in maniera, continua, fastidiosa, ma che non mi permetteva, erm, di..di..di fare dei movimenti, fino a quell punto normali.” Literally, the passage translates: “A thing, like this, that you would perceive, in a...continuous, bothering, but that wouldn’t allow me, erm, to..to..to make movements hitherto normal.” Fastidio can be translated as both a ‘minor pain’ (or an ‘ache’) or as ‘something that annoys/irritated/bothers’. As will be see, Fabio uses the term in both senses.

of agency, as the following example quite clearly illustrates (quoted in Yamamoto 2006, pp. 1, 21, 23):

If the scallops are to be enrolled, they must first be *willing to anchor themselves to the collectors*. [...] In fact the researchers will have to lead their longest and most difficult negotiations with the scallops (emphasis in the original).

In the above example, entities at the lower end of the biological spectrum (scallops) are talked about *as if* they possessed volition. Clearly, the author of the sentence cannot be credited with the belief that molluscs possess volition, especially the same volition that human actors display, and can be somehow persuaded to behave in a certain way. However, in the scallops example the author efficiently communicates to his readers the difficulty of successfully cultivating St. Brieux Bay scallops by endowing them with agency. In Extract (5.34), Fabio does something similar in relation to his pain. However, extract it is devoid of emotive language. There are no instances of emotionally charged lexicon. This – a characteristic of the entire interview – contributes to portraying an identity of somebody who, in spite of everything, remains balanced and ‘in control’. Obviously, this is not a claim about this speaker’s ‘real’ personality; and it is certainly possible that the projected image is due – at least in part – to the fact that Fabio is not in pain at the time of speaking. What is being focussed on here is the identity that the speaker is building and projecting through narrative. It should always be kept in mind that narrative truth and reality (for lack of a better word) are not necessarily one and the same thing.

As mentioned, In the ALOMAR Plus corpus Fabio is unique for the precision with which he describes the psychological effects of constant pain. In extract (5.35), he relates the impact of pain in its transition from *ache* (*fastidio*) to pain proper (*dolore*).

Extract (5.35) (F I: 2)

Fabio: Well, with “pain” I actually mean this intensity, these cramps with these strong burnings in the muscles.

Simone: But in the ‘ache phase’...I mean...these burnings, these cramps were still there? But not as intense? Or was it something completely different?

Fabio: No, they were there but not as intense.

Simone: I see so it was [INAUDIBLE].

Fabio: I mean an ache [It.:*fastidio*] is, erm, let's say...initially it was an ache, so it wouldn't give you pain, well, it was something you'd perceive that...that would begin to take hold inside your body and then with this ache also came pain.

1Simone: Mhm.

Fabio: After which it became a pain, a pain that would still be annoying, and I'm talking more of a psychological *fastidio*⁴¹, more than physical.

Simone: Mhm.

Fabio: In the sense that, erm, it makes me nervous so than when pain reached a climax, it would create a...at least for me, something...more like a mental stress, so it would give me..., it would cause me...stress would cause me more problems than pain itself, also because pain was not...was not like a climax that would then go down, it was a constant thing. it was constant, a pain with the same intensity, the same...presence, that was always there. So it wasn't enough to say: “I'll go to bed, I'll rest”, no. So, there was, it was there when I fell asleep, this pain was there. I would wake up and it would come back so the nights were bad, they'd become, well, bad. I repeat it was something more stressful, more unnerving, than pain itself, than pain in itself, yes.

⁴¹ See previous footnote.

in (5.35), it is interesting to note that as soon as the speaker begins to address the topic of pain (as opposed to 'ache' *fastidio*) there is a higher degree of involvement, signalled by the proximal demonstratives 'this' and 'these'. Pragmatically and discursively, these function metaphorically to indicate psychological proximity and signal the relevance of the topic (i.e. experienced pain).

Morse and Mitcham (1998) investigated the use of 'disembodied language' by burn-patients. They showed how patients in the early stages of treatments refer to their badly affected body parts using the definite article (the) or demonstratives (*this/these*) rather than the possessive (e.g. *my*, in *my hand*), which — in English — is the expected, unmarked form. Later, as the treatment progressed, they would start using embodied language again. However, in Italian one's body parts are normally referred to using the definite article (historically derived from the Latin demonstrative), which is therefore unmarked. Although, in the quoted examples, Fabio is referring to his experience of pain, rather than a body part, the use of the demonstrative is marked. It highlights proximity to, rather than distance from, the speaker. This indicates that the experience is still highly relevant. Representing the experience of pain as 'close to self', through demonstratives for example, signals this prominence. Secondly, the dramatic nature of the experience is signalled by the fact that the narrative is framed as *habitual*. This not only indicated the repetitive nature of pathological events normally associated with chronic illness, it is also likely to engender involvement in the interlocutor by 'drawing' him into the speaker's world of incessant pain. The many roles of repetition in conversation have been discussed by, among others, Tannen

(1989). Pain, Fabio tells us, was ‘constant’; it was ‘always there’. Here repetition not only indexes, ‘iconically’, in a way, the reoccurrence of the painful event. Crucially, it reinforces the importance of the topic — its psychological prominence, once again.

Like other speakers in the corpus, Fabio also appears keen to represent himself as possessing and displaying agency (i.e. independence) in his life-story. He may be unable to control the comings and goings of his pain but he shows a determination not to succumb to it. He does so by pursuing his interests, such as skiing and going to the gym, sometimes even contravening his doctor’s recommendations. Incidentally, in the sentence where he states this, he figures both as *grammatical patient* – receiving the prescription – and, subsequently, as *agent* – rejecting it. His narratives show him actively resisting the prescribed pharmacological treatment and, indirectly, medical authority. This idea is reinforced when he says that, at one point, he even substituted (like some of the other informants) painkillers with his own analgesic technique based on mental focussing.

Throughout the interview, Fabio repeatedly says that he is an ‘active’ person, engaging in a number of physical activities. This type of identity, the active persona, is a *trait d’union* between the Fabio ‘before’ the onset of symptoms and the present one. It indexes a desire, on the speaker’s part, to be identified thus: affected but not ‘broken’ or changed by his illness. Extract (5.36) immediately follows (5.35) in the interview:

Extract (5.36) (F I: 2)

Simone: It was...it was the effect of pain on your life, on your activity in general?

Fabio: Exactly, on my activity, Yes, because being a person...I'm speaking personally, clearly, being an active person, this would hamper me.

Here, Fabio presents himself as an active individual. He does so by using the present continuous (the gerund, in Italian), which normally describes a state of affairs which is timeless, and generally true. The feeling of being 'hampered' is encoded by a *because* clause, which justifies and explains it.

The following extracts, (5.36) and (5.37), which refer, respectively, to the time following his surgery and to the present, reiterate the concept.

Extract (5.36) (F I: 4)

Simone: And after the operation, how did the situation change?

Fabio: After the operation...well, let's say that the operation had become a hope, finally being able to fully start my activity again, what I do. But it wasn't so because precisely because I am very active the convalescence days after the operation [...], I didn't follow the doctor's recommendations like I should have, so I started my activities again and so...let's say that the result [of the] operation has been almost negative. Let's say half and half, at intervals the pain returns, but suddenly.

Extract (5.36) presents Fabio's non compliance with his clinician's recommendations, which itself resulted — in Fabio's own judgement — in a less than satisfactory recovery, as a function of his being very active. The causal connection is clearly made with a *because* clause and highlighted by the use of the adverb *precisely* as intensifier. Fabio acknowledges that disregarding his doctor's orders was against his best interests but depicts the

choice as inevitable. This demonstration of agency, in spite of its negative results (the return of pain), is for Fabio an act of self-affirmation and indexical of a coherent, unbroken identity. The fact that his identity has not changed is confirmed in extract (5.37), which relates to the present time:

Extract (5.37) (F I:6)

Simone: [the pain you feel now] somehow can interfere with your activities?

Fabio: Clearly, clearly, clearly. Yes, because I repeat, again, being a person who does a thousand things, this would hamper me [the pain], in the sense that, apart from my job, and so when I work I try to do things as best I can, and so this would hamper me.

Simone: And still does?

Fabio: And still does. In winter, for example, I do sport, so I go skiing, so I ski and you say: “well, anyway, whether I ski or not the pain is still there.” So I prefer to ski.

First, it is interesting to note how strongly Fabio’s feelings towards pain are. This is indicated by the repetition (three times) of the adverb *clearly*. The concept is reinforced by the affirmative *yes* and by the *because* clause which follows it. Fabio positions himself, yet again, as a highly active individual, both in his professional and his private life. This resilience in the face of pain — and resistance to it — is reiterated several times and through various linguistic means. Fabio then makes a general statement about his personality and work-ethic. By reporting his inner thoughts he makes the interlocutor privy to his reasoning: pain may be free to come and go but Fabio is free to ignore it,

in an act of defiance which preserves the integrity of his identity. And in the final comment this is made clear.

Summary

Fabio uses narrative to manage his identity. His illness, because of the type of pain experience it entails, is potentially very disruptive. Pain is represented by this speaker as an *actor* which displays highly agentive power. Grammatically, it appears in numerous *material clauses* where Fabio has the role of *Goal*. However, through numerous narratives, he manages to present an unbroken identity, reified in the continuing of a very active life-style even when the latter proves detrimental. His stance towards his illness and — in particular — the bodily pain it causes is one of strong opposition. In Fabio's case, one can talk more of *resistance* than *acceptance*. However, maintaining the integrity of his identity comes at a cost: continued vigilance and unending struggle.

5.6 Concluding remarks

The analysis in this chapter shows that the lived, embodied experience of bodily pain related to chronic illness is highly disruptive of the life-course. Speakers in the ALOMAR Plus corpus show remarkable similarities in the issues they have had to face (and still face) following the onset of illness. Bodily pain has been shown to be a highly disruptive force, in particular because of its 'invisibility'.

The analysis in this chapter has shown that of all the conditions discussed (SLE, RA, SDH), RA poses some of the major problems because of the paradoxical nature of its symptoms. Whilst the presence of deformity in the joints, especially the hands, can be the source of embarrassment and isolation, this is also the most visible sign of illness which provides the ill person social legitimacy. However, it is often in the absence of deformity of the joints that the physical pain is present and causes the most intense suffering. In spite of this, onlookers tend to identify deformities as the source of pain and suffering.

The broadly narrative analytical approach adopted for this chapter has shed light on a number of factors. Through narrative, speakers in the corpus are able to shape and present overall coherent identities in spite of the fluctuation in life-events, and symptoms experienced as a result of having a chronic illness. Unlike other forms of linguistic output, such as the case history taken – for example – during a medical consultation, narrative (in its broader sense) allows speaker to weave the different strands of their experiences into a coherent whole, in spite of the internal contradictions and paradoxes.

The same approach has shown that in the experience of the ALOMAR Plus speakers, physical pain is undoubtedly a source of suffering and disruption. This appears to be especially the case for patients affected by RA. However, as the analysis in this chapter has shown that, within the experience of chronic illness, it is often the pharmacological treatment which is most disruptive and the cause of most suffering. This is likely to go unnoticed in medical consultations, where pharmacological treatment is — understandably — seen as the solution (at least in part, since for these conditions there is no

cure) to the problem. Rather like the deformity-pain problem mentioned hitherto, the underestimation of the physical and psychological consequences of treatment may be underestimated both in the literature and in the consultation room. For patients, voicing concerns regarding their treatments with third parties and medical professionals is potentially threatening and thus results in further 'silencing'. With regards to interactions with medical professionals, the analysis presented in this chapter has revealed mixed attitudes. For most informants, especially in the early stages of their illnesses, these interactions have been less than satisfactory. However, there is a tendency to refrain from overt criticism. I have argued that, having the experience of being disbelieved, most informants are keen to present themselves as credible, factual, and rational, in which overt criticism is hard to place.

Finally, attention to canonically narrative and non-narrative passages has shown that most speakers are keen to project an 'active', agentive identity. Although various aspects of their lives may have been limited, all speakers use their narratives to place themselves in their social worlds as active participants, often having forged new, 'preferred' identities. In at least two cases, speakers overtly credited the onset of illness as the motivating force behind the emergence of this new identity. The analysis shows that this kind of operation is not devoid of contradictions but since the narrative (re)shaping of self is an ongoing process, rather than an achieved status, speakers are able to respond to new challenges as and when they appear.

Chapter 6: Thesis conclusions

The inspiration for the present research arose from reading of Scarry's (1985) important work which has as its topic — among other things — the effects of bodily pain on human language.

This overall aim of the thesis has been to investigate the ways in which a group of Italian speakers used the lexicogrammatical resources of Italian to encode the experience of physical pain — within the larger experience of chronic illness. It has done so by assembling an original corpus of interviews with chronically-ill patients, six women affected by from one of two autoimmune diseases SLE (*Systemic Lupus Erythematosus*) and RA (*Rheumatoid Arthritis*) and one man suffering from SDH (*Spinal Disc Herniation*). In doing so, it has contributed to the growing body of literature on *health communication* and in particular to the body of work looking at the lexicogrammatical encoding of the experience of pain.

One of the original contributions of this thesis has been the use of *Systemic Functional Grammar* and of Halliday's (1998) approach to studying for the first time the encoding of bodily pain in Italian. Up to the present time, such approach had only been used to investigate the linguistic encoding of the experience in English (Halliday, 1988), Japanese (Hori, 2006), German (Overlach, 2008), and Greek (Lascaratou and Hatzidaki, 2000; Lascaratou, 2003; 2007). As well as extending Halliday's framework to Italian, this thesis has widened the scope of the analysis by analysing the way in which speakers in the corpus use the lexicogrammar of Italian to evaluate their whole experience of living with physical pain caused by chronic illness. It has

done so by using the analytical apparatus of *Appraisal Theory* (Martin and White, 2005), a framework for the analysis of evaluative language grounded in SFG. These two strands of analysis were brought together in chapter five where, by using a broadly narrative analytical approach, the attention was turned on what kind of identities emerge once speakers overcome the silencing effects of pain mentioned by Scarry (*op cit*).

6.1 *The lexicogrammatical encoding of physical pain in Italian in the ALOMAR Plus corpus*

For the speakers in the ALOMAR Plus corpus, the most common construal of pain is as *thing*, nominally (203 out of a total of 247 of ‘pain items’), normally lexicalised as *dolore* or, in a minority of cases, *sofferenza*, which I have referred to as ‘key lexical items’.

When thus construed, pain appears in configurations where it is a participant in a number of process-types, mainly *relational* and *material* ones. In one case, a configuration where pain is specifically attributed to a body part is set up *mal di testa* ‘headache’ appears. This type of configuration (pain + body part), which is common in English, is also grammatical in Italian but is not favoured in the present corpus.

Construing pain as an entity allows speakers to achieve a number of things. By encoding it as an “it”, pain is easily identified and circumscribed. It can be made ‘other’ and placed at a distance from the self; it can also be brought into proximity. Pain, when nominalised, can be ‘owned’, through the use of possessives, as in *il mio dolore* ‘my pain’, or *il mio mal di testa* ‘my headache’. Such configurations, however, do not appear in the ALOMAR

Plus corpus. The informants do indeed configure possession but they favour *relational processes* (in SFG, these are processes of ‘having’ and ‘being’), realised by a form of the verb *to have*, where pain, the *Attribute*, is possessed by the individual, the *Carrier*, as in *avevo un dolore al petto* ‘I had a pain in the chest’.

It was suggested that the reason behind the absence, in the corpus, of configurations where a body part (rather than the individual) is the *Carrier* (which the grammar of Italian would allow) is that such configuration would, from a message-structure point of view, shift the focus of the message from the speaker to the body part in question, thus ‘obscuring’ the speaker.

Construing pain as an *thing* also allows speakers in the corpus to present it as an entity which ‘acts’ in the sufferer’s world and displays varying degrees of agency (see below). The understanding of both bodily pain and disease as entities possessing and showing degrees of agency are essential to many commonly-held folk beliefs and contribute to the process of ‘othering’ mentioned earlier.

The prevalence of the lexical (and, I argue, cognitive) construal of pain as ‘entity’ in the ALOMAR Plus corpus is also likely to be due to reasons I call ‘situational’. Although for all my informants illness is an ongoing condition, it has been – to a degree – ‘historicised’. Chronic illness and its attending pain are generally (but not always, as the case of Annamaria shows) not welcome but they have become familiar states; their construal as *entities* allows the informants to speak of them with a degree of detachment. In turn, the distance and the ‘familiarity’ which have evolved are reflected in this type of construal.

Although the size of the Alomar Plus corpus does not allow for this degree of generalisation, it is likely that speakers for whom pain was a more recent, or present *at* or *close to* the time of speaking would favour construals of pain as a process, through, a verb. Other ‘pain corpora’, such as Lascaratou’s (2007), show a prevalence of verbal construals of pain; however, such corpora consist of transcriptions of doctor-patient consultations where patient have gone to see a doctor regarding a current complaint. In such cases, pain expressions such as *I hurt*, *I’m hurting* or, to a lesser degree ‘*my+body part is hurting*’ function as ‘pain avowals’ which declare that the individual is suffering and can be seen as a substitute for the ‘primitive cry’ of the one in pain. In addition, they mostly relate to acute, rather than chronic conditions. A further development of the current enquiry would be to compare linguistic data relating to both acute and chronic pain in order to verify if there are positive correlations between one type of pain and a particular kind of construal.

As pointed out by Halliday, pain has both temporal and spatial location within the body. In the ALOMAR Plus corpus, when pain is *participant* in a process its location is encoded as *Circumstance*, through adverbials, adverbial groups and prepositional phrases. In the case of its temporal extension, speakers in the corpus also encode it adjectivally, either as *Epithet* or *Attribute*. However, contrary to expectations, the present corpus does not show many instances of the temporal extension of pain construed as *Attribute* in a *relational* clause (e.g. *il dolore era costante*, ‘the pain was constant’), where pain is the *Carrier*. The locus of pain too is normally encoded *circumstantially* in the ALOMAR Plus corpus, usually through an adjunct of place. For the most common types

of pain, whilst English resorts to compounding (*headache*) the lexicogrammar of Italian encodes them by making the locus of pain a prepositional phrase following the 'head' in a noun group (*mal di testa* 'headache'), however, as pointed out, this is not commonly done by the ALOMAR Plus speakers.

The intensity of pain, as well as its quality, is a relevant topic, both for the patient and the medical professional. When pain is construed as a *participant*, its quality (type) and quantity (intensity) tend to be encoded as qualities, through adjectives. However, whereas English often construes pain adjectivally, speakers in the ALOMAR Plus corpus resort to nouns (*En.* 'A burning pain'; *It.* *Un bruciore* 'a burning', noun). Some terms are a blend of pain type and intensity and, to an extent, refer to how and where pain propagates in the body. Such is the case of *una pugnalata*, 'a stabbing'. The intensity of the pain sensation is also encoded through diminutives (*un dolorino* 'a small pain'), which, in some cases, also encodes types of stance, such as *affect*.

Second for number of occurrences in the ALOMAR Plus corpus is the construal of pain as process. This type of encoding allows speakers to highlight the dynamic, 'active' nature of pain and to attribute varying degrees of agency to it. Italian lacks *personal-intransitive* constructions equivalent to the English 'I hurt/am hurting', which, I have argued, configures the experience of pain and suffering holistically.

Speakers in the ALOMAR Plus corpus favour constructions that, when pain is construed as process, place it in more impersonal settings, such as *fa male* 'it hurts [me]'. Also common are configurations that 'thematise' the person, as in *mi fa male* 'to me it hurts'. These constructions are frequent in the corpus.

Pain is construed as a quality only in a minority of cases. When this happens, it is construed as an *Attribute* of a body part in a relational clause. There are no occurrences of pain residing in the whole person; it is almost exclusively a localised phenomenon. Again, I suggest that this 'localisation' is a result of the 'diminished urgency' of the experience of pain due both to the interview (as opposed to medical encounter) setting and to the chronic (thus 'historicised') nature of the problem.

The analysis in chapter three shows that pain, perceptually and psychologically, is a very complex experience. Since it often the case the a person's verbal output is the only window on the pain, attention to the way it is encoded can prove very important not only as a means of understanding the experience but, crucially, as a diagnostic tool which could lead to a more precise identification of the underlying issue. An analysis such as the one presented here, which focuses not only on the lexicon but also on the 'grammatical apparatus' (the *lexicogrammar*) shows that the task of encapsulating an experience as complex as pain weighs on the linguistic system at more than one level.

Because of the size of the ALOMAR Plus corpus, these conclusions cannot be generalised as certain indicators of the ways in which the lexicogrammar of Italian *as a whole* construes the experience of pain. Such generalisations would require a much larger corpus. In spite of this, and especially because of the consistency of the findings *within* the corpus, they suggest certain tendencies. Further research with a larger corpus of speech produced in a number of circumstances would be needed to make more general claims.

6.2 Pain, illness, and APPRAISAL

The experiences of illness and of pain often coexist. Pain does not suppress language, although it challenges it. It can be said that pain stretches language, pushing it to occupy spaces that perhaps it did not occupy before. The language of pain is not only language that has as its referent the specific, though complex, perceptual experience which is pain. The language of pain is also language that grows 'around' the experience of pain. The embodied individual in pain perceives pain but experiences suffering. This suffering is language-generating; it pushes the individual to position him or herself, to take on a *stance*.

I have addressed this stance by resorting to *Appraisal Theory* (as developed by Martin and White, 2005) and used it as a tool to identify the presence of subjectivity in the multitude of evaluations that the individual who experiences pain expresses. The experience of pain triggers *stancetaking*; it 'personalises' language. Appraisal is therefore a highly effective tool for the identification and analysis of subjectivity, intended as the presence of the subject's own perspective and 'take' on the events that have befallen her or him.

Unsurprisingly, most speakers in the corpus evaluate pain negatively. However, the majority refrain from using emotionally charged language, which I have defined as language where, to use Martin and Rose's (2003) metaphor, the emotive volume is turned up. This finding is rather surprising and demands explanation.

I have suggested that the main reason for this is to construct and project, discursively, an image of credibility and 'objectivity', which would be compromised by resorting to more emotive language. Speakers need to

appear as 'credible witnesses' of their own life-stories, which all too often are doubted or disbelieved outright, leading to not only the invisibility of pain and suffering but also — crucially — to the invisibility of the *suffering individual* her/himself.

By utilising language that often appears to be mutated from the language of medicine and, more generally, medical encounters, the speakers in the ALOMAR Plus corpus frame their accounts as credible. They especially work towards avoiding the charge of being overemotional and, therefore, unreliable. This response, encoded in a specific type of language, has its origin in previous experience. All participants, at some point or another during the interviews, express the desire not to 'exaggerate' their problems, intrinsically equating what might be generally termed 'emotion' with lesser or lack of credibility. What appears clearly in the language of such accounts is the echo of previous encounters with disbelieving or doubting interlocutors. It is therefore likely that in encoding their experiences, my informants are not only addressing their current interlocutor (the interviewer); their linguistic output is shaped by their previous encounters, their *health communications*, with a number of individuals and institutions.

Of all the encoded *attitudes*, *affect* is the most common in the ALOMAR Plus corpus. Speakers, however, favour *evoked* (indirect) expressions of affect rather than *inscribed* (direct) ones. I suggest that the reasons behind this choice are to do with what I mention above: the desire to discursively lend credibility to their own accounts by presenting them as more 'factual' than

'emotive'. Once again this discursive practice echoed past encounters in my informants have been openly or indirectly disbelieved.

After *affect*, the second most encoded *attitude* is *appreciation*. Through it, my informants are able to make factual statements. These, especially when expressed as declaratives in the indicative mood can also be read as instances of *evoked affect*. Again, this linguistic strategy allows the speakers to present themselves as reliable, by making factual statement presented as factual and that the interlocutor can easily align with. However, such statements indirectly reveal speakers' feelings and sensations. They invite the interlocutor's agreement and sympathy (albeit indirectly), thus enlisting him or her as 'co-author' of the narrative on offer.

Unsurprisingly, pain does elicit mainly negative evaluations, although in the majority of cases this is couched in language that can be considered 'measured' and not overtly emotional. Where pain receives highly negative evaluations, it is also accompanied by other linguistic traces that indicate the high level of distress it causes the person. Such is the case of Anna. For her, the appearance of pain has been a highly traumatic event with enduring consequences. Crucially, in her case this is reflected not only in the choice of emotionally charged lexicon but in vivid metaphors of violence and war, of intense heat, light and destruction, and in fragmented syntax. I suggest that traditional verbally-based tools to evaluate both the intensity and quality of pain, but especially its impact on the individual, can be inadequate since the encoding of the former and the latter is encoded lexicogrammatically and

discursively rather than only lexically, as many questionnaires (such as the McGill Pain Questionnaire) used in medical settings appear to suggest.

However, the use of *Appraisal Theory* in chapter two has resulted in an unexpected finding. It is the pharmacological treatments used to control pain and the progress of SLE and RA that are the object of the most negative (both in number and intensity) evaluations. Especially when based on cortisone, treatment is construed discursively and lexicogrammatically as an entity that *does* unpleasant things to the sufferer, often an *Actor* in *material processes* with the individual appearing as the *Goal*. The pharmacological treatment is endowed by the speakers in the corpus with more agentivity than pain itself and is associated with a high number of violent metaphors. This surprising finding points to what is possibly one neglected area of the impact on individuals of pain in chronic illness. If the well being of the chronically ill individual is to be addressed holistically, this hitherto underestimated aspect ought to be included in considerations aimed at restoring health. Attention to the language of evaluation thus becomes interesting and relevant not only to the linguist but also to the practitioner and health professional.

The informants for this study do not often evaluate other individuals in their accounts. *Judgement* is the least frequent of the *attitudes* expressed. It is used to evaluate the behaviour of medical professionals and family members. Negative evaluations of the former are rare; where they appear, they are mild. I suggest that this is related to the speakers' desire to project an image of reliability, reasonability, devoid of emotive and emotional (in the common

sense of the term) overtones. With regards to family members, the speakers usually evaluate them in positive terms. Negative *judgement* of family members is present but generally indirect and mild. Mainly it is related to their perceived inability to fully appreciate the patient's predicament.

6.3 *Identities in pain*

As noted, Scarry (1985) claimed that the process of 'reconstruction' of the person in pain's world only occurs once she/he is able to impose once again coherence upon her or his world, after having 'brought it back', as it were, into existence.

Adopting a broadly narrative analytical approach, chapter five has looked at the ALOMAR Plus corpus interviews to find out what kind of identities were constructed and presented by the participants in connection with their experience of chronic pain related to chronic illness. One particular concern has been to look at *agency* in the participants' story, in particular in order to establish if they still appear as *actors* in their own life stories.

6.3.1 *Identity*

For all participants, the onset of chronic illness and related pain has represented a moment of rupture with their previous identities, requiring varying degrees of readjustment. Contrary to expectations, the degree of disruption to the sense of self does not show, in the ALOMAR Plus corpus, a direct link with the severity of the condition. In one case (Annamaria), the

onset of illness has represented the possibility of taking on a preferred identity, such as dedicating one's life to a fulfilling occupation, such as volunteering. However, the analysis has revealed that the rebuilding of a coherent identity, or the shaping of a new, preferred one, is not a homogeneous process and that it is ongoing and in a constant state of flux. In the ALOMAR Plus corpus, identity coherence does not mean lack of contradiction in thought or behaviour. I have suggested that the shaping of identity in chronic illness and especially in the presence of pain should be considered a fluid rather than a solid state for which a number of linguistic strategies are used. Even in the presence of the same pathology, the degree of overall biographical and identity disruption (in the sense of alteration to a planned life course and sense of self) varies. Crucially, this is something that can be only picked up by a close reading of the linguistic datum.

Agency

Part of the analysis in this thesis has been devoted to the notion of *agency* in the collected corpus. I have argued for its relevance in the construal and (re)presentation of the individual's experience of living with chronic illness and chronic pain. The overall aim was to test the accuracy of the perception, common in popular thought and folk medicine, but also in some early research on doctor-patient interaction, (as pointed out in chapter one), that when ill and in pain the individual is fundamentally powerless, thus resulting in the common 'victim' image.

I began by providing a definition of *agency* based on semantic and grammatical criteria. I identified the notions of *intentionality* and *volition* as central to an understanding of *agency*. In the analysis, I looked at the degree of agency my informants attribute to themselves vis-à-vis their illness and pain and the resulting degree of disempowerment, loosely defined as loss of freedom to act and to pursue one's own agenda. One of the overarching questions was whether my informants perceived a loss of agency, resulting from being ill, and if so to what degree. Another question was whether there were multiple foci of agency and, if so, what were they.

Overall, for my informants the experience of chronic illness and pain does not result in a complete loss of agency. They retain considerable freedom to act, although this might be reduced. I suggest that it is useful to distinguish between two levels: the *micro-level* (single events, isolated instances) and the *macro-level*, the more general, overall picture.

At the *micro-level*, the speaker's *agency* is often limited both by pain and by the overall experience of chronic illness. Chronic illness, and especially pain, has a limiting effect; what was once normal, taken for granted, and generally possible becomes difficult or entirely impossible. Jobs may have to be left; everyday activities, such as shopping for food or driving may be extremely limited. One's favourite activities, such as sport, may have to be given up.

At clause level both illness and pain often appear as *Actor* in *material processes*; often, in *material clauses*, illness and pain are the *Actor* and the speaker the *patient*, in the grammatical sense, or *Goal*, in SFG terms. Pharmacological treatment is often represented, at clause level, as *Actor* negatively affecting the speaker.

However, when the focus is broadened, at the *macro-level*, the picture becomes more complex. My informants engage in a number of activities, displaying what I term 'real agency'. In some cases, once the initial shock of having become ill is gone, the individual displays considerable agency, for instance by in engaging in activities which were not possible before, like volunteering.

This research confirms that the view of the ill as passive in encounters with the medical profession is at least problematic. My informants take the initiative in a number of activities, such as questioning a doctor's prescription or diagnosis. Occasionally, they give up treatments that they feel are not beneficial. The idea of the (medical) patient as passive is not supported by this study. Especially in chronic illness, roles are negotiated and continually shifting. Even when pain is present the idea that the person affected by it sees herself or himself as a victim appears simplistic, at least in view of the findings of the present study.

Appendix

This appendix includes the raw data – in the form of full transcripts of the interviews collected for this thesis. The original Italian transcripts appear before their English translations. In each section, the speakers appear in alphabetical order, according to their pseudonym.

Transcription conventions

...	longer pause and/or hesitation (not timed)
:	lengthening of word or syllable-final vowel, which in some cases indicated hesitation
?	question marks show end of a stretch of talk interpreted as a question or, more generally, rising intonation
<LAUGHS>	angled brackets give additional information, especially of paralinguistic nature
{ah}	curly brackets appearing in a speaker's turn indicate overlapping talk by the interlocutor or other speaker
“ ... ”	quotation marks indicate direct quotations of other people's speech or a verbatim account of speakers' own words as uttered on a specific, recalled occasion
<u>Underlined</u>	underlined words indicate emphasis

1 Anna

- Interviewer: niente, volevo, così, questo è un: un colloquio abbastanza libero quindi non ci sono domande particolari o risposte giuste piuttosto che sbagliate, ehm, le chiederei di parlarmi un po', in modo generale, della sua esperienza, quando ha iniziato ad avere problemi, come, eh, come se n'è accorta, sentendosi libera di dire tutto quello che: le viene.
- Anna: quindi non prettamente sul dolore, proprio sull'
- I: inizialmente, appunto come è iniziato, come è iniziata quest'esperienza e poi che tipo di:
- Anna: ... tipi di dolore:
- I: sì, poi ... successivo ... ecco lei quando ha cominciato avere: problemi.
- Anna: e: sicchè, [il?] fatto della malattia, chiaro perché: anche prima ma: forse non è: è inerente alla malattia chiaramente: quasi subito il dolore: ... forte, e: via via cresce, e, almeno nel mio caso, [e?] quindi diventa proprio lancinante, al punto proprio: ci son stati dei momenti, prima, mhm, e anche durante la cura, che: eh: diventava talmente: acuto, che al pensiero che ritornasse questo dolore, dopo qualche minuto dopo qualche ora, eh: pensavo proprio che non potevo andare continuare la vita così, dicevo a mio marito, "guarda qua, non ce la faccio, mi vien la voglia di buttarmi dalla finestra, non è possibile", il cuore: batteva forte forte, al punto proprio di: di perdere i sensi, quindi questo è durato, per un bel periodo, un bel periodo di: almeno tre anni, e poi: finalmente: qualche altra cura diciamo che, allentava un po', questi periodi non erano così frequenti, e quando veniva questo dolore era sempre molto forte, però, durava meno, ehm, come come giorni diciamo, diventava quindicinale diventava: eh via via insomma.
- I: certo, veniva ogni quindici giorni o durava quindici giorni?
- Anna: no no, veniva ogni quindici giorni, se durava quindici giorni di fila era proprio da: niente, da finire subito perché non era possibile, era proprio, un: che: quando si, avvicinava, ... ogni quindici giorni, questo periodo del quindici giorni, una volta al mese è capitato, una volta ogni due mesi, all'inizio, 'nsomma via via, [ed avvicinava?] sempre di più, ah: frequente, e, era triste 'nsomma, anche le medicine: pur, facendo molto uso di di più medicine, era: veramente: forte e, forte.
- I: dove, dove le venivano i dolori signora?
- Anna: allora io ho cominciato colle mani
- I: le mani.
- Anna: partiva: da qua [indica].
- I: dal, dal polso?
- Anna: sì, o qua [indica].
- I: okay.

Anna: si infiammava leggermente mi prendeva su tutti i tendini fin qui [indica], arrivare qui [indica].

I: fino alla: all'ascella ...

Anna: sì sì sì, e e poi regolarmente, mi prendeva qui [indica] a: alla schiena.

I: la schiena.

Anna: e sembrava avessi qualcosa: di brutto proprio perché: i dottori ancora non capivano ... al all'inizio, questo è durato per, sempre, andando avanti con le cure dicevamo, provare, ecco.

I: questo quanti anni fa, signora, è iniziato?

Anna: emh, venti: ventisei anni, venticinque anni fa.

I: venticinque anni fa.

Anna: e quindi: poi, piano piano, insomma: qualcosa si: recuperava, solo che la malattia faceva i danni.

I: mhm.

Anna: nel frattempo, na volta si stortava questo una volta insomma, nel nel frattempo ho fatto dieci interventi sulle mani ...

I: le mani, dieci interventi, chirurgici alle mani?

Anna: dieci interventi sì di pulizia dei tendini, e: e una protesi perché c'era ... un buco ... e: quindi la malattia: dopo ho cominciato a diventare con: le cure più forti diciamo che poi in commerci si: le devo dire anche: il nome delle cure? No?

I: se se se ricorda: se no ...

Anna: sì beh, si è passato dagli immunosoppre, siamo arrivati agli immunosoppressori diciamo, antinfiammatori cortisonici tutte queste cose: solite fino agli immunosoppressori, gli immunosoppressori è stato una: è stato proprio un sollievo diciamo, proprio, quindi: senza il dolore, e dopo c'era solo il dolore di: del disastro che aveva fatto: [la malattia, diciamo?]

I: un dolore: [tipo: morale?]

Anna: però, e non era, un dolore molto più blando, magari a:

I: quindi sempre un dolore fisico, ... parlare di un dolore fisico.

Anna: e: sì però ...

I: passata questa fase acuta no?

Anna: sì sì sì però: eh: diciamo che, è un dolore che si sopporta, oramai siamo un po' anche allenati diciamo.

I: sì.

Anna: e quindi: perché quando viene: ... forte invece adesso appunto, dopo la cura, c'è voluto almeno un: quattro mesi prima di, sette anni fa credo che: ho incominciato con

questa: e quindi adesso: diciamo che sto riparando: semplicemente i danni, però ci sono ancora i dolori, adesso per esempio mi devo operare un piede.

I: dolori ai ai ai piedi, ha adesso?

Anna: già operato un piede cinque anni fa, operato il polso.

I: il polso.

Anna: ecco, diciamo che questi fanno tutti parte della:

I: e quelli ai piedi, come sono?

Anna: e, e, quelli al piede: sono: a: abbastanza tremendi anche loro perché: sono come proprio dele: eh: ah: ha presente, quando il fabbro: picchia il, ferro caldo.

I: sì.

Anna: che fa scintille.

I: sì.

Anna: ecco, ci sono tutte quest scintille doloranti {Marta: “cco, lei è più bravi di me [a dire le cose?]”}, nei vari punti del piede, anche perché: evidentemente il piede eh è: sopporta il peso della persona.

I: certo.

Anna: evidentemente, perché li sente da, nelle dita, sotto le dita, li sente: ai lati, ah sopra al metatarso, eh addirittura: al calcagno diciamo, e: anche quello operato, questo che è quello da operare, ma anche ...

I: perché un piede l'ha già avuto operato.

Anna: sì sì.

I: mhm mh.

Anna: che sì, cammino bene però, siccome l'intervento che è stato fatto, io non avevo, non avendo: avuto l'alluce valgo, loro: eh non han potuto operarmi.

I: sì.

Anna: fino all'alluce perché: l'alluce non aveva niente.

I: mhm mhm, l'alluce valgo è quello che sporge? Da a lato?

Anna: sì, sì, che non è che ce l'hanno solo [i reumatoidi?] ce l'hanno mh: quasi ereditariamente le persone:

I: sì molte persone sì.

Anna: molte persone anche giovani, il mio era un po' atipico come ehm quindi, diciamo che io, l'alluce era, normale, mentre erano scese, tutte quattro le metatarso, delle altre dita del piede, quindi, hanno legato eh, le quattro dita, diciamo, però no è, m'avevano detto anche che non: a avrei avuto dei problemi, perché non avendo fatto in contemporanea, dato che non c'era bisogno, l'intervento all'alluce valgo, perché non esisteva l'alluce valgo, eh avrei avuto problemi dopo e questi problemi sono usciti un

anno e mezzo due fa: quando eh il l'alluce ha cominciato a spostarsi involontariamente, nella parte destra, del delle dita.

I: sì.

Anna: e quindi, era come, tirare un qualcosa, che doveva essere allungato diciamo.

I: mh mh.

Anna: ma eh: e: l'alluce l'ha fatto spontaneamente quindi, non le dico i dolori, nell'osso proprio del: [malloppo?], perché, se io, lo metto in posizione.

I: sì.

Anna: lei vede il dito, normale.

I: mhm mhm.

Anna: però è un dito dolorante, che non so adesso neanche cosa potranno fare ma è un dito dolorante, e, ha delle fitte pazzesche proprio: per fortuna durano poco, ecco, quindi quello che posso dire io, è che, sia il piede operato che il piede m: che devo operare, quello operato ha il vantaggio di essere stato operato quindi il metatarso no fa male, perchè l'osso: è messo in linea quindi non scende.

I: mhm mhm.

Anna: mentre questo che non è stato operato: [spesso?] riscende.

I: sì.

Anna: mi buca le scarpe, mi fa male, eh: addirittura, se metto un fazzoletto dentro, cioè, proprio, niente, cammino col plantare ortopedico ma, è molto difficoltoso perché fa male comunque il piede, poi le dita sopra che diventano così: quindi, adesso questo insomma.

I: [curve?] si curvano:?

Anna: sì sì sì, e perché ...

I: [...]

Anna: facendo male si rattrapiscono così, quindi, diventano così, 'nfatti, le due dita del piede di qua: vengono se, verranno segate come quelle di [qua, legate?] proprio, di modo che poi si allineano così.

I: il, il suo ...

Anna: il dolore è forte, anche questo, sopportabile, diciamo.

I: in questo momento, lei, mentre noi stiamo parlando, ha dei dolori?

Anna: no.

I: no?

Anna: questo momento no, però ci son dei momenti, all'improvviso, c che posso contare a decine: a decine alla volta.

I: mhm.

Anna: è proprio un: scintille <ride>

I: come, sì.

Anna: certo poi come: il dolore diventa proprio un: lampo, [cin cin? ... piedi?].

I: intenso?

Anna: sì intensissimo, ecco, intensissimo.

I: e: lei come direbbe che è cambia e la sua, la sua diagnosi è di artrite reumatoide?

Anna: sì sì,e:

I: dopo quanto l'ha avuta la diagnosi?

Anna: la diagnosi diciamo che l'ho avuta: perché prima mi ero curata da un ortopedico diciamo, e: l'ortopedico non aveva capito bene neanche lui poi quando ha visto, gli esami che: ehm il reumatest eh era sempre più alto e sempre più alto, eh 'nsomma non ha potuto più curarmi e la malattia diciamo che, l'ha capita un ortopedico, in vacanza.

I: mh mh.

Anna: era in vacanza:, nel palazzo dove abitavo anch'io, e quindi: m'aveva visto: con in braccio la bambina, che urlava perché si era fatta male, e m'ha visto le mani così e m'ha chiesto, dice "ma lei ... c'ha l'artrite reumatoide?" Ho detto "sì," cioè ho detto "sì non: scusi:, ma lei, dice, è malata di artrite reumatoide?" Ho detto "non lo so, so che ho dolori", ha detto "ma guardi che a Milano c'è il [nome ospedale] visto che lei abita" io non sapevo neanche dov'era.

I: sì.

Anna: perché, voglio dire, quando uno sta bene non:

I: non ci pensa non ...

Anna: non ci pensa non va a cercare gli ospedali, e quindi: m'ha detto guardi così così, c'è il professor B., che poi io non ho conosciuto ma lui comunque c'era, e: così ho cominciato la mia: via crucis a curarmi, con i farmaci dovuti, perché prima un po': ... aspirine: le e: iniezioni di vitamina: queste cose qua, ma: nie niente proprio di ehm: di veramente: eh curato dal reumatologo, dal reumatologo ecco.

I: lei come direbbe che: è cambiata la sua vita, grazie, cioè, per questa malattia?

Anna: per questa malattia? Sì si è cambiata molto, nell'umore soprattutto, ero: normalmente ero un burlona, ero: eh, però: diciamo così impegnata, anche nelle cose che facevo: eh colla mia famiglia insomma, una serie di cose, ecco e: è cambiato molto perché adesso sono irascibile proprio: basta poco insomma.

I: mh mh.

Anna: anche se poi ...

I: le ha cambiato il carattere quindi ...

Anna: m'ha cambiato il carattere sì, e i giorni che sto bene invece riprendo abbastanza:

I: ad essere ...

Anna: però: vado su e giù, basta poco per salire basta poco per scendere.

I: certo.

Anna: eh: diciamo che così ecco, anche se: ho tutti intorno a me però: eh: alle volte penso che non mi capiscano ma non perché non mi capiscono perché è difficile eh: anche dirti sempre: come dire, venire sempre a coccolarti.

I: sì.

Anna: perché, io ho bisogno di quello {sì} e loro lo fanno sì, però nel frattempo, m: non mi alleviano diciamo {sì} perché: quando poi c'hai eh anche tutti questi: movimenti di giornate che {mh} passi: da un medico all'altro {sì} perché poi la reumatoide non finisce con {sì} con la reumatoide, provoca un sacco di altre:

I: di altri problemi.

Anna: problemi e quindi, eh si passano proprio delle giornate a: nei vari ospedali nei vari medici e: 'nsomma, n'se ne esce mai, non se ne esce mai.

I: lei trova ...

Anna: si convive.

I: trova difficile: coi suoi familiari o col dal medico, spiegarsi?

Anna: no.

I: comunicare, quello che è il suo dolore?

Anna: no comunico spiego molto bene, nel senso che io cerco di spiegare bene, a qualsiasi medico, cerco di dir di farle capire proprio il come, per esempio faccio un esempio, a ottobre ho avuto, un di notte un dolore qui.

I: alla al pe, al al allo sterno {proprio qui al torace}.

Anna: allo sterno {sì} proprio in mezzo al seno {sì} qui, che è partito piano piano di qui

I: d al fianco? {che[viene?]} sempre più forte}

Anna: sì da così, quando è arrivato qui: c'è stata un'esplosione, come se: vedesse scoppiare una bomba.

I: sì.

Anna: mh, deflagrazione.

I: sì.

Anna: questo, è la parola esatta di, dolore che ho sentito io, per fortuna non è [durato?]
penso più di un minuto un minuto e mezzo {sì}, per me era un'eternità, anche perché, alle due di notte non sapevo, eh: sì, ho dovuto chiamare mio marito e mia figlia, però, eh: o vai subito al pronto soccorso però, anche loro han cercato di ehm: questo non mi era mai successo quindi io {sì} a: avendo avuto la nonna {mh} il papa la sorella del

papà morti d'infarto, questo mi ha preoccupato molto, quindi po mi prende l'agitazione, e man mano che vado avanti con l'età.

I: sì, il dolore an anche a me è capitato dolore al, al petto {allo sterno} che ti spaventa [...] allo sterno magari non così forte {... sentito} e magari dopo ... io tra l'altro mi ricordavo una volta ho avuto problemi di reflusso, gastrico {sì} e dà un dolore molto forte qua, al basso sterno che io non avevo mai provato, ero in aereo mi ricordo mi sono molto spaventato pensavo che fosse qualcosa al al cuore non avevo idea che fosse una cosa del genere {e il reflusso che torna su qualcosa:} sì dallo stomaco {dallo stomaco}, ma comunque è molto comune che la gente si preoccupi {sì sì beh io} che alla gamba {certo} non so.

Anna: io ripeto, mi sono: poi al mattino alle sette e mezza perché poi me n'è venuto: ah: ancora uno due {mh mh} però n: n: sempre inc così no, sempre [in?] forte, magari non partiva di qui {dall'altro lato} e arrivava piano piano piano mi prendeva fino a qui sotto.

I: fino al petto poi sotto l'ascella:

Anna: sì, [poi?] sotto l'ascella sì, e ho sentito anche: molta gente anche il mio medico m'ha detto che ce ne son stati parecchi quest'inverno di: {mh mh} quindi: ho fatto un sacco d'esami in fatti ho finito, la settimana scorsa di fare: [...] doppler, ecodoppler, e quindi al pronto soccorso, subito, han visto che non c'era: non c'è stato, nessun infarto nessun inizio m'han fatto l'esame: degli enzimi {sì} cioè, e: niente, non c'è stato niente {mh} il cuore: va bene, solo che: io malgrado il cuore va bene, quando sento, che magari, c'è qualche dolorino, che penso che mi arrivi a fare così: eh: mi spavento {certo} e quindi lì, io eh: devo proprio: chiedere aiuto, ai miei o a chi c'è perché: svengo proprio mi sento proprio male.

I: sì c'è un timore che viene dal: dal dolore in sé e dal timore di qualcosa che potrebbe venire.

Anna: sì adesso c'è proprio la paura.

I: sì.

Anna: la la paura, che è quella di eh non farcela, di, che mi capiti un infarto: roba del genere, perché: poi insomma via via, [quando ne ho proprio tante] ho avuto un carcinoma della pelle: qui, ne ho avuto un altro qui.

I: e sono sempre legati alla: all'artrite reumatoide {no} o anche a altre cose.

Anna: però sono legati forse allo stress, ... io sono molto stressata, sono una che mi mi stresso, e cerco anche <ride> quasi quasi cerco ... come dire, cerco sempre di complicarmi le la vita mio marito mi dice perché è vero, compro le cose le devo comprare sempre che mi: che mi rendono fatica ecco {mh} sono un po': masochista in questo senso, come dire mi faccio male da me, ecco, 'nvece dovrei lasciare perdere sono un po' testona ecco {mh} un po' un carattere così insomma.

I: e lei pensa che questo sia influenzato molto dalla malattia? Questo suo modo di essere?

Anna: e. certamente, poi adesso c'è anche la vecchiaia perché (mhm) io sessantasei anni quindi voglio dire, c'è anche, da mettere in conto gli anni che passano (mh mh), poi

problemi in famiglia, non so mio marito che è stato male, quindi son tutti stress che: si subiscono.

I: certo.

Anna: perché di mio sono sensibilissima proprio come un: una corda di violino.

I: già lo era, prima del (sì sì io: sì) [quando c'è stato?]

Anna: a me mi basta vedere: un cane che soffre che: che già mi prende insomma.

I: senta u un'altra cosa, come: quando ha visto cambiare il suo corpo, per la malattia.

Anna: e: l'ho visto quasi subito.

I: come:

Anna: fisicamente lei dice?

I: fisicamente come cioè esteticamente? sì, la deformazione, ma no come lo ha m: è qualche cosa che: ehm l'ha turbata, oltre al al al dolore in sé era qualche cosa.

Anna: no anche perché, devo dire, che grazie anche alle cure poi ehm per chi ci crede grazie anche a dio, io penso che, si è fortunati tante volte no, pur nella malattia perché è: 'ciamo c'è gente, ho visto gente passare davanti a me molto più, molto più disastrate diciamo, quindi, io con le mani ci faccio ancora tante cose ancora.

I: certo.

Anna: le uso e ne abuso, a mio discapito però, dico vabè insomma, intanto le uso perché se no che me le sono aggiustate a fare, come dire <ride> ma diciamo che dovrei, usarle ma non abusarne, io invece sono un po', un po' stupida in questo senso, ecco, anche se i miei mi dicono lascia stare lascia stare ma, io sono un po', così, e: però devo dire insomma sì le mani sono disastrate ma: non so se lei ha visto altre mani.

I: alcune, non è che ne ho viste.

Anna: però non è che mi importi molto se la gente mi guarda le mani o cosa, mi dà fastidio perché cammino male e e quindi adesso facendo l'intervento penso di camminare meglio, penso di mettere su un paio di scarpe non così eh: che son dolenti, anche: le scarpe non vanno mai bene, però: no non, poi nessuno, per adesso nessuno mi ha fatto mai pesare questa cosa, poi c'è sempre qualcuno che magari ti guarda ma non, non me ne importa per niente insomma.

I: va bene signora la ringrazio per: c'è qualche cosa che vuole aggiungere.

Anna: no: penso di avere detto tutto nei:

I: grazie.

Anna: di niente.

I: grazie mille.

2 Annamaria

- Interviewer: bene, ah, lei signora da quanto ... da quanto tempo so ..., prima di tutto posso chiederle esattamente di cosa dal punto di vista medico, di che patologia lei soffre?
- Annamaria: io soffro di un lupus eri [inudibile] sistemico.
- I: da ... quando ha avuto questa diagnosi?
- A: la diagnosi l'ho avuta nel 1985, mentre i primi sintomi mi sono iniziati nel '74, dopo la nascita di mio figlio.
- I: nel '74, e che tipo di sintomi erano?
- A: avevo molti dolori articolari, le ginocchia si gonfiavano, le mani anche, e, tant'è che non riuscivo neanche a prendere in braccio il bambino, quindi facevo fatica ad accudirlo, e niente, i dolori articolari soprattutto sono andati avanti per una decina d'anni solo quelli.
- I: ma erano, non erano però continui, cioè erano persistenti oppure periodici?
- A: erano, erano, sì sì, erano persistenti, soprattutto le ginocchia sempre gonfie, eh, e le mani, le mani e le ginocchia sono sempre state le parti più sofferenti.
- I: e inizialmente il medico, cioè, lei è stata subito da un medico, per ..., quando sono iniziati, ha visto subito qualcuno o le hanno cosa le dicevano?
- A: o sono andata, sono andata da un ortopedico, il quale mi ha dato del cortisone, senza farmi fare nessun tipo di esame. Mi ha detto subito che io avevo un'artrite reumatoide, e mi ha dato cortisone, eh, guardando solo l'aspetto delle mie dita, delle mani, eh io vabè, per un mese ho preso sto cortisone, però poi mi rendevo conto che senza una diagnosi, pur avendo io solo ventun'anni, ero ancora giovane, però mi dicevo, senza una diagnosi prendo il cortisone, e poi? Cosa succede? Quindi dopo un mese io ho smesso di prenderlo.
- I: e, e i sintomi erano durante la, la terapia con il cortisone era ... si sentiva meglio
- A: sì, io stavo molto bene, con il cortisone stavo molto bene, però dopo un mese quando ho smesso di prenderlo ho ricominciato con i dolori. Il mio medico di base non mi diceva niente e il pediatra di mio figlio si è accorto che io non stavo bene perché ho portato il bambino a fare una visita, ha visto che avevo difficoltà a muovermi, e mi ha chiesto cos'avessi. Gliel'ho detto, e lui mi ha consigliato di venire al [nome ospedale], dove c'era un centro di reumatologia. Io sono venuta al [nome ospedale], ho fatto i primi accertamenti, e il medico che mi ha visto, siccome gli esami erano tutti negativi, mi aveva detto cheee, ... secondo lui poteva essere qualcosa ma, pensava che fosse solo ... un fattore ... psicosomatico.
- I: quindi.... pensava fosse
- A: un fattore psicologico, lui mi ha detto che secondo lui era un fattore psicologico perché qua ... ogni volta che venivo a fare una visita non avevo mai niente da fargli vedere, perché le mie mani si gonfiavano e si sgonfiavano e le ginocchia la stessa cosa, e ogni volta che venivo da lui non avevo niente ... da far vedere ...

- I: e il dolore c'era sempre, c'era solamente quando c'era il gonfiore?
- A: il dolore c'era maggiormente quando si gonfiavano, certo. E quindi ... vabè, poi mi aveva detto di venire a farmi vedere una volta che avessi avuto qualcosa di gonfio, senza appuntamento, e dopo due giorni sono arrivata con un ginocchio gonfio, e dice: bè allora non è un problema psicologico, perché altrimenti non si sarebbe gonfiato il ginocchio, quindi mi ha analizzato il liquido [inudibile] ginocchio, e ... mi ha detto che avevo un'artrite reumatoide. Che però dagli esami del sangue non si era ancora manifestata. Quindi lui non mi ha dato niente di farmaci importanti, mi ha dato solo degli antinfiammatori ... e mi ha detto di continuare cioè ... m'ha detto "signora io non so più cosa dirle, venga quand'è peggiorata." Io avevo ventun'anni, la cosa non mi è piaciuta molto ... però le cose sono andate così, in effetti, perché io sono andata avanti solo con antinfiammatori ... al momento del bisogno, che era abbastanza frequente, vale a dire che, magari, cioè per tre quattro giorni alla settimana, anche cinque, io avevo bisogno di prendere antinfiammatori. Poi queste ginocchia che si gonfiavano e poi si sgonfiavano, stavano gonfie una settimana io facevo anche un mestiere abbastanza pesante, perché ero tessitrice, di conseguenza, cioè, con il continuare a camminare, però io ho sempre continuato a farlo, nonostante tutto, io anche con le mie ginocchia gonfie andavo al lavoro, ma ... tanto anche stare a casa non avrebbe cambiato la mia vita. Niente, riuscivo a lavorare ugualmente ...
- I: ma quindi la, la, la diagnosi di questo secondo medico era sostanzialmente simile ... o uguale a quella del primo?
- A: eh, sì, il primo l'aveva detta, senza ...
- I: Senza però fare nessun tipo d'esame.
- A: fare nessun tipo di esame, solo avendo visto le mani che erano gonfie, mentre l'altro ha analizzato il liquido che mi ha tolto dal ginocchio. E niente, però poi appunto, m'ha detto: Signora io non so più cosa farle perché gli esami del sangue son sempre negativi quindi venga quand'è peggiorata. Io son andata avanti per dieci anni così. E poi in effetti sono peggiorata, nel senso che, ... eh: non è un ... una cosa che si dice solo ma io l'ho riscontrata sulla mia pelle, che quando: non si sta bene psicologicamente, nei momenti di crisi queste malattie prendono il sopravvento. E infatti, stavo passando un momento di crisi... eh ... mi sono sottoposta a uno stress sia fisico che morale non indifferente e ho iniziato ad avere maggiori problemi. Quindi problemi sulla pelle, i dolori si erano fatti più acuti.
- I: Sulla pelle che tipo di problema aveva?
- A: avevo dei ... delle macchie rosse, proprio sotto la cute, che al tatto erano dolenti e non capivo cosa mi stava succedendo insomma, perché erano dei sintomi che non avevo mai avuto prima. E quindi sono ritornata a farmi vedere, però da un altro medico, non più da quello di prima perché nel frattempo in questi dieci anni era nato un day-hospital, qui al [nome ospedale], io sono... mi han consigliato di andare da, dal reumatologo, che è il mio reumatologo tuttora, e mi ha fatto una diagnosi, dopo aver fatto diversi esami, e mi ha detto che avevo una malattia da un nome molto brutto ma di non spaventarmi, perché non era niente di così tragico, che si poteva tenere sotto controllo...mi ha detto quali sarebbero state le fasi peggiori della malattia. Purtroppo vabè l'ho saputo dopo ma tanto non cambia niente, che è una malattia per la quale si può morire

I: Mh.

A: perché, mh, prende prevalentemente gli organi non solo le articolazioni.

I: [certo?]

A: E di conseguenza se prende organi vitali, va da se che... non è molto facile. E niente, io comunque sono riuscita a convivere bene con ...

I: Questo nell'Ottantacinque, la diagnosi...

A: questo nell'Ottantacinque.

I: la certezza.

A: Sì

I: e il fatto di aver avuto ... una diagnosi certa ha cavi... ha cambiato qualcosa per lei, nella sua esperienza della malattia o ... come ha reagito ...

A: ma, io devo dire che non ... la cosa non mi ha sconvolta. Cioè, l'ho presa abbastanza tranquillamente ... non ... io devo dire che poi sono una persona con un carattere positivo, che non ... non faccio drammi, vabè, voglio dire, ho cercato di prenderla meglio che potevo. Io ho continuato la mia vita, come se niente fosse ... avevo un problema che aveva, finalmente tra virgolette, un nome, però ... questo voleva anche dire iniziare a fare una terapia più pesante.

I: [Inudibile].

A: di conseguenza, certo, ho dovuto iniziare a prendere il cortisone, e lo sto prendendo tuttora, perché è una malattia che si tiene sotto controllo solo col cortisone, poi, man mano che son passati gli anni si sono aggiunte diverse cose, perché poi anche se ... non sono cose tragiche però, dopo poco, che ho iniziato a fare il cortisone mi è venuta una pleurite, una pericardite, e questo mi ha segnato molto perché ho dovuto ... per tre mesi sono stata costretta a stare a casa dal lavoro. E ho dovuto dormire per tre mesi su una sdraio perché non riuscivo più a respirare. E quando ho iniziato a tornare a letto, in ogni caso ho dovuto dormire, quasi per una decina d'anni con tre cuscini, perché non potevo più sdraiarmi, perché avevo dolori al torace. Perché purtroppo, dopo che ... eh ... ho iniziato ad avere questi dolori al torace, non si era capito subito che avevo una pleurite, io poi, all'inizio della malattia, avevo paura di disturbare il mio medico no? Perché ... gli avevo telefonato per dirgli che avevo questi problemi ...

I: mhm.

A: ... lui mi ha fatto fare delle lastre al torace, e mi ha detto "e poi mi legga l'esito per telefono." Io ho fatto le lastre, siccome appunto abito fuori Milano ho fatto fatto queste lastre ... avevo difficoltà a muovermi, perché con questa mancanza di respiro ... venire a Milano non era facilissimo. E quindi, quando ho fatto queste lastre la diagnosi era che non avevano riscontrato niente quindi quando io ho telefonato al mio medico, mi dice: bè, io avevo paura che fosse una pleurite, però visto che non lo è sarà solo un dolore intercostale. E questo era il mese di aprile. Io non avevo un day-hospital fino al mese di giugno..

I: che tipo ... scusi che tipo di dolore era?

A: io avevo un dolore molto forte, a respirare. Avevo delle fitte al torace, e ... e non solo, sentivo anche che il cuore era interessato. Eh, non batteva con la frequenza solita, no? Quindi mi sentivo ... proprio un dolore molto forte al torace, quindi ... è stato un periodo veramente duro. Eh, non mi ricordavo più, adesso che ci ripenso [ride] è stato un periodo duro. E quindi niente ... potevo camminare solo piano, perché solo, solo affrettare un pochino il passo anche solo in casa, eh, mi ... sentivo queste fitte che mi impedivano di respirare. E quindi ... anche se i miei mi dicevano: ma vai a farti vedere dal tuo medico a Milano, ma no, ma tanto adesso il day-hospital ... quindi ... sempre per la paura, di ... poter sembrare una lagna, no?

I: si.

A: e quindi ... quando sono finalmente arrivato ... il giorno del day-hospital e sono arrivata qua in ospedale, a fatica, il mio dottore si è spaventato perché poi mi ha fatto questa lastra e ha visto che avevo un versamento pleurico, tutti e due i polmoni e avevo una pericardite, quindi il cuore ingrossato, il pericardio.

I: questi erano delle ... [inudibile.] effetti collaterali della cura del cortisone, o erano legati al fatto ...

A: no, no, al fatto della malattia.

I: della malattia.

A: era la malattia proprio che aveva ... si era sviluppata e quindi iniziava a dare questi sintomi.

I: e dopo qua, tre mesi è durato più o meno questo, questa crisi ...

A: si questa crisi è durata così, si, poi ..eh ... doveva aumentarmi subito il cortisone, la dose di cortisone, eh, solo che non avendo..cioè era poco che mi conosceva come paziente, e allora mi ha mandata a fare un'indagine allo stomaco. Perché il cortisone va da sé che può rovinare lo stomaco. Mi dice, "vediamo che lo stomaco sia a posto, poi le aumento il cortisone." Purtroppo avevo un'ulcera che non sapevo di avere quindi per un altro mese non ho potuto aumentare la terapia.. e quindi le cose si sono protratte ... e questo ha fatto sì che mi venissero delle aderenze, tra le pleure e.. e di conseguenza il mio respiro affannoso è diventato tale proprio a causa delle aderenze, non mi permettevano più di espandere il torace, per respirare. E questa è una cosa che mi sono, poi vabè: dopo un mese ho potuto aumentare la terapia, i dolori si sono.. eh .. non dico che sono finiti perché non è vero.. eh.. però stavo molto meglio ...

I: sempre queste, queste ... quando parla di queste, di queste fitte ...

A: si fitte al torace, si, si, si. Si che è stata la cosa che mi ha fatto soffrire più di tutto, perché ovviamente ha limitato la mia vita anche, anche il fatto di essere rimasta seduta a dormire per tutto questo tempo ... perché abbassarmi non mi permetteva di ... cioè sdraiarmi sul letto non mi permetteva di respirare ...

I: di respirare

A: ... non è stato facile ... <coughs> anche perché mi ha portato una conseguenza, anche se non ne abbiamo la certezza, eh, mi è venuto un tumore ... al fondo schiena [inudibile] continuando a stare seduta in quella posizione a letto, si vede che questi tessuti erano sottoposti ad uno stress ... eh ... non comune e ho iniziato ad avere una

ciste, che mi è stata tolta in day-hospital pensando che fosse solo una ciste invece era un tumore maligno. E quindi ...

- I: questo le dava dei, dei, de ... se .. se n'è accorta semplicemente per la, perché, per averla sentita o comunque ...[inudibile].
- A: mi sono accorta perché standoci, standoci seduta sopra mi faceva molto male.
- I: che tipo di dolore le dava?
- A: era un dolore acuto, solo al tatto comunque, solo quando mi sedevo: oppure se la, se toccavo questa, questa ciste eh e mi faceva molto male, come se mi bruciasse anche, no? E niente, quindi quando ho avvisato il mio medico, il mio reumatologo, dico: guardi che ho questa cosa proprio sul, vicino al coccige che mi fa male, e m'ha detto: vabè la, la togliamo,, poi come tutte le cose la analizziamo. Perché pensavamo proprio che fosse dovuto al continuo ...
- I: alla pressione ...
- A: si infatti. E invece poi, quando è stata analizzata era ... un tumore maligno.
- I: questo in che anno?
- A: e questo è successo nel novantasei.
- I: nel novantasei. E: lei quindi è rimasta, è rimasta in ospedale per questo.
- A: si ho dovuto essere ricoverata per accertamenti, subito per fare tutte le indagini del caso, poi sono stata rioperata perché ovviamente avevano tolto pensando ad una ciste e invece poi han dovuto fare: la pulizia completa. Sono stata fortunata perché sono riusciti a togliere tutto, non ho avuto bisogno di fare né chemioterapia né radioterapia. Dopo un anno pareva che ci fosse una recidiva, perché il problema si era ripresentato, facendo le indagini di controllo avevano trovato che c'era ancora: un nodulo e quindi sono stata rioperata, però si sono accorti che non era una recidiva ma era solo un nodulo che era andato in necrosi, proprio dovuto alla posizione, sempre stando ancora seduta, e da allora mi sono imposta di dormire sdraiata, adesso non riesco a dormire con : un cuscino solo, però con due cuscini da sdraiata ho imparato ...
- I: ma, adesso quindi, lei ha ancora un problema del polmonare per cui, il respiro le comunque ha ancora dei dolori, o
- A: mi succede, mi succedono dei periodi in cui ho parecchi dolori ancora al torace, e ...
- I: sempre di quello stesso tipo di cui mi parlava prima?
- A: si, si. Molto meno intenso rispetto a quel periodo ... eh ... che però, mi impediscono comunque di .. di avere una respirazione corretta, di conseguenza quando ho questi dolori io non posso camminare in fretta come sono abituata, non posso sdraiarmi, e di conseguenza ... sono leggermente limitata insomma, ecco.
- I: Sì. E poi da quel periodo invece, da allora fino, fino oggi, il resto ... cioè la malattia, il male ha avuto anche qualch si è manifestato anche in qualche altro modo ...
- A: si ho iniziato ad avere dei problemi al nervo ottico.
- I: mh mh.

- A: ho iniziato ... cioè mi veniva una macchia nera, davanti all'occhio vedevo una macchia nera, che nel giro di un'ora e mezza cambiava colore, diventava bianca. No, se chiudevo gli occhi diventava bianca, eh, questa macchia la vedevo bianca. Se invece li aprivo rimaneva nera, e poi si riassorbiva e si rimpiccioliva nel giro di un'ora e mezza circa. Sono andata a fare le indagini, dall'oculista che mi aveva già in cura, perché queste terapie possono colpire
- I: mh.
- A: gli occhi, e lui, l'oculista non vedeva niente. M'ha detto "se lei . Il momento che ha questo problema riesce ad andare in un pronto soccorso, e farsi valutare la situazione ..."
- I: un po' la storia vecchia del ...
- A: [inudibile.]
- I: gonfiore, per cui non c'era
- A: erto. E allora ... sono riuscita, in un momento così ... anche perché, essendo un problema che si risolveva nel giro di un'ora e mezza, cioè, dovevo fare in fretta a far valutare la cosa. Quindi sono riuscita ad andare in un pronto soccorso, e mi han detto che era un'ischemia al nervo ottico. E siccome il lupus, tra le ... i vari problemi, può aver quello del: il problema della il problema della coagulazione del sangue ...
- I: mh mh.
- A: e io sono a rischio di trombosi.
- I: mh mh
- A: quindi ... me n'ero già accorta perché ho avuto delle tromboflebiti eh, in ... negli anni passati. Quindi prendevo già l'Aspirina 500 per ... cercare di tenere il sangue più fluido. Però, quando sono capitati questi episodi agli occhi poi ho iniziato ad avere problemi: qualche volta non mi ricordavo dov'ero ... non era una sensazione piacevole. E quindi il mio reumatologo ha deciso di farmi ... entrare in terapia anticoagulante, e quindi adesso sono in terapia anticoagulante. Vado a fare i miei controlli del sangue, dipende, una volta alla settimana, ogni quindici giorni, al massimo ogni tre settimane ... e mi dosano la terapia del farmaco per rendere il sangue fluido.
- I: questo però era un pro ... non le dava ... sensazioni di dolore il problema all'occhio
- A: No, dolore no, era proprio ... il fatto di non vederci ...
- I: [inudibile.]
- A: ... oppure ... quello di ... non avere eh la lucidità è una cosa: brutta. E' una brutta sensazione quella di non ... capire dove sei, di ...
- I: ma mentre le succedeva lei si rendeva conto che qualcosa le stava capitando, o solo a posteriori?

- A: no, no, no, me ne rendevo conto, perché magari ... uscivo dall'ospedale e ... c'era un momento che dicevo: boh, cosa sto facendo qua? Dove sono? Cioè, erano cose di cioè, frazioni di secondo. Però ... cose veramente ... <ride> poco piacevoli ...
- I: si spaventava ...
- A: e beh, era ... antipatica. Una sensazione di insicurezza. E poi insomma, è chiaro che, qualsiasi dolore fisico, io penso che si possa ... anche gestire, ma una cosa mentale ... penso che sia quella che spaventa più di tutto.
- I: mh mh. Quindi questo l'aveva più forse più ... l'aveva preoccupata più di ... rispetto ai suoi dolori ... non so, alle articolazioni o:
- A: si. Sì, senza dubbio sì
- I: perché?
- A: e perché il fatto di non essere più presente con: con il cervello <ride> cioè perché il dolore io penso di poterlo gestire. Qualsiasi cosa, mi fa male, lo sopporto, lo gestisco. Però, se sei fuori di testa: è dura.
- I: e questa .. per quello invece .. i primi sintomi che ha vissuto, appunto, i dolori, i gonfiori, i dolori alle articolazioni, sono qualcosa che lei ha ancora, di cui soffre ancora?
- A: sì, ... sì, sì, sì. Sì, sì. Ormai ci facciamo compagnia tranquillamente. Io dico sempre che io e il mio lupus siamo diventati amici. Lui: mi lascia un po' di spazio e io faccio altrettanto con lui. Poi quando magari mi dà qualche problema in più, in genere dico "si vede che ha bisogno di un po' di pappa", allora devo aumentare un po' la dose della terapia, poi si mette tranquillo e conviviamo bene.
- I: <ride> è interessante come immagine del ...
- A: <ride>
- I: come se lei lo visualizzasse, quasi come fosse ..
- A: sì, sì, sì. E infatti quando: mia mamma provato a dire "questa maledetta, questo maledetto lupus [inudibile,]", "non chiamarlo così, che poi se la prende con me. Teniamocelo buono, cerchiamo di convivere tranquillamente, senza: farlo arrabbiare".
- I: se: vabè, immagino che probabilmente l'avrà fatto quando, parlando con i medici. Ma: se anche dovesse, se qualcuno le chiedesse che tipo di dolore è, il dolore che lei sperimenta, per esempio nell'articolazione, lei come lo descriverebbe?
- A: <deep breath> non è facile: descrivere il dolore, <ride> non è facile: vabè, poi ce ne sono di diversi tipi, perché, il dolore eh .. vorrei dire un bruciore ma non è, non è un bruciore. E' proprio una cosa acuta. In alcuni casi, sembra di: cioè tante volte si sentono queste frasi che ti sembrano esagerate, però, sembra che qualcuno ti stia girando un coltello dentro, no? Cioè: e in effetti molto spesso è così, anche se sono cose che io non dico mai perché non : anche sentirle dire mi da fastidio, mi sembra quasi che, che si voglia enfatizzare , no?
- I: mh

- A: cioè renderlo ancora più: più pesante, però in effetti è così, qualche volta il dolore è proprio come se fosse un coltello che ti entra: quello al torace è stato comunque: tremendo, quelle veramente sembravano delle pugnalate <long pause>
- I: sì, penso sia difficile immaginarlo. Credo sia, appunto una delle difficoltà, no? Ma, quando ... parlando con il medico, con le persone intorno, il fatto che per lei è difficile descriverlo: eh .. la frustrava ...
- I: stavamo dicendo, era, non so il fatto che .. questa difficoltà nel riuscire a descrivere quello che le stava succedendo, quello che lei ..sente a livello fisico, le: come .. l'ha vissuto in modo particolare, non, non, aveva qualche effetto su di lei ..c'era, c'è della frustrazione quando non riesce ..
- A: no, quello che, mi dava fastidio era il fatto di arrivare senza niente di visibile quando dovevo fare la visita dal medico. Anche perché, dire mi fa male, il medico ..cioè se è competente in materia ... probabilmente capisce che cosa s'intende "mi fa male", però il "mi fa male" voleva dire anche non riuscire ad usare un' articolazione, quindi vuol dire non riuscire a piegarla, non riuscire a: eh, cioè la sofferenza di questo genere. Ma, eh, l'aspetto visivo, era quello che avrebbe dato al medico la sicurezza di questa: perché ..
- I: cioè, se avesse visto qualche cosa ...
- A: le articolazioni, sì, ecco, le articolazioni si gonfiavano, erano tumefatte e calde. Di conseguenza avrebbe capito che in effetti c'era qualcosa. Perché descrivere così, "mi fa male", "non posso usare il polso, piuttosto che questo dito" cioè molto spesso il medico non può capire in effetti quanto male hai. Non è facile. Perché poi ognuno ha la sua soglia del dolore. C'è quello che riesce a sopportare un dolore fortissimo, quello che con un dolore molto basso: cioè, va già in crisi.
- I: E invece nel rapporto con: i familiari, gli amici questo .. spesso incapacità di riuscire a descrivere precisamente quello: il tipo di dolore, [inudibile.] la preoccupava, frustrava, riusciva comunque a: rapportarsi alle persone, o comunque si sentiva magari, forse isolata per non riuscire ...
- A: no, no, io devo dire che, eh, i miei sono sempre stati molto comprensivi nel senso che, poi mi conoscono e sanno che se mi lamento è perché c'è qualcosa effettivamente che non va, altrimenti non non mi sarei lamentata. Io poi non sono una che drammatizza o che racconta molto, nel senso che, vabè, mi fa male ma poi non è che mi interessa di entrare in particolari. Anche perché, se dici a un familiare "mi fa male" generalmente ti credono. Non pensano che tu la stai mettendo giù dura, per intenderci. Mentre farsi capire da un medico è diverso, insomma. Il medico non ti conosce quindi, magari può immaginare che tu: sei tragica, che magari è una cosa meno pesante di quella che stai cercando di descrivere. Mentre in casa no. In casa: anzi, non mi piace essere compatita, assolutamente. E' una cosa che non, che non mi interessa, anche perché non mi serve essere compatita. E molto spesso sono io che devo dare coraggio agli altri, perché: questo anche quando ho avuto il tumore, perché gli altri erano disperati, e la meno disperata di tutti ero io alla fine.
- I: beh, è strano perché sembra che capiti abbastanza spesso, che alla fine chi si trova ...
- A: è quello che deve dar coraggio agli altri.

- I: ad aver: il problema, comunque sia, deve poi farsi carico degli altri, che sembra che riescano a, a gestire ...
- A: io mi ricordo quando ho avuto il problema respiratorio, una sera in particolare che ero sul letto, sempre seduta, con questo respiro affannoso, ed è una cosa tremenda, e mio marito sulla porta della camera che mi guardava con un'aria come per dire "dimmi cosa posso fare", e io l'ho mandato via, "vai via che non ti voglio vedere" <ride>. Perché veramente, è stato un periodo nero ed ero ... cioè non respirare fa diventar nervosi, eh, innervosisce molto <ride>
- I: Immagino <ride>, immagino che sia ...
- A: ecco, e per il resto: no per il resto, i miei, diciamo che non, penso che non, non che si rendano conto, sanno benissimo che io ho questi problemi però non li ho mai fatti pesare a nessuno. Perché innanzitutto non pesano tanto neanche a me. Di conseguenza ...
- I: quest, questo ... prima mi aveva parlato delle macchie che ogni tanto le comparivano
- A: si.
- I: sul corpo. Le succede ancora?
- A: ma: sono queste macchioline che mi sono, queste macchie che sono uscite sotto pelle, ma sul palmo delle mani e dei piedi. Eh, queste ogni tanto escono, dipende dal periodo, eh, mi sono uscite poi, altri, dei noduli sulle gambe, queste cose sono abbastanza frequenti. E anche lì devo aumentare un po' la dose di cortisone fino a che non ...
- I: e queste fanno male?
- A: si, sono molto dolenti.
- I: sta parlando dei noduli o delle macchioline?
- A: Dei noduli.
- I: Dei noduli.
- A: dei noduli sulle gambe, perché pare che siano dei noduli che si appoggiano proprio sul nervo, di conseguenza, ogni volta che fai un movimento con la gamba, col piede, senti questa fitta continua.
- I: quindi sono tipo delle fitte?
- A: Sì.
- I: Non dei bruciori, fitte?
- A: si, no, no, no, proprio: una fitta, si.
- I: però se lei rimane [inudibile.] se rimane immobile non le fanno male?
- A: fa male. Non come quando cammino ovviamente, non come quando mi muovo.
- I: e invece le macchie? [inudibile.] che tipo?

- A: e invece le macchie: no le macchie erano soffe... erano dolenti se le toccavo. Altrimenti no, non è che facessero male. Erano come, anche quelli, come dei nodulini che si erano formati sotto pelle, sul palmo delle mani e dei piedi. E quando mi succede, ancora mi fanno male, chiaramente, camminare sento. Perché si arrossa, sia la pianta del piede che quella delle mani, si arrossa proprio a macchie, e diventa sofferente. Comunque è anche una mancanza di circolazione anche.
- I: lei ha, cioè ha dei momenti in cui è completamente libera dal dolore adesso?
- A: sì.
- I: quindi non è un .. ci son dei momenti ...
- A: sì, si ci stavo pensando <ride> son talmente abituata. No, una cosa ad esempio che, che ho capito sin dall'inizio che: devo riuscire ad apprezzare i momenti in cui sto bene. Ad esempio se ho le ginocchia gonfie ho delle difficoltà a scendere le scale, salirle, camminare. Ma quando sto bene, io posso scendere le scale saltellando, sono felicissima. Cose che persone che stanno sempre bene non si rendono neanche conto di avere. E questa è una felicità che non tutti riescono a provare.
- I: si ricorda com'era la vita prima che cominciasse tutto questo per lei?
- A: sì, io sono sempre stata una persona molto attiva, eh, mi è sempre piaciuto molto lavorare, ma anche fare fatiche non mi è mai pesato. L'ho sempre fatto volentieri, devo sempre essere in movimento, sempre sentirmi utile, fare qualcosa. E, devo dire che nonostante tutto riesco a farlo ancora oggi, anche con i dolori. Chiaro, sono un po' limitata rispetto a prima, non riesco più ad esempio, ad abbassarmi, mettermi in ginocchio, fare queste cose, ho delle difficoltà. Adesso ho dei nipotini, i bambini di mio fratello, e mi piacerebbe poter fare una corsa. Ogni tanto c'è il piccolino che mi dice "dai zia, prendimi". Eh, è una parola <ride>
- I: e' difficile ...
- A: correr dietro a un bambino è diventato per me molto pesante.
- I: correre dietro a un bambino è difficile un po' per tutti <ride>. Se, se le capita di provare un .. del dolore che, probabilmente non legato alla malattia, come può essere, non so, il mal di testa che a tutti viene, o un taglio, una bruciatura, lei lo vive in modo ..pensa che lo vive in modo diverso? Vive, cioè, non so, perché pensavo a ... lei prima ha parlato di questo, questa figura, questo lupus, che si nutre, quindi dà dei problemi in qualche modo. Però probabilmente, siccome essendo ancora viva e: avendo delle sensazioni, come a tutti capita di avere altri problemi che non sono legati. Non lo so, lo percepisce in modo diverso? Cioè c'è come, per lei, c'è come il dolore del lupus e gli altri dolori? E se sì, come sono diversi, come li percepisce? Oppure, è tutto comunque alla fine ...
- A: no, no, no, sono diversi. Ad esempio, stavo pensando, forse per quello mi sono scottata l'altro giorno, perché dovevo rispondere alla sua domanda, forse ho sentito <ride>
- I: ah si? Grazie per la collaborazione <ride>
- A: ho sentito un bruciore molto intenso, e chiaramente molto diverso dai dolori che sento di solito. Quindi, scappare subito sotto l'acqua fresca, e mettermi un po' di crema, ed era fastidioso sentire questa, eh, molto più fastidioso che sentire dolore alle ginocchia,

piuttosto che i dolori alle mani. A questi dolori ci sono anche probabilmente abituata. E poi un: dolore di una bruciatura è un dolore molto forte, molto intenso, quindi ... si spera che passi in fretta.

I: mh, mh, ehm, per esempio se dovesse paragonare, non so, le fitte che aveva, che non son stati molto forte, dolorose.

A: Sì.

I: vome, in che modo pensa che, secondo lei che differe... come descriverebbe la differenza del, della fitta che era comunque una cosa legata ...

A: on quelle al torace, ad esempio?

I: sì. E' un dolore intenso quale può essere .. invece uno ... quando avevo sedici anni ho rovesciato <ride> una pentola di acqua bollente sulle gambe ...

A: noo.

I: e la ricordo come l'esperienza più terribile della mia vita <ride>

A: me lo immagino. No io devo dire che: il dolore di una bruciatura è un dolore forte, eh, che però sai che passa. Nel senso che, eh, è una cosa che dici "vabè adesso vado sotto l'acqua fresca" [inudibile.] certo, è chiaro la bruciatura di un ferro da stiro non è che sia: una pentola d'acqua bollente che ti cade sulle gambe. Quindi dici, "vabè, passa, mi metto qualcosa di fresco", mentre un dolore come le fitte che provavo al torace: mi condizionavano molto. Quelle mi condizionavano molto la vita, perché avevo difficoltà a respirare, e questa era una cosa ... Mi impediva di fare tante cose.

I: per finire, solo una cosa. Mi ha colpito molto l'immagine che aveva usato del lupus come una, il lupus come malattia, come questa specie di mostro, qualcosa che c'è dentro di lei.

M. A: No che non è un mostro.

I: Una ...

A: un lupetto.

I: un lupo, una piccola cosa amichevole ... la malattia però, e il lupus. Se invece dovesse immaginare, non lo so raffigurare invece, il dolore, indipendentemente dal, il dolore in sé. Che, che immagine le verrebbe in mente?

A: non brutta.

I: non brutta?

A: no, no, una cosa che fa parte della vita. Poi: devo dire che non so neanche se mi piacerebbe guarire da questa malattia.

I: ah.

A: perché mi ha insegnato tante cose. E, io sono riuscita a, a fare nella vita una cosa che mi piace molto, che è quella di rendermi utile agli altri. E ho potuto farlo grazie al lupus. Perché io non avrei potuto permettermi di non lavorare. Io ho l'invalidità, ho lavorato 24 anni, quindi: io sono a casa con la pensione di invalidità, anche se non è tanta, ma io mi accontento di poco.

I: mh, mh

A: quindi questo mi permette di: venire a Milano e fare volontariato ed essere vicino ai malati. E' una cosa che mi piace molto.

I: grazie.

A: a lei.

3 Gina

- Interviewer: volevo chiederle se magari per iniziare mi parlava un po' della sua esperienza, di come è iniziata {la mia malattia} eh ... la malattia, e di come appunto, un po' la genesi della sua storia.
- Gina: ma, io ho incominciato ... che m: mi venivano dei dolori sul, sulle ginocchia, o magari ai piedi, e maggiormente me ne accorgevo quando andavo in montagna, perché sono appassionata della montagna. E quando dovevo fare la discesa, mi si gonfiavano le ginocchia rimanevo bloccata. Poi magari a casa, eh: a volte mi si gonfiava la mano, a volte il braccio, però mh, con febbre anche, ma non mi preoccupavo più di tanto perché mi dicevano, e ma tanto se i dolori girano vuol dire che non è una cosa grave.
- I: che, che dolori erano questi che, provava inizialmente?
- G: erano dolori molto forti, alle ginocchia proprio mi bloccavano: l'a ... l'articolazione. E lo stesso succedeva sulle mani o sui polsi. Febbre alta e dolori forti, perché poi si gonfiava: l'articolazione rimaneva bloccata. Ma: al momento ripeto, non non ho dato peso più di tanto, invece c'è stato una mattina che non riuscivo neanche alzarmi dal letto. E: telefonato al medico di famiglia: al momento ha detto di venire qui: al [nome ospedale].., però: era piuttosto lontano, ho passato sopra alla cosa, e dopo: ho cominciato a fare alcuni esami: del sangue così, però, na volta sono andata: da un medico poi m'ha mandato da un altro medico, prima m'hanno curato per i denti, sembrava che avessi degli ascessi ai denti, poi invece dicevano che era: un'inflammazione così, e intanto son passati: quasi due anni. Quando è stata scoperta la malattia, che non ne potevo più, sono andata: dal: da un cardiologo, che era: amico di famiglia, del della mia amica, e: e lui come mi ha visto le mani ha detto che avevo l'artrite reumatoide. M' ha mandato a: a [nome ospedale] a fare degli accertamenti, e da lì è incominciata: proprio tutto, la cura vera e propria dell'artrite reumatoide. Cominciato a stare un po' meglio, però: logicamente: è stata un po' duretta, specialmente i primi tempi.
- I: questo scusi, quanti anni fa sono iniziati: i problemi?
- G: e: dunque, venti: due anni fa.
- I: ventidue anni fa. E la diagnosi: è stata dopo quanti anni?
- G: due anni.
- I: dopo due anni.
- G: da quando ho iniziato ad avere i dolori, sì.
- I: da allora come è progredita poi la malattia?
- G: è progredita con le deformazioni varie, sulle mani, e sui piedi. Ho già fatto: due operazioni ceh ho messo delle protesi: alle mani, specialmente: eh: ... articolazioni qua, e, però sto abbastanza bene ... a parte magari qualche episodio: magari che si fanno dei lavori senza accorgersi che maga, ieri per esempio ho tagliato, un po' di verdura e oggi ho, tutto il dito gonfio che non riesco a, {e le fa male?} ad avere la forza di, di prendere una cosa ecco.

- I: e: {si, fa male} è dolente? {si} questi dolori, è innanzitutto, solamente alle articolazioni? Sono solo alla:
- G: alle piccole articolazioni: poi prende a volte le spalle, e: il dolore più: acuto e più: fastidioso, diciamo, doloroso, è quando mi prende: qua dietro alla schiena e si vede che proprio c'è: la muscolatura che si infiamma, e anche a respirare: proprio non riesco. Magari quando devo andare a letto, solamente fare questo movimento di scendere giù, e: un dolore fortissimo, che mi blocca persino la respirazione.
- I: quindi molto intenso?
- G: molto intenso.
- I: e invece quelli alle: alle articolazioni che tipo di, come li descriverebbe?
- G: son sempre forti, che a volte proprio: sente quasi: che glielo stanno strappando, metto il ghiaccio: se no altro qualcosa: mi, [allevia?]
- I: sono simili a bruciori oppure no? ... sono anche di diverso tipo?
- G: son proprio come delle, non so, non come degli aghi, che che son proprio come un qualcosa che strappa, sinceramente non c'ho mai fatto caso, se è più: non so, non so descriverlo, so che è forte.
- I: e vanno: e quando, quando le vengono durano: durano diverso tempo: sono: eh:
- G: ma, i primi tempi duravano magari un giorno, desso invece: magari due tre giorni, prima di: di alleviare proprio il dolore completamente.
- I: nonostante, prenda: gli ...
- G: nonostante antinfiammatori e tutto, e la cura di fondo.
- I: ahm: lei come, come direbbe che è: eh la malattia ha influenzato la sua vita?
- G: all'inizio: è stata dura, perché avevo ancora i bambini piccolini, e di conseguenza: anche loro sono stati un po': non dico traumatizzati però quasi. Perché due per tre ero lì bloccata e loro, aiutavano il papà insomma, nelle faccende domestiche. E: di conseguenza: cioè la mia vita è cambiata, a poco a poco però: c'ho fatto l'abitudine, e adesso, mi sembra di essere una persona normale, se non mi guardo le mani, mi sembra di essere.
- I: anche perché, mi sta dicendo che comunque, gli episodi dolorosi non sono più come:
- G: non sono più frequenti come prima, adesso è abbastanza controllata diciamo come malattia.
- I: e lei ha trovato: nel momento in cui ha cominciato a avvicinarsi a: al, ai medici: o alle altre persone, è stato, e: era difficile? La, la comunicazione, con, con l'establishment medico: eh: era difficoltosa: ha trovato comprensione: oppure ...
- G: no beh, andando da, da reumatologi per quanto le malattie le conoscono, ho trovato abbastanza comprensione non ho avuto difficoltà.

[interruzione]

- I: ahm, niente, quindi, mhm quando, eh: ... lei ha sempre a che fare con persone, oltre che con i malatti però con gente che non ha la sua stessa esperienza, ah, trova: ehm come trova, riesce a comunicare quello che: che è la sua esperienza o pensa che sia, molto difficoltoso?
- G: Non, non comunico la, la mia malattia a nessuno. Cioè non, non ho occasione di dire, quello che ho, quello che provo.
- I: ma magari, ... immaginavo magari le sarà capitato qualche volta di: magari di dover essere coinvolta in qualche attività che non le è stato possibile:
- G: mi rifiuto, perché: anche in parrocchia andavo a fare: appunto la segretaria, così: c'erano dei lavori, tranquillamente non ho mai, nascosto la mia malattia, anche perché si vede. E dico no, questo lavoro non lo posso fare perché la mia malattia non me lo permette. Sì, dico la verità, magari: ci sono delle volte che, ci s, mhm, mi sento un po' in imbarazzo con queste mani, Però: si superano.
- I: E: il suo rapporto con il suo corpo com'è? In seguito alla: un rapporto: non lo so, lo vive come qualcosa di: tra virgolette forse di: di nemico, di: di di di una fonte di, ah: di problemi, o ...
- G: non [so? Sono?] vado d'accordo con me stessa.
- I: ma perché, pensavo, a alcuni può anche capitare di identificare, forse il corpo l'origine di, non non non {dei guai} [di non volersi] creare quasi un distacco fra, la la propria mente e quello che invece è la la sede di, ah: {della sofferenza} della sofferenza forse ... credo che sia diverso per ogni persona.
- G: penso di sì dipende da come, da come si accetta la malattia. Io penso che, tante volte magari ci son delle persone che proprio la rifiutano, la malattia o magari, hanno dei grossi problemi, le dico la verità, c'è stato un periodo che anch'io ho avuto dei problemi proprio perché, tutti i giorni che non stavo bene, tutti i giorni che avevo qualcosa: di fatti: avevo fatto un colloquio con, la psicologa, proprio per questo però, lei aveva stabilito che non avevo dei problemi, era solo magari un momentino più di sconforto.
- I: questo era più, verso l'inizio.
- G: molto indietro, dopo da allora, forse è stato quello, anche una spinta, a, a reagire. Da allora è iniziata proprio la salita.
- I: e il suo lavoro all'interno dell'associazione le: come lo vede rispetto a, è uno dei fattori che l'aiutano a, a: appunto a stare meglio con se stessa?
- G: sì, si si indubbiamente perché, ci si sente utili lo stesso. Anzichè essere in casa solamente, tra le quattro mura: cioè ci si sente: utili anche, ad altre persone che hanno il tuo stesso problema.
- I: c'è una certa comunità, tra:
- G: sì, tra di noi, sì. Cioè mi sento veramente: anche, cioè, dopo un po' che non ci si vede: anche oggi, che è un'occasione del, dell'assem, cioè dell'incontro che abbiamo, nel pomeriggio, è stata un'occasione per ritrovarci dopo tanto tempo, perché non è che ci

si trova tutte sempre, spesso, quando invece ci sono quest'incontri ci si ritrova e: proprio: c'è quasi un affetto tra tutte, forse, condividiamo tutti la stessa pena.

- I: sente, forse, più compresa dalle persone che, che soffrono come lei?
- G: sì, indubbiamente. Specialmente, all'inizio le persone che ti son vicine, a parte mio marito e i miei figli, ma le persone esterne non non capivano, la malattia, perché magari, io soffrivo e il giorno prima che ero là: a terra, al telefono come stai, sto male, così, ma il giorno dopo mi vedevano come nulla fosse, allora dicono ma "sta qua mi prende in giro", e invece, son proprio, le malattie reumatiche che sono: una cosa molto oscura, che oggi stai male e domani invece non hai più niente.
- I: ... un po' confonde lo stereotipo che le persone hanno di malattia che dovrebbe essere qualcosa forse, nell'immaginario comune che ti blocca in modo, costante a letto per un, non so mesi {sì, è vero}
- G: e, guardi io mi sono trovata il mese, no il mese di novembre, con delle mie ex colleghe, che è tanto tempo che non le vedevo io son stata a casa dall'ufficio che, non avevo niente, son stata a casa perché ho avuto il secondo bambino, e: dopo hanno parlato con mia sorella, perché lavoravamo tutte e due nella stessa azienda, e le han detto oh ma com'è conciata la G., con quelle mani, ma io non ho niente in confronto, cioè si sono immaginate chissà che cosa perché ho le mani deformate, no? Eh, però al momento loro non han detto niente però: hanno avuto proprio questa, questo impatto, mentre all'inizio le deformazioni non c'erano ancora, e allora: magari, lei stava male oggi domani non aveva più niente, sembra che non abbia mai niente, e invece: comporta prendere dei medicinali che sono anche piuttosto pesanti, per poter stare in piedi tutti i giorni.
- I: quindi c'era un po' questa situazione paradossale, per cui, prima, che magari non c'erano le deformazioni, ma c'era una forte {non era capito} sofferenza, non veniva compresa, adesso magari, si vedono i segni fisici, ma la sofferenza è, {è meno} è diminuita, le persone immaginino che invece sia più sofferenza perché vedono i segni ...
- G: sì, è vero.
- I: va bene signora, la ringrazio per, per avermi aiutato, c'è qualcosaltro che vuole, dire che pensa che è importante che magari non le ho chiesto:
- G: no, io penso di vivere bene adesso con la mia malattia <ride> anche se adesso cominciano i problemi grossi forse.
- I: perché?
- G: perché incomincia il fegato, i reni:, il cuore, gli occhi, adesso c'è, l'altro risvolto <ride> però
- I: sempre legato all'artrite reumatoide.
- G: e beh, i medicinali, da una parte fan bene ma dall'altra, per quanto son ventidueanni che me la curo.
- I: [...]
- G: sì.

I: grazie.

G: di niente.

4 Marta

- Interviewer: la prima domanda, volevo chiederle un po' se, voleva parlare di quella che è la sua esperienza con la malattia. Quando è iniziata giusto per: eh ...
- M: io ho iniziato a cinquantotto anni ed ero, mai avuto nessuna malattia nella mia vita, ero veramente, mi consideravo fortunata, perché non avevo mai avuto nulla, e improvvisamente da un piccolo dolore, da un dito, è nata, tutto un susseguirsi di questa patologia, che c'ha l'artrite reumatoide.
- I: mh mh
- M: che, eh: man mano m'ha preso le mani. I piedi eh: diagnosticarla non è stato facile perché io sono: con gli esami sieronegativa, cioè non: agli esa:mi clinici non risultava nulla, per cui c'è stata fatta una ricerca approfondita di tutto quello che poteva essere . non eh inerente a un'artrite reumatoide poi alla fine è stata diagnosticato e adesso ne porto le conseguenze perché nel giro praticamente di Quattro anni mi son trovata con piedi e mani compromessi al punto da dover operare.
- I: e questo: diceva che il problema è iniziato a un dito ...
- M: a un dito sì.
- I: che tipo di:
- M: mi è stato diagnosticato un semplicissimo dall'ortopedico un semplicissima: tendinite, eh: per cui non ha dato importanza a questa cosa, poi invece, successivamente ho avuto: dei problemi alle mani mhm sì dico alle mani bruciare, eh di notte avevo dei dolori fortissimi alle mani, poi il piede ha cominciato a gonfiarsi un po' la caviglia poi l'altro e così:
- I: ed erano tutti: cioè sia alla caviglia: tutti: erano, la prima manifestazione era di tipo dolorosa, oppure era non so prima c'era il gonfiore e non dolore
- M: no no ... le mani è stata dolorosa perché naturalmente con: con anche il tunnel carpale che naturalmente viene compromesso anche da questa infiammazione per cui dava dei dolori alle mani: particolarmente di notte, questi bruciori da: insopportabili, eh niente un po' di gonfiore.
- I: quindi era erano bruciori questi ...
- M: sì bruciore poi gonfiore . poi: la ma eh anche la caviglia ha iniziato a gonfiarsi, poi anche l'altra per cui ecco poi eh:
- I: e il primo, quel problema al dito che lei ha avuto inizialmente ... che tipo di dolor le dava era una qualcosa di:
- M: niente avevo male: avevo male, male a: questo pollice del dito per cui sono andata dall'ortopedico dicendo come mai avevo questo dolore, e lui m'ha detto è una ...
- [una porzione dell'intervista e' mancante a causa di un danno al nastro]
- M: poteva poteva, adesso poi io parlo da ignorante, non voglio <ride> di ... maga ... però questo m'è rimasto in mente chiaramente per cui è stato fatto tutto il possibile e alla

fine mi hanno detto no, lei non ha niente altro, persino anche a livello neurologico, sono andata al Besta mi hanno fatto anche la: come si chiama, la lombare.

I: la lombare.

M: tutto anche il sistema nervoso ero a posto dal punto di vista, cioè fisico non ... per cui mi hanno consigliato di seguire sempre la reumatologia e con altre terapie

I: e in tutto quel periodo . e anche in questo periodo: il, il dolore lei lo aveva in modo continuo? Oppure erano, non so, tra non so il periodo ... in cui c'è stato ...

M: ma ma insomma intanto sono stata bastonata di antinfiammatori: cortisone: all'inizio. per cui naturalmente: i bruciori che avevo alle mani quest cose mi si sono: calmati: abbastanza, non posso dire . che: ecco, eh il dolore naturalmente anche ai piedi m'era venuto camminavo male perché naturalmente deformandosi le articolazioni poi creano ... problemi. si induriscono le articolazioni, si si cammina male per cui ho dovuto intervenire anche, mi si è, avevo i piedi dritti le mani dritte normali <ride> per cui ho dovuto il dolore dato da queste malformazioni che ti ehm eh induriscono i: eh le: le articolazioni naturalmente i movimenti delle mani dei piedi e il dolore è un dolore almeno nel mio caso più che: quel dolore . cioè dici "oddio oddio adesso sto male, prendo subito un antidolorifico", ma è una cosa che praticamente t'accompagna un po' tutto il giorno . perché più che dolore è un indurimento un: un'incapacità di: di sentir difatti non chiudi bene le mani, non puoi essere e per cui hai sempre questa ... tensione, a livello muscolare: articolare insomma.

I: ma questa sensazione che lei descrive, lei la prova anche quando: per esempio è ferma immobile, seduta che non sta facendo niente quando è a riposo, oppure è qualcosa che le si manifestava quando: cerca di muoversi, di fare qualche ...

M: a volte anche quando si è a riposo si ha questa, a volte ci sono anche dolori che si manifestano anche a riposo . però naturalmente il riposo, consente di: e io ieri anch'io mi son data della stupida perché ho portato una borsa.

I: mhm.

M: vado a far la spesa, e stupidamente anche solo dalla macchina alla, al coso, l'ho invece che prenderla colle mani come si fa normalmente l'ho appoggiata sul: l'avambraccio e io stamattina mi sento tutto: ... si vede che praticamente il nervo si è così e: e ho detto non non posso assolutamente portare più una borsa neanche sull'avambraccio, quindi devo ... mi sono <ride>

I: quindi adesso le fa: ha, generalmente adesso lei ha: in questo momento per esempio, mentre parliamo, ha delle sensazioni di: di dolore che, c come come si sente?

M: eh dunque, eh: mhm, naturalmente uno poi come, riesce anche abituarsi a uno stato che non è normale, ... come tendo a dire, dolore questo momento no ma c'è sempre, sempre quella per esempio nelle caviglie nella cosa quella co, sensazione di ehm indurimento che ... che magari le: magari non so muovo il piede perché, mi sembra di avere qualcosa che mi stringe mi: mi ostacola no, allora devo, magari parlo son lì bella tranquilla però magari muovo il piede, perché mi, sento che c'è questa cosa, la mano si sente perché e sì [perché] una cosa . come dico nel mio caso, più che di dolore acuto che richiede, è una sensazione di, di indurimento che è: alla fine però insomma disturba se non come il dolore: quasi ecco

I: come, come direbbe che ha influenzato la sua vita, avere, un'artrite reumatoide? Come l'ha cambiata?

M: e beh insomma, direi che l'ha influenzata: nonostante io sia una abbastanza combattiva perché riesco a: sinceramente mio marito mi dice sempre che se fosse capitato a lui <ride> mi dice, cioè, riesco a reagire ancora bene, perché:

I: ... è difficile ... quando non si prova comunque a capire come si potrebbe reagire.

M: infatti, io son sempre stata abituata a: andare fare correre a: camminare come dico prima di ammalarmi, è stato nel giugno del novantasette, io venti giorni prima, tanto è vero che ho persino dato colpa a questa camminata che ho fatto, ho fatto una camminata su una: su in montagna nell'Appennino.

I: mhm.

M: a duemila metri, cioè da mille metri sono andata ... a duemila, son tornata indietro che ero molto molto: cioè a un certo punto ho dovuto abbandonare perché, ho lasciato la compagnia <ride> perché, [infatti?] son tornata indietro da sola perché non ce la facevo più ho fatto uno sforzo, forse non ero più a camminare così tanto, però stavo bene insomma, come dico ero una persona sana e anche avevo voglia di far le cose e naturalmente la mia vita è cambiata nel senso che, non posso più dire domani vado, faccio un viaggio . domani vedrò come sto, eh se posso fare, se posso andare, anche stamattina avevo un appuntamento con una mia: ... però io stamattina sinceramente: non mi sentivo, e: anche se, cioè se fosse stato urgente, una cosa però, non posso tanto più programmare la mia vita, ecco primo, non posso programmare la mia vita, e questo naturalmente cambia molte cose.

I: è tutto più: lasciato alla ...

M: e insomma.

I: alla giornata.

M: io: a questo punto sì, a questo punto sì, la cosa che mi aiuta molto è il fatto di saper guidare.

I: mhm

M: perché siccome non cammino molto, ch'è naturalmente: a, non camminando molto, il fatto di poter guidare ancora <ride> mi aiuta moltissimo.

I: perché guidare invece riesce?

M: sì.

I: bene senza problemi.

M: no no no, riesco abbastanza bene no no non c'è problema anzi, non ho problemi, il fatto di poter dire vado al supermercato anche se cammino poco [acquisto?] le mie cose mi sento realizzata, io ho provato a star a casa due mesi perché son stata operata a una mano non potevo guidare, mi sentivo una malata grave . perché non potevo andare in giro e dico se vado in giro e cammino quel poco e poi mi stanco, quindi andare sui mezzi pubblici ho paura.

I: perché?

M: perché avevo una mano sola.

I: ah.

M: non posso: andare <ride> con una mano, da sola, cioè non mi sentivo auto sufficiente, per cui ...

I: questo anche adesso avrebbe: delle, le darebbe problemi andare sui mezzi pubblici ...

M: no adesso adesso con due mani[...]

I: a perché prima n ne poteva usare una: inizialmente una sola?

M: e sì, sono stata operata: a una mano, eh allora, appunto dico bene, il fatto di guidare mi ha mi ha aiutato moltissimo, veramente, e questo ...

I: per per non dipende per la dipendenza che ...

M: sì sì, assolutamente, anche perché con col tipo di malattia che abbiamo: io dovrei sempre chiedere a mio marito accompagnami a far gli esami, accompagnami a a dal ... medico, accompagnami a far le pratiche per fare: le le impegnative, ogni giorno ce n'è una cioè.

I: certo.

M: bisogna: e le pratiche per avere magari non so, i plantari devo andare dall'ortopedico, le sca, ma scherza, vuol dire un uomo, <ride> avrebbe ...

I: dovrebbe essere sì molto, si sempre appunto a disposizione.

M: io dico sempre a mio marito che è stato fortunato che ho preso la patente trent'anni fa.

I: sì certo <ride>

M: quando lui non voleva, che mi diceva, perché prendi la patente.

I: e invece poi è diventata utile.

M: da bravo maschilista di una volta <ride>

I: adesso invece <ride> ha fatto, ha fatto bene.

M: e infatti infatti.

I: e senta, rispetto a: altri dolori che non sono legati a: alla malattia, che può provare o che ha provato in passato, come li paragonerebbe . non so que dolori che tutti hanno, magari cadendo per cui si prende una botta che fa male oppure, eh, un una bruciatura, cioè questi dolori ehm come sono rispetto . a quello invece è un: un dolore non legato alla malattia?

M: ma, dal punto di vista fisico, uno cade si fa male a: sopporta il dolore:, un dolore: dovuto a queste cose, passa, quindi uno le supera, a un certo punto, invece questo tipo di malattia, è senza ritorno cioè anche: pensi sempre ecco se son così poi domani potrò ancora guidare, potrò ancora.

I: mhm.

- M: insomma limita molto la: per cui è un: dire che è più grave delle altre cose, ch'è una malattia cronica insomma, diciamo che, che uno poi l'affronti più o meno: poi naturalmente davanti: io almeno quello che ho passato nella mia vita ho avuto dei grossi dispiaceri però, m: mi: anche abbastanza importanti perché ho perso due bambini, adesso vabè, appena nati perché ho avuto due gravidanze ... bambini ... sono mancati appena nati.
- I: sì.
- M: per cui sono cose gravi.
- I: mhm.
- M: dal punto di vista fisico, mentale, però, eh la superi e: così, però se fosse capitato a me di ammalarmi, quando ho perso i bambini quando avevo trent'anni di artrite reumatoide, penso che la mia vita sarebbe stata veramente peggio di quello che, delle esperienze che ho avuto insomma, io ho vissuto abbastanza bene diciamo, mi sento veramente quando mi dicono queste cose da: da quando hanno ventitrent'anni veramente sono: eh la loro vita è stata rovinata eh insomma, da questa malattia ...
- I: quindi: okay, va bene la ringrazio molto.
- M: [...]
- I: c'è qualcos'altro che vuole dire che vuole aggiungere?
- M: <ride> no no assolutamente io mi auguro che la sua ricerca <ride> aiuti qualche cosa ma ...
- I: speriamo, no grazie, grazie mille.

5 Sandra

- Interviewer: allora, vuole magari cominciare parlandomi un po' della: in generale della sua esperienza, di quando ha incominciato.
- Sandra: allora, io ho 32 anni, mi sono ammalata nel 1983, avevo 11 anni sono 21 anni che sono malata. Dunque ho cominciato, andavo alle scuole medie e avevo: ero: svogliata, sì si può dire. Ho cominciato ad avere febbre, dolori, però non avevo una febbre continua, avevo una febriciattola andava e veniva per cui non sempre dimostravo ecco di ave, di star male. Poi una volta avevo male a un braccio, una volta sotto il piede e i dolori giravano. Finché un giorno sono andata dal medico, e: quel giorno avevo proprio 39 di febbre, era molto alta. Da quella volta lì niente praticamente sono andata sempre peggiorando.
- I: questi dolori di cui mi parlava, al piede piuttosto che al braccio, che tipo di dolori erano, li ricorda?
- Sandra: allora io faccio fatica a ricordarmelo, perché nel momento in cui sto bene, io cancello dalla mia mente il dolore che provo; nel momento in cui mi fa male anche solo un dito, riaffiora la sensazione di dolore che ho provato. Diciamo che: era un dolore molto acuto, del tipo che non riuscivo proprio ad appoggiare il piede, piuttosto che usare una mano. Però diciamo che: più che altro, si è manifestato: alzandosi la febbre, io quando ho una ricaduta molto forte, mi blocco. Mi blocco a livello proprio articolare, con dolori forti a livello delle articolazioni del bacino, delle anche e delle spalle, e diciamo così devo comunque essere aiutata a far tutto. Alzarmi vestirmi lavarmi, ah, diciamo addirittura anche per poter far colazione alzare la tazza del latte.
- I: quindi sono molto:
- Sandra: molto forti, in fase acuta di malattia. Perché in questo momento che ho avuto l'ultima ricaduta nel: 97, in cui si è comunque manifestata con dolori e febbre, ho praticamente: cioè adesso sono: sono tranquilla ecco, i dolori sono molto relativi, sono proprio a livello di una mano, da dove ho cominciato nel 97, e: ma però sono molto gestibili. Diciamo che son sempre stata trattata con molto cortisone, non so se vent'anni fa era questo il tipo di trattamento, perché sentendo parlare altre persone comunque, adesso non ne danno quanto ne ho preso io. Io ho preso veramente tanto cortisone ho fatto diversi boli di cortisone, e:
- I: che cosa sono i boli?
- Sandra: i boli di cortisone son delle flebo, di metilprednisone, proprio cortisone in vena, praticamente. Praticamente sono fatti in tre giorni, un bolo ogni giorno, e: servirebbero per proprio tamponare la malattia. A me li hanno dovuti fare anche consecutivamente, perché: praticamente non rispondevo alle medicine. Mi hanno integrato degli immunosoppressori, che ho sempre preso per molti anni, e niente con l'immunosoppressore poi sono riuscita a calare il cortisone, a prenderne una dose minima ecco. Non ho avuto molte ricadute, diciamo della malattia. Quelle che ho avuto sono state molto forti.
- I: la diagnosi quando, quando l'ha avuta, mi diceva questa volta che ha avuto:
- Sandra: però parliamo di Lupus, non parliamo di artrite reumatoide?

I: quindi la sua diagnosi è di Lupus?

Sandra: Sì, me l'hanno diagnosticata subito. Io sono, diciamo che eh:

I: dopo questa volta, [...] dopo questa volta, prima mi diceva che aveva avuto [...] prima tanti dolori poi, l'esperienza di febbre molto alta ed era andata dal medico.

Sandra: esatto.

I: ed è lì che c'è stata la diagnosi.

Sandra: la diagnosi c'è stata, praticamente dopo due mesi, in cui io da aprile, no dopo un mese, perché da aprile che mi sono fermata nel letto a maggio, a fine maggio mi hanno ricoverato, e mi hanno diagnosticato subito la malattia, perché, il giorno dopo, praticamente mi è venuto l'eritema a farfalla, oltre i dolori, oltre la febbre alta tipo 40 41 di febbre. Io non ricordo proprio come è andata, soltanto che appunto lì sì, lì: le hanno diagnosticato subito perché appunto: cioè c'era l'eritema a farfalla, c'erano le cellule, che era appunto: proprio l'esame per riconoscere una volta, questo tipo di malattia, c'erano gli anticorpi, molto alti, c'era una VES, vabè:

I: la VES, cos'è?

Sandra: praticamente serve per, l'indice di infiammazione.

I: ah, ok.

Sandra: e niente, ecco questi vari aspetti degli esami. I dolori, i dolori sono molto acuti in fase acuta di malattia.

I: che tipo di dolori sono, sono se:, come descriverli.

Sandra: dunque sono dolori che senti inizialmente sotto pelle. Non sono né all'osso né nel muscolo, oppure possono essere ben distinti, o nelle ossa, o nei muscoli. E' un fastidio una smania, un: questa è una cosa che precede il dolore vero e proprio. Dopodiché, almeno quello che sento io è proprio un dolore, un dolore acuto, proprio sordo, di quelli proprio forti. Non riesco a usare un termine: vero e proprio, dolori che non ti permettono di: mhm, di svolgere diciamo: una vita normalmente, ma anche le cose più banali come scrivere, piuttosto che lavarsi, piuttosto che vestirsi ecco.

I: ma, sono, quando lei ha questi dolori, ci sono solo se lei cerca di fare un'attività.

Sandra: non riesco.

I: o, o anche se è ferma immobile, lì così.

Sandra: anche se sono ferma immobile, sì. Sì sì anche se sono ferma immobile il dolore c'è. Magari ecco, diciamo non riesco magari a mettermi in piedi, una volta però che sono in piedi, piano piano, riesco ad assumere la posizione eretta. Però non sempre facile, e sempre devo essere comunque aiutata. Poi altri: non riesco a trovare un termine sinceramente.

I: quindi non sono, non sono simili: perché a volte li immagino simili a dei bruciori ma ...

Sandra: mhm, quello è una fase prima de: del dolore acuto. E' una, e io la chiamo, è la fase prima che mi arrivi proprio il dolore vero e proprio, ecco, quella fase di bruciore, appunto no, io sento proprio il dolore alle articolazioni. Cioè distingo bene, le articolazioni ... per articolazione, e basta.

I: quindi ha una fase iniziale con, dove s, si prepara, poi ha la fase, quella acuta che è questo: questo dolore sordo che diceva prima è quello della fase acuta?

Sandra: esatto. E' proprio un dolore molto forte che non ti permette di svolgere la vita normalmente ecco, le attività quotidiane che uno svolge ecco.

I: ahm, lei come direbbe che: che l'ha influenzata, che effetto ha avuto su di lei questo, avere la malattia il dolore?

Sandra: la malattia? Il dolore non più di tanto, perché, a parte le fasi acute, dopo è molto gestibile. Di conseguenza dopo aver tamponato con le medicine, si riesce comunque, diciamo, a, a svolgere le proprie attività, non è che non si riesca. Per quanto riguarda invece: il fatto di essere: beh oddio, io sono: come posso dire, spiegarmi. Ogni scelta che ho fatto [end of tape. Question repeated.] diciamo che ogni scelta io ho dov, ho fatto nella mia vita, è sempre stata influenzata dalla malattia, perché è sempre stata presente, fin da piccola, e tutto ha sempre comportato, un problema. Un problema dover andare al mare, un problema dover, uscire con le amiche, un prob, qualsiasi cosa. Tuttora, e sono sposata, i problemi ci sono. Ogni mia scelta ha: voglio dire una conseguenza, perché la malattia si è sviluppata quando io ero piccola e ci son cresciuta insieme. Di conseguenza: viaggio parallelo.

I: sì è iniziato veramente:

Sandra: che avevo 11 anni.

I: sei si ricorda com'era la vita prima di ammalarsi?

Sandra: sinceramente io non ho avuto mai una malattia mai una febbre, mai: niente di niente, ho avuto solo il morbillo, a tre anni, e poi non ho avuto più niente. Fino agli 11 anni, che poi ecco. Dopodiché ci sono state delle conseguenze molto forti per il fatto delle terapie. Ho avuto osteoporosi alla colonna vertebrale con il crollo proprio della vertebra sono stata ingessata, e ho un'osteocondrite al ginocchio.

I: Osteocondrite?

Sandra: Osteocondrite. Molto molto rara, [non?] si trovano [nemmeno?] degli scritti <ride>

I: che cosa, di cosa, non:?

Sandra: praticamente l'osso si si asciuga, e poi si sgretola. La sostanza è questa, mi hanno, perforato il ginocchio in un'artroscopia, in modo che il sangue ossigeni l'osso, che, mi dicono comunque che non serve a molto. Io, a volte mi è capitato, dopo molti anni comunque di avere, dei dolori molto forti al ginocchi da non potere appoggiare il piede. Mi è capitato tra l'altro in vacanza <ride> non sapevo neanche che cosa fare. Mi hanno spiegato che l'unica cosa era il riposo, quando c'aveva voglia se ne andava, non c'erano pastiglie, non c'erano pomate. Niente, perché non sanno neanche niente, non sanno molto di questo tipo di problema. Poi altri tipi di problemi: vabè, la vita sociale: diciamo che non è, dipende anche molto dal carattere della persona. Diciamo che da quando mi sono sposata: è anche venuto di più fuori il mio carattere, di conseguenza son riuscita anche a combattere meglio le cose. Prima magari mi

lasciavo molto più andare, però, mai dire mai, anche perché io da quando mi sono spo, così mi sono sentita male l'ultima volta un anno prima di sposarmi, di conseguenza da quando mi sono sposata non ho più avuto ricadute, per cui quando io non sto male, parlo, bene del mio vissuto di malattia, quando io sono in fase acuta, non parlatemi della mia malattia, perché è una cosa che non mi appartiene. Proprio: tendo a dissociarmi.

I: nel momento in cui sta avendo una crisi.

Sandra: sì sì, proprio: io è: da quando frequento l'associazione che riesco a parlare della mia malattia, se no lei mi vedeva, non vedeva che io ero malata perché non si vede, e io non gliene avrei mai parlato. Non per voglia di nascondersi, per più una sensazione di inferiorità.

I: nei confronti degli altri?

Sandra: nei confronti degli altri, sì. Che poi sia giusta o sbagliata, che sia per il carattere che ho, troppo emotivo, così: è la verità questo. Però diciamo che piano piano sto cercando di venir fuori. Di: di assumere più sicurezza.

I: però, mi diceva che invece nel momento in cui è, in fase acuta:

Sandra: quello ma, <ride> lo rivediamo magari quando starò male, perché ho sempre reagito così. Non riesco, cioè: io sto male, lasciatemi stare, quando starò bene ci, ne riparlamo.

I: Adesso non so, è difficile dirlo, ma pensa che sia un tipo di: di strategia per, per allontanarsi {è un rifiuto} da questa cosa nel momento in cui {è un rifiuto} per sopra

Sandra: e' un rifiuto, è proprio un rifiuto nei confronti della malattia perché nel momento in cui stai male, stai affrontando delle cure pesanti, oltre a: a star male fisicamente proprio, per cui avere, non aver più voglia di, di niente perché sei talmente assorto dai tuoi dolori, o da altri problemi che ti procura la malattia, che non hai voglia di: stare a pensare ad altre cose. Ma comunque sia: cioè è proprio una forma di autodifesa, eh: anche perché le: le medicine che ti danno sono, molto forti e ti comportano veramente degli sbalzi di umore, dei cambiamenti di fisionomia, che quella è una cosa proprio che pesa, che pesa tanto {lei direbbe che:} proprio tanto. Lì mi sento proprio diversissima.

I: Da come invece è normalmente?

Sandra: sì, non sono più io. Ma proprio cambio, cambio caratterialmente. Sì.

I: e, lei direbbe che il, SE è cambiato, come è cambiato il rapporto con il suo corpo?

Sandra: che domandina.

I: <ride.

Sandra: eh: il mio corpo, il mio corpo è stato devastato di conseguenza non ho un buon rapporto con il mio corpo perché le ripeto magari, potrà informarsi, ecco, presso dei medici. Le dosi di cortisone che ho preso io sono, purtroppo poi sul mio fisico molto giovane, me l'ha proprio devastato. Per fortuna non siamo tantissime ad essere così devastate, però: è successo, pazienza, cosa dobbiamo fare. Mi guardo poco <ride>

I: Si guarda poco?

- Sandra: Sì, <ride> [inudibile].
- I: <ride> è interessante il rapporto che la malattia {sì:} ci ci ci, il, la posizione che assumiamo di fronte al nostro: al nostro corpo no?
- Sandra: e è così, benché: voglio dire abbia mio marito che mi voglia bene tutte quelle cose, vabè [inudibile.] però: se devo andare a scavare dentro di me: è tutto molto difficile.
- I: e lei trova: beh forse, adesso le sto parlando come ma, trova: facile difficile parlare della sua ma, del, prima mi ha spiegato di quello che la difficoltà che è maggiore nel momento di fase acuta: eh: piuttosto di un momento che invece non sta soffrendo. Ma, per parlare intendo le, il descrivere quello che che le accade, anche per esempio quando soffre, il tipo di dolore, eh: trova che sia una un'impresa difficile {sì} per lei?
- Sandra: per me è difficile, sì molto anche perché non sempre riesco a dare dei termini, ecco corretti di quello che però, anche perché, okay il dolore fisico, però centrano di, diversi tipi di dolore. C'è il dolore da tensione, io sto male ogni mese volendo guardare, prima de, del ciclo mestruale io sto male, ho una fase acuta di dolori, che mi prende dalle braccia alle spalle così, fino a quando io ho il ciclo, dopo sto benissimo, vai a sapere perché non lo sanno neanche i dottori, però ho anche questo tipo di problema ecco, che allora quando: quando ho questi, dolori forti dico "ossigur che cosa sta succedendo?" Allora ragiono, guardo un attimo il calendario poi, "beh aspettiamo fino al giorno tot", quando vedo che dopo sto meglio allora non mi preoccupa, se no comincerei a preoccuparmi ecco.
- I: e naturalmente visto che ha cominciato a soffrirne così: così giovane non può sapere se sono dolori no no che sarebbero normalmente legati al ...
- Sandra: eh, non credo perché: non credo perché: voglio dire non comprendono soltanto: la fascia renale o la schiena, son proprio dolori legati proprio alla tensione, come se io non, diventassi tutta tesa e avrei, avessi questi dolori ecco: più che altro muscolari però.
- I: senta quando: le capita un: dolore non legato alla malattia, che può essere che ne so la caduta, piuttosto che la scottatura: ehm {sa quante volte} <ride> qualsiasi cosa, quante, che come come come lo vive cioè è cambiata: la ...
- Sandra: bah oddio, adesso non si vede neanche più, mi ero scottata anche qua sulla mano, avevo una bolla ma tanto chisseneffrega, tanto dico un segno in più un segno in meno <ride> onestamente, non me ne faccio più di tanto. L'unica cosa che magari mi peserebbe di più è sul viso, se dovessi, e dico ecco anche quello no per piacere, <ride> abbiate pietà almeno il viso risparmiatemelo ecco, per il resto non mi interessa, sinceramente.
- I: ma, c'è un, non lo so un dolore non legato alla malattia {okay} secondo lei.
- Sandra: beh l'altro giorno faccio un esempio no, l'altro giorno sta, c'era il balcone bagnato e io nel girarmi, ho sbattuto contro, eh, lo stipite delle porte finestre. Ho tuttora male <ride> perché mi son data una bella botta, però: è diverso eh, non è lo stesso dolore, è molto diverso, si riesce a riconoscere
- I: ma lei pensa che: {è una botta} l'aver sperimentato il dolore della malattia, le fa vedere in modo diverso, i dolori che: eh, di altro tipo:

Sandra: ma magari ne do meno peso, ne do meno peso. Anche se ultimamente, anche quando io stessa sto male coi dolori diciamo della malattia, cerco comunque di darmi coraggio, perché dico sempre, cavolo, sabri devi andare avanti, devi farcela, fallo oggi che magari domani non sai come stai. Ecco ultimamente tendo a farmi questo tipo di discorsi [inudibile].

I: per finire, in, se le facessi un'altra domanda difficile probabilmente {proviamo} in generale, eh: che cos'è il dolore?

Sandra: che cos'è il dolore? Il dolore fisico? O il dolore e, emozionale? {beh quello che per lei, la prima cosa che pensa?} quello, quello di più? Quello a cui penso maggiormente è il dolore, eh proprio: emozionale, quello mi pesa di più. Riuscire ad affrontare, ecco con più serenità forse riuscirei ad affrontare molto di più anche il dolore fisico. Benché fin, le posso assicurare che fino a quando non sono proprio bloccata io vado avanti, vado a lavorare, spolvero [inudibile] quando non ce la faccio più è perché sono arrivata, proprio al crollo. Così mi è capitato fino adesso.

I: cioè che cosa fa?

Sandra: io: sono impiegata in un'azienda sono in ufficio spedizioni però, da un anno a questa parte, prima ho sempre fatto archivio, fisicamente archivio, per cui forse è anche per quello che, principalmente mi ha preso le mani, diciamo, quando ho avuto l'ultima ricaduta, perché: negli ultimi sette anni ho usato molto le mani e ho: sollevato dei pesi, facendo ecco questo tipo di lavoro {di lavoro} sì.

I: ma lavora ancora a tempo pieno adesso?

Sandra: no: no no, io: ho chiesto inizialmente, son dieci anni che lavoro inizialmente ho chiesto un part-time a sei ore, perché non avendo mai lavorato, non ero in grado di stabilire se, ce la facevo a lavorare otto ore, quando mi son sposata, era praticamente più mia mamma che mi faceva i mestieri, che io che lavoravo in casa, perché quando arrivavo alle 4 a casa, io non ce la facevo più ero stanchissima non c'avevo voglia di fare niente. Non perché ero svogliata <ride> ero stanca. Allora ho chiesto una riduzione d'orario adesso faccio un part-time a 4 ore, in modo da gestirmi nell'arco del pomeriggio, le faccende di casa. Ecco allora riesco: a gestirmi abbastanza da sola. Non che non vengo aiutata e, perché in alcune cose devono comunque aiutarmi {però riesce a fare:} sì, riesco a svolgere le mie attività da sola tranquillamente.

I: va bene la ringrazio: la ringrazio molto. C'è qualcosa che vuole aggiungere: che ...

Sandra: non saprei.

I: ok.

Sandra: se può bastare:?

I: va benissimo, grazie mille.

6 Veronica

- Interviewer: niente, può magari parlarmi un po' della sua esperienza signora, quando: {della mia, malattia?} si, quando è iniziata, com'è:
- Veronica: dunque, io avevo 17 anni, facevo, atletica leggera a livello agonistico, e: fondo, 800 metri, campestri: ho cominciato ad accusare questi dolori, e morale, per farla in breve, invece di finire a fare le gare sono finita <RIDE> al [nome ospedale].
- I: <RIDE> un'altra gara.
- V: un'altra gara, che è durata tutta una vita.
- I: e questi dolori dove li accusava inizialmente, dove sono iniziati?
- V: nelle mani e soprattutto nei piedi, tanto è vero che il mio allenatore mi diceva che io facevo apposta ad accusare i dolori per non, sforzarmi, perché lui aveva l'idea, eh: di farmi fare, allora le donne non lo facevano il fondo, quindi oltre l'allenamento normale per le gare, mi faceva fare anche allenamento per il fondo, ed è stato proprio lì, nell'articolazione del piede, in modo diverso, che ho cominciato ad accusare, questi dolori, e da allora li ho sempre avuti.
- I: ai piedi, inizialmente.
- V: ai piedi e, le mani ma le mani: non erano, però i piedi non era sempre erano proprio dolori, che si facevano sentire soprattutto alla fine dell'allenamento, però, ho sofferto questi dolori per, dunque 17 25 anni, la bellezza di: o quasi: otto anni, senza: che nessuno mi riconoscesse la mia malattia, perché la mia malattia era sieronegativa, quindi dagli esami del sangue, no si ide, evidenziava niente, io avevo, un tono muscolare, forte, perché facevo atletica, nessuna tumefazione nessun segno particolare, per cui un medico addirittura m'ha detto che era una malattia psicosomatica e che dovevo andare a curarmi da un'altra parte. Poi, però, appunto ho cominciato ad avere tumefazioni, e: nel frattempo il mio medico: allora era di famiglia non era di base, ha: voluto che io venissi qua dal professor B., che adesso non c'è più, era il primario di: reumatologia, e mi ha diagnosticato l'artrite reumatoide. M'ha fatto un bel grafico dove mi, mi spiegava che, la mia vita sarebbe sempre stata accompagnata da questa malattia, che avrei avuto degli alti e dei bassi, dei momenti mhm: di fase acuta momenti in cui sarei stata bene, però ogni volta sia la fase acuta che la fase in cui sarei stata bene, sarebbe stata sempre meno bene, della volta precedente, la fase buona, e più forte la fase: depressiva.
- I: e scusi, quanti anni fa diceva che è iniziato il problema:
- V: e quarant'annif: quarant'uno quest'anno ne faccio cinq, compio cinquantotto anni ad agosto, e avevo diciannove, adesso, 17 anni li avevo, ecco.
- I: e dopo quanti anni è arrivata la diagnosi:
- V: a 25 anni, dopo circa: 8, sette otto : sette anni e mezzo otto otto anni.
- I: lì è stato quando lei ha saputo per certo di soffrire {che avevo l'artrite reumatoide, si} di artrite reumatoide. Senta, inizialmente, questi dolori che lei sentiva: beh prima ai

piedi, poi mi diceva: alle mani, che che, se dovesse descriverli, che tipo di dolori erano?

- V: è passato tanto di quel tempo, ... dunque allora: era un dolore, aspetti mi faccia pensare, la mano ricordo che un pomeriggio era un dolore acuto fisso, eh: che ... come: è apparso se n'è andato, ma è durato tutto un pomeriggio, a ecco vede pensando me n'è venuto uno anche all'inguine, anche quello, erano tutti dolori acuti ma fissi, non era che si alternavano, un attimo erano più o meno forti, eran sempre fissi mentre quelli dei piedi erano dolori, a camminare, non era proprio dolore, eh: presente: come per esempio mi si è presentato nella mano che lo sentivo anche a tenere la mano a riposo, quello dei piedi regolarmente io li sentivo, alla fine dell'allenamento, ed erano, quasi, dolori, un bruciore un: eh ricordo che il mio allenatore stavamo facendo la staffetta, aveva in mano il testimone, per prendermi in giro, non penso che l'abbia fatto per cattiveria, mi ha preso, ha preso il testimone e m:mi ha colpito sotto un piede dove mi faceva male, è stato un dolore atroce, acuto fortissimo, allora, lì lui ha smesso di prendermi in giro perché devo, probabilmente, trasfigurata, perché, stato un dolore fortissimo, però: vabè.
- I: però ancora non c'erano segni, cioè che si vedessero, non c'erano ...
- V: no, tra l'altro io avevo un paio di mani molto articolate, tant'è vero che molti mi dicevano, hai le mani di un pianista.
- I: <RIDE> glielo stavo dicendo, sì.
- V: infatti, per cui, eh: mi dicevano muova le mani: e io muovevo, facevo tutto quello che loro mi chiede, dice no qui non c'è un'artrite, e, gliel'ho detto, le gambe erano un pa, un bel paio di gambe con tono muscolare molto presente perché, facendo fondo, io correvo tutti i giorni, facevo chilometri su chilometri, per cui: mhm: poteva anche dar adito al fatto che, fosse una, <RIDE> un discorso psicosomatico, e invece no poi era ...
- I: e poi, com'è cambiato invece, la situazione?
- V: bah, allora: {dopo la diagnosi: e andando avanti con il tempo?} co:, andando avanti con il tempo, io ho sempre avuto una forma lenta ma aggressiva, nel senso che, ho, non ho memoria, però potrei anche averli subito di me, perché io cancello, cioè se io adesso sto soffrendo, fra un quarto d'ora, se no soffro più dimentico: il dolore, è una mia forma di difesa, eh: penso, di non aver mai avuto, dolori come molti dicono di avere che, non si riesce a sopportare, io ho i dolori, e per esempio adesso mi fanno male le mani: però, ho: sono dolori sopportabili raramente ho avuto dolori così forti, da non: da non avere neanche la capacità di comunicare con gli altri e aver bisogno d'isolarmi, perché io quando ho avuto queste crisi, regolarmente io mi isolo, ho bisogno di chiudermi in me stessa, e: e recuperare, le mie forze le mie energie, dopodiché mi passa e: alle volte m'addormento anche sul dolore, perché: mi concentra, sì se non è un dolore: veramente forte, ma se è un dolore tipico della mia malattia, ch'è lì fermo: o: io mi concentro sul punto in cui mi fa male, eh l'arto, e: dopodiché se sono isolata tranquilla con me stessa, riesco anche a addormentarmi sul dolore.
- I: questa è una cosa, una tecnica che ha sviluppato da sola: o {si} qualche cosa che.
- V: no no no no, ho fatto tutto da sola {ho capito} pian pianino me la sono: non so se, neanche autoimposta, mi è venuto spontaneo comportarmi in questo modo.

- I: quindi, questo, questo suo isolarsi è per, far fronte meglio a quello.
- V: a isolare il dolore e superare per prima, m: molto prima la crisi, perché, anche con gli interventi che ho subito, sono 18 a questo, io mi sono resa conto che se io sto buona tranquilla, non comunico con gli altri ma mi concentro, il dolore è meno: intenso, se invece devo parlare perché: anche magari ho bisogno di qualcosa, e dopo il dolore: diventa più forte, tempo di riprendere a controllarlo però, ci sono quei momenti che il dolore è decisamente più forte.
- I: spero <RIDE> che non si senta male {no non no, sono dolori controllabilissimi perché, è la ma, quando sale un po' mi fa male ma, no no stia tranquillo, no <RIDE> le direi di no}.
- I: senta, e adesso, perché si trova in ospedale?
- V: perché ho: subito un intervento, [ho] la protesi al ginocchio, la seconda gamba perché l'altra l'ho già: me l'hanno già impiantata due anni fa, e adesso ...
- I: e la protesi per: per ridare funzionalità al ginocchio?
- V: esatto, perché avevo il ginocchio valgo, ma parecchio valgo, e: quindi {valgo vuol dire quando vengono:?) quando va in fuori {sporgono, ok, sì} quando è, quando, io avevo in pratica, l: la coscia che, rientrava, e dal ginocchio al piede, valgo, usciva verso: l'esterno, ed era: oramai facevo fatica a camminare, e camminavo anche curva.
- I: e quello le faceva male?
- V: allora mi ha fatto male, fino a quando non: non si è, completamente deformato dopodiché, mi faceva male, è diventato un dolore meccanico nel senso che, se io stavo tranquilla non facevo nessuno sforzo, il ginocchio non lo sentivo, e di, posso anche dire che potevo anche, vivere normalmente in casa, però solamente volevo uscire a fare quattro passi, poi io ero sicura che il giorno dopo mi avrebbe fatto male però, è un dolore meccanico, non è un dolore dovuto alla malattia, cioè oramai le parti sono, rovinate sfregando infiammandole: e il giorno dopo ...
- I: e che: e che che dolore le dava questo: era cosa, non so, come un brucio:re come era: che tipo di dolore:
- V: e, e allora se si gonfia, allora è: più che altro appunto una sensazione di caldo di bruciore: un dolore: e, caldo, che brucia, se invece ma raramente perché di solito io con le ginocchia i problemi li ho avuti con questo liquido che mi si formava, il panno sinoviale che fuoriusciva e : quindi mi si formava tutto questo liquido, se non era: proprio, un dolore: m: nel movimento, in pratica se io mi stavo se stavo ferma seduta non avevo niente nel momento in cui articolavo la gamba, avevo, il dolore da sfregamento, ma non m: mai dolori così: insopportabili, raramente li ho avuti.
- I: e quindi la progressione quale è stata una volta, cioè dopo la diagnosi?
- V: allora, io ho, dunque ... devo tornare indietro, di quarant'anni<RIDE>, m: no [nomi dei figli] li avevo già avuti, per fortuna perché poi mi avevano detto che era meglio non fare figli, e la diano, dunque ho avuto, per esempio, eh: quando mi si sono, bloccati i polsi, dei dolori continui fissi e poi alla fine: i polsi: le tutte le ossa che ci sono, nel metacarpo si sono, quasi consolidate per cui vede, il mio movimento è: questo qua. E' una costanza il dolore, nel senso che più o meno intenso o: c'è, ce l'ho sempre avuto, infatti gliel'ho detto è progressiva, lenta però: per cui, eh: non è mai

stato, quel dolore che mi impediva comunque di, vivere, di: uscire di andare a scuola, però nello stesso tempo io ce l'avevo, con me è stato sempre un mio compagno ecco, <RIDE> di 40 anni, l'anno scorso io ho compiuto 57 anni, l'artrite ne ha compiuti 40 gli ho detto, dai fammi il favore, fammi diventare più giovane tu tieniti i 57 anni, <RIDE> s'è tenuta i suoi 40 anni.

I: e: adesso, in questo momento, sta: ha, sta soffrendo, ha del dolore adesso mentre noi parliamo?

V: sì, adesso io, ma è un bruciore, non è un dolore, ce l'ho sul ginocchi dove m'hanno operata, ce l'ho in salita, quando arriva alla massima, piegatura del ginocchio allora ce l'ho, ecco io però ho un fatto per esempio se, capita di avere un dolore a un piede a una mano, a una spalla, ho avuto dolori forti alle, più che forti costanti, alla cervicale tanto è vero che ho avuto la lussazione per esempio dell'... quindi m'hanno dovuto operare, e: io accumulo i dolori, quindi eh: quello che sento è: il più forte, gli altri non mi rendo neanche conto di averli, mi rendo ecco vede adesso ho fatto questo movimento, il il gomito mi fa male mi ha fatto male ma è un dolore meccanico, perché, anche il gomito vede è valgo, e l'ho sentito altrimenti: non: non mi sarei accorta di avere il dolore al, cioè nell'usare le articolazioni se un' articolazione è dolorante, se se non la sento perché ce n'è un altro più forte, nel movimento in cui mi muovo m'accorgo che anche quella articolazione: mi fa male, è un discorso di accumulazione di dolori.

I: e: visto che lei ha convissuto così a lungo con il, eh: con questo tipo di dolori, ah: quando le capita, non so un dolore non legato alla malattia, non so prende dentro, contro uno spigolo: una scottatura col ferro da stiro, qualsiasi cosa, li vive? In modo diverso?

V: no, è sempre dolore, è sempre dolore quindi: innesco innesco subito il meccanismo di difesa, eh:

I: che è quello dell'isolamento, che mi diceva prima?

V: o dell'isolamento o di concentrazione e: sì con l'isolamento l'ho fatto raramente nei momenti in cui proprio stavo male, però io riesco a concentrarmi e, a: non dico isolarlo perché il dolore c'è e lo sento, però, se per esempio quando sono qua seduta faccio un esempio, e mi fa male il ginocchio, solamente accendere la televisione e guardare qualcosa, io riesco a distogliere la mente dal dolore, c'è, lo sento, ma ne, non è più il dolore insopportabile com'era un attimo prima, ho bisogno di fare qualcosa per: dimenticarlo, comunque il meccanismo di difesa dal dolore è: qualsiasi sia la: la fonte è sempre quello, penso che oramai si sia innescato in me: questo, questo meccanismo, questa difesa, credo.

I: va bene, signora la ringrazio molto.

V: niente.

I: c'è qualcosa che vuole dire che magari, ci tiene a fare, a: dire o qualcosa?

V: no, perché, ecco c'è una cosa importante e appunto che però gliel'ho già detto il discorso della memoria, nel senso che, è probabilmente una difesa anche quella, ah: che però non mi aiuta nei colloqui con i medici perché, come si sente, se io in quel momento [interruzione] se io in quel momento non ho, dolori, e magari sono stata male al punto di chiamare al medico e dire ho bisogno di un controllo, <RIDE> in quel momento mi viene spontaneo dire bene perché, ho cancellato tutto ciò che {è

passato} esatto, è passato e quindi è da mettere {ok} da parte. La ringrazio,
arrivederla

I: la ringrazio signora, la ringrazio molto.

V: ci mancherebbe.

7 Fabio

- Interviewer: che tipo di problema hai avuto?
- Fabio: allora, il mio problema è protusione discale. Eh, che potrebbe essere paragonata a, tipo ernia al disco, insomma.
- I: questo quando è che è avvenuto [inudibile].
- F: questo è avvenuto, allora l'intervento è stato fatto a dicembre del 2002. Primi di dicembre del 2002.
- I: ok.
- F: e questo problema, si è avvertito circa un anno prima, ha cominciato ad avvertirsi.
- I: e, come si era presentato?
- F: allora, premetto che, questo tipo di disturbo, mhm, prima dell'intervento si era presentato già anni prima. Circa un sette otto anni prima, che miracolosamente era scomparso come era venuto. E' durato alcuni mesi, anzi no, direi, forse un anno, con cui ho convissuto, in maniera non tranquilla. Però, siccome quello era un periodo abbastanza particolare della mia vita per cui non, ho sopportato, tra virgolette, il dolore. E poi, miracolosamente è scomparso. Miracolosamente e fortunatamente. Dopo anni, probabilmente a causa di un cambiamento, di lavoro, di tipologia di reparto, quindi con carichi di lavoro diversi, il dolore si è ripresentato. Com'era scomparso si è ripresentato. Inizialmente come un fastidio, quindi un fastidio, un qualcosa, eh, tipo la gocciolina che scende nel lavandino.
- I: mh mh.
- F: una cosa, così, che avvertivi, in maniera, continua, fastidiosa, ma che non, non, quando dico fastidiosa intendo, che non mi permetteva, eh, di, di, fare dei movimenti, fino a quel punto normali, ma diciamo, mi, mi causava degli handicap. Dopodiché pian piano, oltre al fastidio è cominciato a insidiarsi anche, dolore.
- I: di che tipo?
- F: dolore, del tipo, eh, come, inizialmente come dei crampi, in maniera lievi. Dopodiché, eh, l'intensità era molto più elevata. Questi, questi fortissimo crampi, eh, quindi proprio come, uno stramento, mh, scioccante dei muscoli. Quindi come se qualcuno ti, ti tirasse, eh, quindi assumeva come, mh, delle, non proprio fitte perché non c'era un culmine del dolore, ma come, un bruciore, come, come, eh, come spilli, da dentro che, che pungevano insomma.
- I: e che cos'è che te lo faceva, mh, che te lo fa descrivere, cioè, che che che cos'era l'elemento determinante per cui prima era fastidio e poi lo descrivi come dolore?
- F: che prima, eh, ecco, mh, il fastidio diciamo riuscivi a, eh, a compensarlo nelle attività che facevi. Quindi se t'impegnavi, eh, ti concentravi su altre cose, eh, diciamo che lo accantonavi. Non è che non non c'era più, però veniva accantonato, no? Mentre col dolore, eh, sì, riuscivi ad accantonarlo, però, cioè appena avevi uno sprazzo di

lucidità, lo percepivi, cioè sapevi che era lì, cioè che c'era lì. Ma perché comunque, eh, nei movimenti più semplici, oltre a essere bloccato sì, il dolore, eh, si presentava. Cioè, lo tenevi sotto controllo, però nei movimenti un po' particolari tipo, quindi non so, da seduto alzarmi di scatto oppure, piegarmi, oppure, eh, diciamo fare la fisioterapia ad un'altra paziente, o a un paziente che avevamo in reparto, eh, ti causava dei movimenti impropri, quindi il dolore, riaffioriva. Non è che si presentava in maniera più acuta, però riaffioriva, lo percepivi di più. Perché i movimenti, eh, ti permettevano di di di accusarlo in maniera, in maniera, più lucida ecco [inudibile].

- I: quindi tra il fastidio e il dolore c'era una differenza di, del grado d'interferenza nelle attività quotidiane, era questo che ti fa, è questo il [inudibile.] determinante per cui una cosa era fastidio e un'altra dolore?
- F: eh, sì nei mo, mh, . diciamo che era più una cosa psicologica. Nel senso che il fastidio, lo riesci ad accantonare di più. Nel senso, lo percepisci ma lo lo lo, diciamo, lo sopporti. Mentre il dolore, eh, però ripeto, la, la mia, mi considero un elemento con una soglia del dolore molto elevato. Quindi, eh, a me fa più effetto, diciamo, sempre tra virgolette, la la la, il concentrarmi su cose diverse che degli antidolorifici. Infatti ho preso antidolorifici, tantissimi, e non mi hanno mai dato sollievo. Cioè non ho mai, eh, ricevuto beneficio dagli antidolorifici. Ho fatto una cura, di diverso, cioè per diverso tempo, proprio prescritta dal medico, quindi con antidolorifici, eh, cortisone, e altre cose, ma non ha, non mi ha dato nessun beneficio. Assolutamente zero, nel senso che il dolore era là e c'era e rimaneva insomma.
- I: ma se tu dovessi, avessi dovuto descrivere la, il tipo di sensazione che provavi in quella fase che tu descrivi come di fastidio, era uguale o simile a quella di dolore solamente meno intensa, o era diverso? Tu [inudibile.] hai parlato, non so di stiramento di muscoli, bruciore.
- F: allora, per fastidio, allora tu, allora per fastidio è un qualcosa che c'è che ti ostacola, quindi ti blocca, eh, ti impedisce di di fare, ah, alcune cose. E questo fastidio, mh, poteva essere che ne so, paragonato: a un qualcosa di comune: potrebbe essere: un mal di testa, con intensità bassa insomma. Un qualcosa che c'è, che rimane, che è fastidioso, così che però sopporti.
- I: ma quindi era ancora ...
- F: mentre quando il fastidio diventa dolore.
- I: mh, mh.
- F: cioè io per dolore intendo proprio questa intensità, cioè questi crampi, con questi bruciori forti ai muscoli.
- I: ma nella fase di di fastidio, quello che voglio dire, c'erano ancora questi bruciori questi crampi però, non così intensi o era una cosa completamente diversa?
- F: No c'erano ma non intensi.
- I: ho capito, quindi era [inudibile].
- F: cioè un fastidio è, eh, allora diciamo, inizialmente era un fastidio, quindi non ti dava un dolore. Cioè era una cosa che percepivi che, che cominciava a insidiarsi nel nel tuo fisico. Dopodiché questo fastidio si è associato anche al dolore.
- I: mh mh.

- F: dopodiché è diventato, eh, dolore, dolore che comunque manteneva sempre il fastidio, il fastidio perché, eh, io parlo poi anche di un fastidio più psicologico, più che fisico.
- I: mh mh.
- F: nel senso che, eh, m'innervosi, cioè, oltre al dolore poi quando è diventato, è sfociato proprio al limite, al culmine ...
- I: mh mh.
- F: creava anche un, un, almeno personalmente una cosa più, più di stress mentale.
- I: mh mh.
- F: cioè mi, mi, mi dava, mi causava più, eh, problema il, lo stress, che, che poi in realtà il dolore stesso.
- I: mh mh.
- F: anche perché il dolore non era descritto come, in alcuni momenti come un picco molto alto poi si abbassava poi si alzava. Era una cosa costante, cioè un dolore costante.
- I: mh mh.
- F: un dolore con la stessa intensità, lo stesso grado di di di di, affermazione.
- I: che però c'era sempre.
- F: che c'era sempre. Quindi non, non, non era sufficiente il fatto, uno dice "vado a letto, mi riposo, e", no. Cioè c'era, eh, nel momento in cui mi addormentavo, c'era questo dolore, mi svegliavo e si ripresentava. Quindi anche le notti, diventavano, cioè brutte, eh, ripeto, era più una cosa snervante, stressante che, che poi il dolore, che il dolore stesso insomma.
- I: era, quello, cioè l'effetto che il dolore aveva sulla tua vita, sulla tua attività in generale?
- F: esatto, sulla mia attività, sì perché essendo una persona, io, parlo chiaramente personalmente, essendo una persona, eh, attiva, questo mi ostacolava.
- I: mh mh.
- F: e quindi aveva un effetto psicologico molto negativo.
- I: mh mh.
- F: quindi debilitante, quindi se devo quantificare, eh, tra eh, la sopportazione psicologica e, eh, fisica, diciamo che era molto più sopportabile per me il dolore fisico, cosa che invece lo stress che questo mi causava non, eh, mi dava più problemi.
- I: Mh mh.
- F: cioè era più insopportabile lo stress che poi in realtà il dolore. Anche se il dolore, quindi mi sono reso conto che la mia sopportazione del dolore era più elevata, cioè avrei potuto più sopportare il dolore più che lo stress che questo mi, mi comportava.
- I: e dopo l'operazione come è cambiata la situazione?

- F: dopo l'operazione, eh, diciamo che, eh, l'operazione era diventata ormai una, una speranza, finalmente a riprendere in maniera completa la la mia attività, quello che faccio. Ma invece non è stato così perché proprio a causa del fatto che io sono molto attivo i giorni di convalescenza che ci sono stati dopo l' l'intervento, che per altro l'intervento non è un intervento invasivo che quindi ti, ti scombussola, cioè ti lascia delle cicatrici. Perché è una cosa fatta in laparoscopia, quindi è una cosa, poco invasiva. Eh, non ho seguito le indicazioni mediche come avrei dovuto, quindi ho ripreso le mie attività, eh, prima del del tempo e quindi, eh, diciamo che il risultato è stato, pressoché negativo, diciamo, metà e metà insomma. Nel senso che tuttora,eh, mentre prima era una cosa costante adesso, eh, ad intervalli si ripresenta il dolore, eh, ma in maniera repentina. Cioè non è che inizia piano piano, cioè che si insidia, che tu lo senti, cioè si presenta punto e basta.
- I: a livello d'intensità e lo stesso di quello che provavi prima dell'operazione, o è diverso?
- F: Eh, no, è ...
- I: cioè se dovessi descrivere questo tipo di dolore a qualcuno che non ne ha mai sentito parlare prima, come lo descriveresti?
- F: allora, diciamo che adesso come intensità di dolore no, è più basso, se parliamo d'intensità ...
- I: e come tipo?
- F: da un, diciamo che da uno a dieci, se allora prima il dolore, prima dell'intervento, era: diciamo a nove.
- I: mh mh
- F: adesso come dolore, è quattro, come fastidio è nove. Nel senso, eh, cioè io poi per fastidio intendo un qualcosa, mh:, che c'è, e che, eh, come se uno ti continuasse a dare, ecco, cerchiamo di paragonarlo in questo modo, come se qualcuno ti desso dei piccoli pizzicotti, eh, sempre nello stesso punto, no? Cioè sul, sul petto per esempio, questi pizzicottino che non sono dolorosi, però sono fastidiosi. Cioè che, uno continua a darti questi pizzicotti, pic pic pic, cioè a un certo punto: cioè lo consideri veramente come un fastidio, un ...
- I: che comunque in qualche modo però riesce a: interferire con le tue attività quotidiane.
- F: chiaro chiaro chiaro, sì. Sì perché ripeto, ancora, essendo una persona che fa mille cose, eh, cioè questo mi ostacolava. Nel senso, a parte il mio lavoro, e quindi quando lavoro cerco di fare al meglio le cose e quindi già questo mi ostacolava, eh ...
- I: e ti ostacola ancora?
- F: e mi ostacola ancora. D'inverno presepio, eh, faccio attività sportiva, quindi scio, e questo chiaramente, eh, dicevi, tanto che io scio che io non scio il dolore c'è sempre, per cui preferisco sciare.
- I: mhm mhm.
- F: in questo senso. Però chiaramente, scii ma non sei tranquillo e sereno e godi della tua discesa, eh, in maniera fantastica, in maniera esuberante. Io poi ho un'attività che mi dura tutto l'anno, di fitness, palestra, quindi questo, eh, mi mi

causa, come: Ecco no, devo dire, che il beneficio di sollievo, è in un luogo di mancanza di gravità, quindi nuotando.

- I: mh mh.
- F: nuotando, eh, non accuso niente. Solo che l'attività di nuoto mi piace e: non mi piace, nel senso che la reputo noiosa. Quindi nuoto sì, per un po' di tempo ma dopodiché, eh, basta. Cioè non ...
- F: senti prima ti avevo chiesto di, mh, creare un'immagine, cioè di dar, se dovessi figurare un po' questo tip, il dolore che tu hai sperimentato di: con un'immagine, e, Me la vuoi, ripetere?
- F: allora, l'immagine è, un operaio, su una strada, questi cantieri stradali, dove quest'operaio, usa un martello pneumatico. Ecco, io:
- I: e tu cosa sei, la strada?
- F: eh, ma no, proprio ...
- I: tu sei la persona che è vicino e sente questo rumore forte?
- F: sì, più che la strada io sono: colui che sente questo rumore assordante, continuo, eh, che ti crea tutti quei problemi di conseguenza, cioè ...
- I: mh mh.
- F: quindi, un qualcosa, che quantifichi come una, un livello massimo no? Perché comunque questo martello, questo rumore che comunque, eh, sempre lì così, e che continua continua: cioè lo vedo, lo vedo, l'ho visto così il dolore, in in quel senso, più che qualcosa di molto catastrofico.
- I: mh mh.
- F: cose di questo genere.
- I: quindi, dolo, l'immagine di dolore come rumore? In un certo senso? [inudibile]
- F: come rumore, come movimento, cioè vedere comunque quest'operaio che con questo martello, gli gli vibra tutto, cioè quindi ...
- I: e ti ti distrae, t'impedisce ...
- F: esatto.
- I: entra nella tua vita.
- F: esatto, ti impedisce di continuarla e che tu crei questa forza, per mantenere questo, questo trapano, cioè quindi devi devi assumere una forza maggiore per sopportare questa, questa resistenza di questo trapano che se tu lo lasciassi andare.
- I: mh mh
- F: quindi: anche questo senso, questo gioco d di di di: ecco, era diventata una una lotta tra me e il dolore, no?
- I: mhm mhm.

F: cioè, vediamo chi è che resiste di più e chi ...

I: mh mhm.

F: quindi è, questo che mi logorava la la la la vita quotidiana, che ora diventata ormai una guerra no? Nel senso di, comunque di rifiutare questa cosa, di volerla rifiutare forse perché poi, metti il fatto che, ti rendi conto che stai andando avanti con l'età e quindi non accetti, certe cose, che poi voglio dire, il dolore si può presentare anche in un ragazzo di vent'anni, se fa un incidente si spacca una gamba:

I: e adesso cos'è, una radio troppo alta?

F: adesso: no diciamo che, eh, quando quando c'è questa cosa questo dolore riaffiora diciamo quello che era poi lo lo stress, no?

I: mhm mh.

F: quindi la la, eh, qui subentra una cosa ancora più psicologica, cioè la la paura di di di di rivivere lo stress come lo vivevi prima.

I: mhm mhm.

F: cioè di essere bloccato nei movimenti di non di non essere più agile: per dire una cavolata soltanto a salire in macchina.

I: quindi un po', più più che effettivamente quello che ti sta capitando è l, quello che è possibile un po' il ricordo che ti si proietta davanti [paura di riviverlo].

F: esatto, esatto. Più che il dolore che mi si presenta. Perché quando sono per strada ad esempio che sto camminando, o che ne so che sto facendo una passeggiata: in maniera tranquilla, all'improvviso ti si blocca la gamba perché hai questa fitta che ti si presenta in maniera ...

I: mhm mhm.

F: a sorpresa.

I: mh mh.

F: allora, oltre al dolore ti viene, l la cosa dici cavolo, perché proprio adesso, cioè ...

I: mh mhm.

F: diventa una cosa, logorante a livello psicologico, più che di di di dolore.

I: mh mh.

F: perché se fosse il dolore punto e basta, uno dice "vabè" ...

I: mh mh.

F: Ce l'hai: un mal di denti voglio dire prendi un analgesico ti passa, per dire, o sai che che vai fai un intervento non so, [inudibile] cioè sai che c'è una fine.

I: mh mh.

F: a un dolore di denti, mente in questo caso no. Perché comunque le protusioni discali, tutto quello che riguarda la la la colonna vertebrale sono cose che che ti rimangono insomma

I: Mh mhm.

F: cioè, in questo senso.

I: grazie.

1.b Anna

- Interviewer: [inaudible] ok, well, it's going to be a rather informal chat, so there are no right or wrong answers, erm, I'd like to start by asking you to tell me a bit, generally, about your experience, when you began having problems, how ... erm ... how did you realise, just feel free to say anything you like.
- Anna: so ... not specifically on pain, on the ...?
- I: to begin with, well how it all began, how this experience began and then {on the types of pain?} yes then [inaudible] then [inaudible] so, when did you start having problems?
- A: and ... yes ... the illness ... clearly because ... even before but ... maybe it's not not to do with the illness clearly ... almost immediately the pain [inaudible] strong, and ... by and by it grows and, at least in my case, then it becomes lancinating, so much so that, there have been moments, before, erm, and even during the therapy, that ... erm ... it would become so ... intense, that only the thought that this pain might return, after a few minutes, a few hours, erm, I would think I really couldn't go on living like that, I would tell my husband "look here, I can't take it anymore, I feel like jumping off the window, it's not possible" ... the heart ... would beat ... fast, so much so ... I'd pass out, and this lasted, for quite a long period of time ... almost three years, and then ... finally ... some therapies let's say they helped, and these periods were not as frequent, and when this pain would come it was still very strong, but, it would last less, erm, in terms of days let's say, it would become fortnightly it would ... erm ... by and by.
- I: I see, it would come every fifteen days or would it last fifteen days?
- A: no, no, it would appear every fifteen days, had it lasted fifteen days it would have meant ... well ... I would have ended it because it wasn't possible, it really was, a ... when, when it was approaching ... every couple of weeks, this period of two weeks, once a month it happened, once every two, at the beginning, it would come on, would be more frequent, and, well it was bad ... even the drugs ... in spite of taking lots of drugs, often, it was ... really strong, strong and ... well, strong.
- I: where would you get these pains?
- A: ok, I began with my hands.
- I: your hands.
- A: It would start ... from here [points].
- I: from ... from the wrist?
- A: yes, or from here [points].
- I: okay.
- A: it would get inflamed slightly it would affect the tendons, up to her [points].
- I: to the armpit ...
- A: yes, yes yes, and, and then normally, it would get me here [points] ... on the back.
- I: the back.

A: and it felt it was something ... serious precisely because ... the doctors still were unable ... at the beginning, and this lasted, always, in spite of the medication, it went on ...

I: and how many years ago did this all begin?

A: erm ... twenty ... twenty-six years ago, twenty-five years.

I: twenty-five.

A: and then ... then ... little by little ... well, something would get better, but the disease was making damages.

I: mhm.

A: in the meantime, once this [points to finger] would get bent, once that one. I had ten operations on my hands ...

I: the hands, ten operations, ten operations on your hands?

A: ten operations yes, to clean the tendons, and ... and a prosthesis because there was ... a hole ... and ... then the disease began ... later with the therapies ... with heavier therapies let's say that with those therapies on the market yes ... do you want ... do you want to know the names of the drugs? No?

I: if you remember ...

A: oh well, I went from the immunosuppressants, we got to the immunosuppressants, anti-inflammatories based on cortisone ... with the anti-inflammatories it was a relief, finally, and so without the pain, well then only the pain of the disaster was left, that the disease had caused {caused by the illness?}.

I: a pain ... a psychological pain?

A: but, it wasn't, a much milder pain, maybe to ...

I: so we're talking of a physical pain ... a physical one?

A: and ... yes, but ...

I: after this acute phase?

A: yes, yes for sure, yes, it's a bearable pain, and now let's say we're kind of used to it ...

I: yes.

A: and so ... because when I get it ... strong ... but now after the therapy ... it took about ... four months, seven years ago, when I began with this ... and so now ... let's say I'm repairing ... simply repairing the damage, but I still get the pains, for example now my foot need surgery.

I: pains in your foot, is that what you have now?

A: [inaudible] one foot was already operated upon five years ago, then the wrist ...

I: the wrist ...

A: well, let's say these are all part of ...

I: and those in your feet, what are they like?

A: well, those in my foot ... are ... quite ... quite bad too because ... they are like, like ... erm ... think of when the blacksmith ... hits the hot iron.

I: yes.

A: and it throws off sparks.

I: yes.

A: that's it, there are all these painful sparks {Marta: there you go, she's better than me at describing} in various places on the foot, also because ... clearly the foot bears the whole weight of the person.

I: sure.

A: obviously, because there you feel from ... in the toes ... under the toes, you feel them ... at the sides, above the metatarsus, erm, in the heel, and ... even the one that was operated, this one [points] is the one that need operating, but also ...

I: and that's because one foot has already been operated?

A: yes yes.

I: mhm mhm.

A: yes, I can walk ok though, but ... because the operation was done, but because I didn't have a protruding toe, they ... they weren't able to operate ...

I: yes.

A: up to the toe, because the toe had nothing wrong with it.

I: a protruding toe ... meaning it pushes out on one side?

A: yes yes, and it's not only people with RA who get it, in many people it's hereditary ...

I: yes, many people.

A: many people even young ones, mine was slightly atypical as ... let's say that my toe was normal, whilst all the four metatarsus bones from the four other toes had moved down, and so they tied the toes but they told me I wouldn't have problems because not having had the operation on the big toe, since it wasn't needed, but that I would have problems later on and indeed all these problems did appears a couple of years ago, when the big toe began to move involuntarily, to the right hand side of the other toes ...

I: yes.

A: and so it felt like pulling on something, that had to be lengthened.

I: mhm mhm.

A: but erm ... the big toe did move somewhat ... so I can't even begin to tell you how painful it was, in the bone of the [inaudible], because, if I, if I place it ...

I: yes.

A: well you see the toe as if it were normal.

I: mhm mhm.

A: but it's a painful toe, and I don't even know what they'll be able to do about it and it gets, terrible pangs really ... luckily they don't last long, yes, so what I can say is that both the operated foot and the other ... that has to be operated, the operated one has the advantage that the metatarsus doesn't hurt, because the bone ... is in a straight line so it doesn't come down.

I: mhm mhm.

A: whilst this one that wasn't operated upon [inaudible] comes back down.

I: yes.

A: it makes holes in my shoes, it hurts me, erm ... even if I place a handkerchief inside, I mean, really ... nothing ... I walk with an insole but, it's still very difficult because the foot still hurts. And then the toes above that become like this ... so, so that's what ...

I: [inaudible] do they bend?

A: yes, oh yes because ...

I: [inaudible].

A: because they hurt, they contract so, so, therefore ... that's how they become. Indeed the two toes of this foot ... they will be sawn/tied⁴² like the ones on this side [points], so that they are lined up.

I: your, your ...

A: the pain is intense, this one too, bearable, let's say.

I: at this time, whilst we're talking, are you in pain?

A: no.

I: no?

A: not now. But there are moments, suddenly, that I can count tens ... tens at once.

I: the ...

A: it's really like a ... sparks <LAUGHS>.

I: like sparks.

A: sure, then like ... the pain becomes like a flash of lightning [tchin- tchin] ... the feet.

I: intense?

A: yes, extremely intense.

I: and how would you say your diagnosis of RA came about?

A: yes, yes.

I: I mean, after how long did you get it?

⁴² The recording is unclear. The word could be 'segate' (sawn off) or 'legate' (tied/bound together).

A: as far as the diagnosis goes, let's say I had it ... because initially I had been followed by an orthopaedist, and ... the orthopaedist hadn't understood what it really was about then when he saw the tests results, that ... the rheuma-test was higher and higher, and he couldn't keep the illness at bay ... let's say it was an orthopaedist who got it right, whilst I was on holiday.

I: mhm mhm.

A: I was on holiday ... in the same building where I was staying, and so ... he saw me ... with my little girl in my arm, she was screaming because she had hurt herself, and he saw my hands like this and he asked me, he goes "*signora* but do you ... do you have RA?" I said "yes", well I said "yes" ... "do you ... do you have RA?" I said "I don't know, I know I have pains". He said "look, there's the [name of hospital] in Milano, and since you live there ...". I didn't even know where it was.

I: yes.

A: because, I mean, when one is well one doesn't ...

I: ... you don't think of it ...

A: you don't think of it, you don't go looking for hospitals and so ... he said to me "look, it's like this. There's Professor B., whom I didn't meet then but he was there". And so I began my ... my *via crucis* with the therapies, with the drugs that were needed. First aspirins, then vitamin injections ... these things ... but nothing ... not really a cure ...

I: how would you say your life has changed because of this illness?

A: for the illness? Yes it changed a lot. In my mood especially, I was ... normally I was a bit of a jester, I was, erm, but, let's say I was busy with many things I did ... with my family but then ... well things changed a lot because now I'm easily angered ... I don't need much ...

I: mhm mhm.

A: even if ...

I: it changed your personality, in other words ...

A: it changed my personality yes, on those days when I'm well I kind of get back to how I was.

I: to be ...

A: but ... I go up and down, it takes little to go up and little to go down.

I: sure.

A: erm ... let's say that ... even if ... even if I have everybody around me but ... erm ... at times I think that they don't understand me but not because they won't understand me, it's because it's difficult erm ... even to keep asking you "how are you", keep looking after you.

I: yes.

A: because that's what I need {yes} and they do it yes, but in the meantime they don't ease {yes} because ... when you have all these ups and downs, these days that ... you go from one doctor to the other {yes} because then RA doesn't just end there {yes}, it causes many other things.

I: other problems?

A: problems and so, you spend entire days at ... in the various hospitals, with the various doctors and ... well, it's never over.

I: do you find ...

A: one learns to live with it.

I: do you find it difficult to communicate about it to your family?

A: no.

I: I mean, to communicate the kind of pain you feel?

A: no I communicate ... I can explain well, in the sense that I try to explain it well, to any doctor, I try to help them understand, just the way it is. For example, back in October I had, one night, a pain her [points].

I: in the sternum? {right here, in the thorax}.

A: in the thorax, right between my breasts, here [points] that began slowly from here [points].

I: from the side? {that gets stronger and stronger}.

A: yes from here, and when it got here [points] ... there was an explosion, as if you saw ... a bomb go off.

I: yes.

A: mhm, an explosion.

I: I see.

A: this is the exact definition of pain that I felt. Luckily it didn't last more than ... I think a minute and a half {yes} but for me it was an eternity. Also because at two in the morning I didn't know what ... I had to call my husband and my daughter, but, erm, either you go straight to A&E ... but they tried to ... this had never happened to me before, and because my grandma, my dad, and my dad's sister who died of a heart attack, I became very worried. I get agitated because of this, and of course as I age ...

I: yes, I experienced chest pain too {the sternum} and it scares you ... maybe it wasn't as strong and maybe ... I remember once I had gastric reflux problems and it gives a very intense pain here [points], in the lower sternum, something I had never experienced. I was on a plane I remember I got very scared because I thought it had to do with the heart, I had no idea it was reflux {reflux coming back up} yes from the stomach {from the stomach} but it's very common for people to become scared {oh yes, I ... I ...} rather than because of a pain in the leg, for example.

A: I repeat, I got ... in the morning around 7.30 because then I got it once or twice again but not as strong, maybe it wouldn't start from here [points] and it would reach here [points].

I: to the breasts, and the armpit ...

A: yes, then under the armpit, and I've also heard lots of people ... my doctor told me many people had it this past winter. But so I had a lot of tests done, last week I finished with the dopler, ecodopler. But in A&E they immediately saw the heart wasn't affected. In spite of this, when I feel even a minor pain I get scared and then I have to ask for help, to my family or whoever is around. Because I pass out ... I really lose it.

I: yes, there is a fear that comes from the pain, from the fear it might be ...

A: yes, now there's really a fear.

I: yes.

A: the fear. The fear of not making it, of getting a heart attack ... something like this, because then, I've had many things, I've had a cancer of the skin ... here [points] and another one here [points].

I: and are they connected to RA? Or to other factors?

A: maybe it's because of stress. I'm very stressed, I stress a lot, I try <LAUGHS> I try to ... how can I put it, I try to complicate things for myself. My husband says, and it's true, I buy things ... and they make me tired. I'm a tad masochistic, in this sense, I make things hard for myself, I should learn to take it easy, but I'm a bit hard headed, it's the way I am.

I: do you think this is influenced by the illness? This way of being?

A: sure. Then now age is another factor, I am sixty-six so ... I mean ... I'm getting older, and family problems. My husband was unwell, and so it's a combination of stresses.

I: sure.

A: I'm already so sensitive, so tense. Like a violin string.

I: were you like this before { yes, oh yes }.

A: I just need to see a puppy that's suffering, and I'm affected.

I: one last thing, when did you begin seeing your body change, because of the illness?

A: almost immediately.

I: how ...

A: do you mean physically?

I: yes physically, the deformity ... is it something that upset you? Quite aside from the pain.

A: not really, because, I must say that thanks to the therapies then, if you believe, also thanks to God, I think you can be lucky, even in illness because ... there's people ... I've seen people in much worse conditions, whilst I can still use my hands for many things.

I: sure.

A: I use them, and some times I abuse of them, to my detriment, but what can I do. I use them, otherwise why did I get them fixed <LAUGHS> but let's say I should use them but with care. But I'm a bit silly in this respect. My family tell me "leave it". but that's what I'm like but I have to say that yes, my hands are damaged but ... I don't know if you've seen other people's hands.

I: I've seen some.

A: but I'm not really bothered if people look at my hands or what. What bothers me is that it's difficult to walk and so I'm hoping that after the operation I'll be able to walk better. I hope to be able to wear a pair of shoes and they won't hurt, because at present shoes are always a problem but ... well so far nobody has made me feel bad

because of this, but then again, there's always somebody who maybe stares at you, but I don't really care.

I: ok, thank you very much, *signora*. Thank you very much. Is there anything you'd like to add?

A: no, I think I've said all I wanted to.

I: thank you then.

A: not at all.

I: thank you.

2.b Annamaria

- Interviewer: Ok, erm, how long ... first of all may I ask what exactly, from a medical point of view, what your pathology is?
- Annamaria: I suffer from Systemic Lupus Erythematosus.
- I: when were you first diagnosed?
- A: I got the diagnosis in 1985, while the first symptoms occurred in 1974, after the birth of my son.
- I: in 1974. What kind of symptoms?
- A: I had many articular [joint] pains, the knees would swell up, the hands too and ... so much so that I couldn't even pick my son up, and so I found looking after him hard, and nothing, the joint pains most of all, they continued for around ten years.
- I: But were they, they weren't continuous, I mean were they continuous or intermittent?
- A: they were, they were, yes yes, continuous, especially the knees, erm, always swollen and the hands, the hands and the knees have always been the sorest parts.
- I: and initially, the doctor ... I mean, you went to see a doctor straight away, to ... when they began, did you see somebody or did they ... what would they say to you?
- A: I went to, I went to an orthopaedist, who gave me cortisone, without conducting any tests. He told me right away that I had RA, and he gave me cortisone, erm, just looking at my fingers, and I ... well, for a month I took this cortisone, but then I realised that without a diagnosis, in spite of me being only twenty-one, I was still young, but I would tell myself "without a diagnosis I'm taking cortisone, and then?" So after a month I stopped taking it.
- I: and the symptoms were ... during the, the therapy with cortisone were you ... were you feeling better?
- A: yes, I was feeling very well, with cortisone I was feeling well, but after a month, when I stopped taking it I began with the pains again. My GP wasn't saying anything ... and my son's paediatrician noticed that I wasn't well because I took [to him] my son and he saw that I had troubles moving, and he ask me what was wrong. I told him, and he advised me to come to [name of the hospital], where there was a rheumatology ward. I came to [name of the hospital], did the initial tests, and the doctor told me that ... in his opinion it could be something but he thought it was only something ... something ... psychosomatic.
- I: so he that ... he thought it was ...
- A: a psychological factor, he told me that for him it was a psychological factor because ... each time I went to see him I had nothing to show to him, because my hands would swell up and down, and the knees the same thing, and each time I came to see him I had nothing to show to him
- I: and was the pain always there or only when the swelling was present?

- A: the pain was there mainly when they were swollen, of course. And so ... well, then he told me ... told me to come back once I had something swollen, without an appointment, and after two days I arrived with a swollen knee, and he says “well, then it’s not a psychological problem otherwise the knee wouldn’t have become swollen, so he analysed the liquid [inaudible] the knee, and ... he told me I had RA. But that it didn’t show in the blood tests. So he gave me no heavy drugs ... only anti-inflammatories ... and told me to carry on. I mean ... he told me “*Signora*, I don’t know what else to say to you, come back when you feel worse”. I was twenty-one, I didn’t like the thing very much ... but that’s how things went because I carried on taking anti-inflammatories as and when, which was often, which means that for three four days a week, even five, I needed to take anti-inflammatories. Then these knees that would swell up and go back to normal again, they would stay swollen for a week at a time ... I had a heavy job, because I was a [textile] weaver and consequently, the continuous walking. But I kept on doing it, in spite of everything, with my swollen knees I would still go to work but ... and anyhow even if I’d stayed at home my life wouldn’t have changed. Nothing, I still managed to work.
- I: so, the diagnosis of this second doctor was basically similar ... or the same as the first one’s?
- A: yes, the first one had said it without ...
- I: without doing any tests.
- A: without doing any tests, just having looked at the hands, which were swollen, whereas the other one analysed the liquid he took from the knee. And nothing, then he told me “*Signora* I don’t know what else to do because the blood tests are always negative. Come back when you’ve got worse”. And I carried on for ten years like that. And then I did indeed get worse in the sense that ... erm ... it’s not ... it’s not something you only say but I’ve actually lived it, that when you’re not well psychologically, in moments of crisis these illnesses take over. And in fact I was going through a moment of crisis ... erm ... I put myself under heavy physical and moral stress and I began experiencing bigger problems. So problems on the skin, the pains had become more intense
- I: on the skin what kind of problems did you have?
- A: I had ... small red spots, just under the skin, that were sore when touched and I didn’t understand what was happening to me because they were symptoms I had never experienced before. And so I went back to be checked, but by another doctor, not by the earlier one because in the meantime an outpatient clinic had been set up here at [name of the hospital]. I am ... they advised me to see the rheumatologist, who is still my rheumatologist, and he gave me a diagnosis, after doing several tests, and he told me I had a disease with a very ugly name but that I shouldn’t get scared, because it wasn’t so tragic, that it could be kept under control ... he told me what the worst phases would be. Unfortunately, well, I only learned that later but anyway it changes nothing, that it’s a disease you can die from.
- I: mhm
- A: because, erm, it mainly affects the organs, not only the joints.
- I [I see]

A: and consequently, if it attacks vital organs, it goes without saying that ... it isn't very easy. And nothing, I managed to live well with ...

I: and this in 1985, the diagnosis ...

A: this in 1985.

I: the certainty.

A: yes.

I: and the fact of having had ... a sure diagnosis ... has it changed anything for you, in your experience of the illness or ... how you reacted ...

A: well, I must say that I didn't ... the thing didn't upset me. I mean, I took it rather well ... I didn't ... I must say that I'm a positive person, I don't ... don't make a drama, ok, I mean, I tried to take it as best I could. I carried on with my life, as if nothing had happened ... I had a problem that had, finally – so to speak – a name but ... this meant starting a heavier therapy.

I: [inaudible]

A: consequently, sure, I had to start taking cortisone, and I'm still taking it, because it's a disease that's kept under control only with cortisone, then, as the years went by other things happened, because then, even though they're not tragic things but, after a while, after starting cortisone I got pleurisy and pericarditis, and this scarred me a lot because I had ... for three months I've had to sleep on deckchair because I couldn't breathe. And when I went back to sleeping in a bed, in any case I've had to sleep, for almost ten years, propped up with three pillows, because I couldn't lie down any longer, because I had pains in my thorax. Because unfortunately, after ... erm ... I began having these pains in the thorax, it wasn't immediately clear I had pleurisy, I then, at the beginning of the illness I was afraid of bothering the doctor, you see? Because I had phoned him to tell him I had these problems.

I: mhm.

A: ... he took x-rays of the chest, and told me "then read me the result on the phone". I did the x-rays, because – as I said – I live outside Milano I did these x-rays ... I had difficulties travelling, because with this shortness of breath ... coming to Milano wasn't easy. And so when I did these x-rays the diagnosis was that they hadn't found anything so when I phoned my doctor, he tells me "well, I feared it might be pleurisy but since it isn't it must be only a pain between the ribs". And this was April. I didn't have another appointment until June.

I: excuse me ... what type of pain was it?

A: I had a very strong pain, when breathing. I had stabbing pains at the thorax, and ... and not only, I felt that the heart was involved too. It didn't beat with the same frequency, you see? So I felt ... I really felt a very strong pain in my thorax, so it's been a really hard time. And, I didn't remember but now that I think of it <LAUGHS> it's been a hard time. And so nothing ... I could only walk slowly, because if I walked even only a bit quicker even at home, erm, I ... I felt these pangs that would make it impossible to breathe. And so ... even my family would say to me "but go to your doctor's in Milano". "No, now I've got my appointment coming up" so ... always the fear of being a nuisance, of appearing to be whingeing, you see?

I: Yes ...

A: and when I finally arrived ... the day of the appointment and I arrived here at the hospital, a step at a time, my doctor got scared because then he ordered an x-ray and saw I had liquid in the lungs, both lungs, and I had pericarditis, so my heart was swollen, the pericardium ...

I: these were ... side-effects of the cortisone therapy ... or were they due ...

A: no, no, they were due to the disease ...

I: the disease.

A: it was the disease that had really ... it had developed and so had begun giving these symptoms.

I: and ... after how long ... three months, the time this crisis lasted, more or less?

A: yes this crisis lasts this much, yes, then ... erm ... he had to immediately increase the cortisone, the dosage, erm, but since he hadn't ... he hadn't known me long as a patient, so he sent me to have my stomach investigated. Because obviously cortisone can ruin the stomach. He tells me "let's see that the stomach is ok first, then I'll increase the dosage". Unfortunately I had an ulcer I didn't know I had so for another month I couldn't increase the prescription ... so things went on ... and this caused me to develop adhesions between the pleura and ... and ... and so my breathing became difficult because of these adhesions, they didn't allow me to expand the chest, to breathe. And this is something that ... well after a month I was able to increase the therapy and the pains ... I'm not saying they stopped because that's not true ... erm ... but I felt much better.

I: still these, these ... when you talk of these pangs ...

A: yes pangs, yes, yes, yes. Yes, which has been the thing that made me suffer the most, because obviously it limited my life also, the fact the fact of having had to sleep sitting up all this time ... because lying down wouldn't allow me to breathe.

I: to breathe

A: it wasn't easy ... also because it led to a consequence, even if we can't be sure, erm, I developed a tumour on my backside [inaudible] by sitting all that time in bed in that position, it must be that the tissues were under constant stress ... erm ...and I began having a cyst, which was removed thinking it was only a cyst but instead it was a malignancy and so ...

I: and this you realised only because ... because you felt it or ... [inaudible].

A: I realised because sitting on it, it hurt a lot.

I: what type of pain was it?

A: it was ... a very acute pain, only if I touched it, only if I sat ... or if I touched this, this cyst erm it would hurt a lot, like a burning, you see? And nothing, so I let my doctor know, my rheumatologist, I say "I got this thing right by the end of the spine and it hurts". And he said "ok, we'll remove it and have it analysed". Because we truly thought it was due to the continuous ...

I: to the pressure ...

A: yes, precisely. Instead, when it was analysed it was ... a malignancy.

I: in what year?

A: this happened in 1996.

I: in 1996. And ... so you ... you stayed ... you stayed in hospital for this?

A: yes, I had to be hospitalised for further tests, right away to investigate all that needed investigating, then I was operated on again because obviously they had excised thinking it was cyst and instead then they had to clean [the area] completely. I was lucky because they were able to take everything out, I didn't need chemo or radiotherapy. After a year it looked like it had come back, because the problem had reappeared. Through some tests they found there was still a nodule and so I was operated again but they found out that it wasn't a relapse but only a nodule which had necrotised, caused by the position, by sitting, and so since then I forced myself to sleep lying down, now I can't sleep with only one pillow, but with two pillows, lying on my back I have learnt

I: but now, so ... you still have a problem of ... the lung so ... your breathing is ... anyway you still have pains or ...

A: it happens, there are periods when I still get numerous chest pains.

I: of the same type you were telling me earlier?

A: yes, yes. Much less intense than that time ... erm ... but that still prevent me from breathing correctly, consequently when I have these pains I can't walk as fast as I'm used to, I can't lie down, and consequently ... I'm slightly limited, yes.

I: yes. And since that time, since then until, until now the rest ... I mean the disease, the disease has it had ... has it manifested itself in any other way?

A: yes I started having problem with the optical nerve.

I: mhm mhm.

A: I began ... I mean I would see a black spot, right in front of the eye I would see a black spot that within half an hour would change colour, it would turn white. No, if I closed my eyes it would turn white, erm, this spot I would see it white. If instead I would open them it would stay black, and then it would be reabsorbed and would get smaller in around half an hour. I went to have some tests done, to the eye specialist's, whose patient I already was, because the therapies can affect ...

I: mhm.

A: the eyes, and he, the eye specialist, couldn't see anything. He told me "if you ... if when this happens you can go to an A&E, and have the situation evaluated ...

I: a bit the old story of ...

A: [inaudible]

I: of the swelling, where there wasn't ...

A: sure. And so ... I was able, in a moment like that ... because with it being a problem that would pass in half an hour, I mean, I had to hurry to have it seen. So I managed to go to an A&E and they told me it was an ischemia of the optical nerve. And since lupus ... among other things, can have that, the problem of ... of blood coagulation ...

I: mhm mhm.

A: I am at risk of thrombosis.

I: mhm mhm.

A: so ... I had already realised because I had had thrombophlebitis ... erm ... in, in years past. So I was already taking Aspirin 500 to ... to try and keep my blood more fluid. But when I started having problems with the eyes then I began to have problems ... at times I wouldn't remember where I was ... it wasn't a pleasant sensation. And so my rheumatologist decided to get me started on an anticoagulant therapy. I go to have my blood tested, it depends, once a week, once a fortnight ... and they adjust the dosage of the drug to fluidify the blood.

I: this though wasn't a problem ... it wasn't painful the eye problem ...

A: no, not pain, no, it was purely the fact of not seeing ...

I: [inaudible]

A: ... or ... not having ... not being lucid is bad. it's a bad sensation not ... not knowing where you are ...

I: but while it was happening did you realise what was going on, or only afterwards?

A: no, no, no, I would realise, because maybe ... I was coming out of the hospital and ... there was a moment when I'd say "I don't know. What am I doing here? Where am I?" I mean ... it would only last a few seconds. But ... things ... <LAUGHS> really not very pleasant.

I: you would get scared ...

A: well, it was not very pleasant. A sensation of ... insecurity. And then obviously, it's clear, any bodily pain I think you can live with it, but a mental thing ... I think that's what scares you the most.

I: mhm mhm. And so you were perhaps more worried ... more worried than by the pains, at the joins, for example ...

A: yes, yes, without a doubt yes.

I: why?

A: because the fact of no longer being all there, with your mind <LAUGHS> I mean because the pain I think I can deal with. Anything, if it hurts I put up with it, I deal with it. But if you're out of your mind ... that's hard.

I: and this ... with regards to ... the first symptoms you experienced, precisely, the pains the swellings of the joints, are they still ... do you still get them?

A: yes ... yes yes yes yes yes. We now keep each other company, easily. I always say that my lupus and I have become friends. He leaves me a bit of space and I him. Then

maybe, when he starts giving me a few more problems, usually I tell myself “he must need a bit more ‘food’” then I have to increase the dosage of the medication, then he calms down again and we coexist in harmony.

- I: <LAUGHS> it’s interesting the image of ...
- A: <LAUGHS>
- I: as if you visualised it, as if it were ...
- A: yes. Yes yes.. and indeed when my mum ... she once said “this damn, this damn lupus [inaudible]”. “Don’t call it that! ‘cause he might take it out on me then. Let’s keep him on our side, let’s keep coexist peacefully, let’s not make him angry”.
- I: if ... I mean, I imagine you’ve done this when, when you were talking to doctors. But ... if you had, if somebody asked you what type of pain it is the pain you feel, for example in your joints, how would you describe it?
- A: <DEEP BREATH> it’s not easy to describe pain <LAUGHS> ... I mean, there are many types, because the pain, erm, I could say a burning but it isn’t, it isn’t a burning. It’s really something acute. Sometimes, it feels like ... I mean you often hear these phrases, that you think are over the top, but ... it feels like is twisting a knife inside of you, you see? I mean ... and indeed often it’s exactly like that, even if these are things I never say because I don’t ... just hearing them bothers me. It feels like ... almost like making it sound worse, you see?
- I: mhm
- A: I mean making it more ... heavier, but truthfully that’s how it is. Sometimes the pain is really like a knife penetrating you ... the one at the thorax was atrocious, that truly felt like being stabbed.
- <LONG PAUSE>
- I: yes I think it’s hard to imagine. I think it is, precisely one of the problems, isn’t it? But when ... talking to the doctor, with people around you , the fact the for you it was hard to describe it did it frustrate you?
- <PHONE RINGS> INTERVIEW INTERRUPTED; RESUMED AFTER THREE MINUTES
- I: we were saying, erm, I don’t know the fact that ... this difficulty in managing to describe what was happening to you, what you were feeling physically, did ... how did you live it, didn’t you, didn’t you, did it have any effects on you ... was there any frustration when you couldn’t ...
- A: no, what bothered me was arriving with nothing to show when I was seeing my doctor. Also because saying “it hurts” ... the doctor ... I mean if he knows his stuff ... he probably understands what you mean by “it hurts”, but the “it hurts” meant not being able to use a joint, it meant not being able to bend it, not being able to .. erm ... I mean this type of pain. But seeing was what would have given the doctor certainty, because ...
- I: you mean if he had actually seen something ...

- A: the joints, yes precisely, the joints would swell, they were hard and hot. So he would have understood that there was indeed something. Because just describing with “it hurts”, “I can’t use the wrist rather than a finger” I mean often the doctor can’t truly understand how much you’re hurting. It isn’t easy. Because then everyone has got his different pain threshold. There’s the one who can bear a very intense pain and the one with a very small one, can’t cope.
- I: and instead in your relationship with your family, with friends this ... often this inability to accurately describe what, the type of pain [inaudible] did it worry you? Frustrate you? Did you still manage to relate to people, or did you maybe feel isolated for not being able to ...
- A: no, no, I must say ... erm, my family have always been very understanding, in the sense that, then they know me and they know that if I complain it’s because there is something ... something that’s really wrong, otherwise I wouldn’t have complained. Then I’m not one to make a drama or tell a lot, in the sense that ok I’m hurting but then I don’t want to go into details. Also because, if you tell a family member “it hurts” generally they believe you. They don’t think you’re exaggerating, you see. But getting a doctor to understand you is different. The doctor doesn’t know you, and maybe he thinks you’re exaggerating, that’s maybe is not as bad as you’re saying. But not at home. At home ... on the contrary, I don’t like being pitied, not at all. It’s something I’m not interested in, also because what’s the use? Often I’m the one who has to give strength to others, because ... this even when I had the tumour, because the other were distraught, and in the end I was the least distraught of all
- I: well, it’s weird because it seems it happens quite a lot, that in the end one finds oneself...
- A: he’s the one that has to give others strength.
- I: to have ... the problem, whatever it might be, he then has to take charge for others, who look like they could cope ...
- A: I remember when I had the breathing problem, one evening in particular I was on my bed, sitting up, with this heavy breathing, and it’s a terrible thing, and my husband by the bedroom door looking at me as if to say “tell me what I can do” and I sent him away “go away I don’t want to see you” <LAUGHS> because really, it’s been a dark period and I was ... I mean not being able to breathe makes you nervous ... really makes you nervous <LAUGHS>.
- I: I can imagine <LAUGHS> I imagine it is ...
- A: yes, as for the rest ... my family, let’s say I think they don’t realise, they know very well I have these problems but I never offloaded them onto anybody else. Principally because they’re not even that heavy for me, consequently ...
- I: this, this ... earlier you told me about the red spots you would sometime get ...
- A: yes ...
- I: on the body. Does that still happen?
- A: well, it’s these little spots that appeared under my skin, but on the palm of my hands and under my feet. Erm, these still come out from time to time, it depends on the

time, erm, I then got some, some nodules on my legs, these things are quite ... frequent. And there too I have to increase the dosage of cortisone until it ...

- I: and do these hurt?
- A: yes, they're very painful.
- I: are you talking of the nodules or the little spots?
- A: the nodules.
- I: the nodules.
- A: the nodules on the legs, because it appears they are nodules that sit right on the nerve, consequently, each time you move the leg ... the foot ... you feel this pang ... continuous
- I: so they're like pangs?
- A: yes.
- I: not burnings, pangs?
- A: yes, no, no, no, really ... a pang, yes.
- I: but you don't move [inaudible] you don't move they don't hurt?
- A: it hurts. Not like when I walk, obviously not like when I walk.
- I: and instead the spots? [inaudible] what type?
- A: well instead the spots ... no the spots were ... were sore if I touched them. Otherwise not, they didn't hurt. They were like ... they too like small nodules that had formed under the skin, on the palms of my hands and the soles of my feet. And it happens now, they still hurt, obviously, when I walk I feel them. Because it becomes red, both the sole of the foot and the palm of my hands, and it gets sore. But it's also due to lack of [blood] circulation.
- I: you have, I mean do you have moments when you are completely free from pain these days?
- A: yes.
- I: so it isn't, there are moments ...
- A: yes. Yes I was just thinking about it <LAUGHS> ... I'm so used to it. no, one thing, for example, which I understood from the beginning, is that ... I must be able to appreciate the times when I'm well. For example if my knees are swollen I find it difficult to walk down the stairs, to climb them, to walk. But when I'm well, I can hop down the stairs, I'm so happy. Things that people who are always well don't even realise they have. And this is a kind of happiness not everyone can feel.
- I: can you remember what life was like before all this began for you?
- A: yes. I've always been a very active person. I've always enjoyed working, even toiling has never been heavy for me. I've always done it gladly, I always have to feel I'm moving about, always felt useful, doing something. And I must say that in spite of

everything I can still do it, even with the pains. Clearly, I'm limited as to what I can do, I can't, I can't get down, kneel any longer, do these things, I have problems. Now I've got nephews and nieces, my brother's children and I'd like to run [with them]. From time to time the little one tells me "auntie, come on, catch me". Well, easy to say <LAUGHS>.

I: it's difficult ...

A: running after a child has become very difficult for me.

I: running after a child is difficult for everybody <LAUGHS>. If it happens that you experience a pain, a pain which probably isn't tied to your illness, like, I don't know, the kind of headache everyone gets, or a cut, a burning, do you ... do you experience it differently? Live it, I mean, I don't know, because I was thinking ... earlier you mentioned, this image, this lupus that feeds, so it gives problem in that respect. But probably, since, 'cause you're alive and ... like everybody ... it happens that you have problems not due ... I don't know, do you experience them differently? I mean like, for you, is there a lupus pain and other pains? And if so, how are they different, how do you perceive them? Or, in the end all is ...

A: no, no, no, they are different. For example, I was thinking, maybe that's why I got burned the other day, to answer your question, maybe I felt <LAUGHS>.

I: oh yes, thank you for the cooperation <LAUGHS>.

A: I felt a burning, very intense, and clearly ... very different from the pains I feel ... usually. And so quick, run under running water, and put some cream on, and it was unpleasant to feel this, erm, much more unpleasant than feeling the pain in my knees, or in my hands. Also it might be that I'm used to those pains. And then ... a burning is a very intense pain, very strong, so you hope ... it goes away quickly.

I: mhm, mhm, erm ... for example if you had to compare, I don't know, the pangs you experienced, that weren't too intense, or painful ...

A: yes.

I: how, in what way do you think, in your view what difference ... how would you describe the difference of ... the pang that was something due to ..

A: like the one at the thorax, for example?

I: yes, compared to an intense pain like ... a ... when I was sixteen I spilled <LAUGHS> boiling water onto my legs ...

A: nooo

I: and I remember it as the most terrible experience in my life <LAUGHS>.

A: I can imagine. No I must say that the pain from scalding is a strong pain, erm, but that passes, in the sense that, erm, it's something where you say "ok now I go under cold water" [inaudible] clearly, the burning from an iron isn't ... a pan full of boiling water that is spilled onto your legs. So you say "ok, it'll pass, I'll put something cool, but a pain like the pangs I felt at the thorax ... they affected me a lot. They affected my life a lot, because it was difficult to breathe, and this was something ... it kept me from doing many things.

I: to wrap up, just one thing. I was struck by the image you used of lupus as, as an illness, this kind of monster, something which is inside of you.

A: no, it's not a monster.

I: a ...

A: a wolf cub.

I: a wolf, a small friendly thing ... the illness however, and lupus. If instead you had to give an image, I can't give one, the pain, independently from pain itself. What image would you think of?

A: not an ugly one.

I: not ugly?

A: no ... no, something which is part of my life. Then ... I must say that I don't even know if I'd like to be cured of this illness.

I: Oh.

A: because it taught me many things, and ... I was able to ... to do something in my life I really like, which is being helpful to other people. And I was able to do it thanks to the lupus. Because I would never have been able not to work. I'm on incapacity benefits, I worked for twenty-four years, so ... I stay at home on benefits, even if they're not a lot, but it's enough for me.

I: mhm mhm.

A: and so this allows me to come to ... Milan and to volunteer and to be near to the ill. It's something I like a lot.

I: thank you.

A: not at all.

3.b Gina

- Interviewer: to begin with, I just wanted to ask you if you could tell me a bit about your experience, how it began {my illness?} erm, and how it developed, the genesis of your story.
- Gina: well, I began by ... I began by feeling pains in my knees, or in my feet. I would mostly feel them when I went to the mountains. Because I very much like the mountains. And as I would come down, my knees would swell and I couldn't continue. Then maybe at home erm ... my hand would swell up, or my arm but mhm I would also get a temperature. But I wasn't worried because they'd say to me "well if pain goes around it's not serious".
- I: what kind of pains were these ones you felt initially?
- G: in my knees they were very strong. I really couldn't move, my joints were blocked. And it was the same with my hands and wrists. High temperature and intense pains ... and then the joint would become swollen and become blocked. But at the time, I repeat, I didn't think much of it. But one morning, I found that I couldn't even get up from my bed. I called my GP, he said to come here to [name of hospital]. But it was rather far, and so I didn't. I did some blood tests. I went to a doctor's who sent me to another doctor. At first they thought it was my teeth, it looked like I had some abscesses, then they said it was an inflammation, something like that. But meanwhile, almost two years went by. When the illness was diagnosed, at that point I really couldn't take it anymore, that's because I had gone to see a cardiologist, a family friend. As soon as he saw my hands, he said I had RA. He sent me to do some tests ... and that's where it all started from, where the therapy for RA started. I began feeling a bit better, but ... obviously ... it was kind of hard, especially at the beginning.
- I: and this ... I'm sorry, when did this all began?
- G: well ... twenty ... twenty-two years ago.
- I: twenty-two years. And after how long did you get a diagnosis?
- G: two years.
- I: after two years.
- G: since I started experiencing the pains of the illness.
- I: and since then, how did the illness progress?
- G: it progressed with various deformities, my hands, my feet. I've already been operated twice. I've had to prosthetic implants ... in my hands, especially ... the joints ... here [points] and ... but I'm all right at present ... a part from a few episodes ... when you maybe do some house work and maybe, without realising ... for example, yesterday I cut, I cut some vegetables and today ... my finger is swollen and I can't {does it hurt?} I don't have the strength to ...
- I: and {yes it hurts} is it painful? {yes} these pains, initially, is it only in the joints? Are they only ...?

G: well, in the smaller joints ... then at times it affects the shoulders, and ... the most acute pain, the most troublesome is when it affects ... here [points] on my back and it must be ... it must be the muscles which get inflamed, and even breathing ... I really can't. at times even just going to bed ... this movement of lowering myself ... a tremendous pain, that really blocks my breathing.

I: so, very intense?

G: very.

I: and what about the joints ... how would you describe the pains there?

G: always intense, so that at times you feel like ... they're ripping them off you. I put ice on them ... or something to alleviate

I: are they like burnings? Or what?

G: they're really like ... how can I say ... like needles, like something that rips you, I can't really say if it's like ... I can't describe it. I just know it's strong.

I: and do they ... when you get them do they last a long time?

G: well, initially they would last maybe a day, now instead ... maybe two or three days, before they begin to wear off.

I: in spite of you taking ...

G: in spite of me taking anti-inflammatories and all, and the main therapy.

I: how ... how would you say that the illness has influenced your life?

G: initially ... it's been hard, because my children were still small, and so ... they too were ... I'm not saying traumatised but almost. Because so often I was blocked and they, they would have to help their daddy with the house work. And ... consequently ... I mean my life changed, but little by little, so I got used to it and now, now I feel I'm like everybody else, if I don't look at my hands, that is.

I: also because You were telling me ... you don't get as much pain as you used to ...

G: no not like before. Now, more or less, the illness is under control.

I: did you find that ... when you started coming into contact with doctors, or other people, was it difficult? Communication, with the medical establishment, were they understanding or ...

G: well ... when going to rheumatologists, even if they know the illness, well I found them to be quite understanding, knowledgeable.

I: so ... anyway ... when you deal ... as you often deal with people in your situation but also with people not in your situation do you find ... do you find it easy to communicate your experience, or do you think it's a difficult task?

G: no, I don't communicate my illness to anybody. I mean, I don't really have a chance to say how I feel.

- I: well ... I was thinking ... it must have happened to you that maybe at time you were involved in activities that you couldn't
- G: I refuse. Even at church I would act as ... as secretary ... there were things to do and I never concealed my condition, also because you can see it. And I say "no, I can't do this job because my condition doesn't allow me". Yes, I tell the truth ... and there are times when I feel slightly embarrassed because of these hands. But you overcome them.
- I: and what is your relationship with your own body like? I mean, after your illness, do you experience it [your body] as a stranger, an enemy, a source of problems?
- G: no, I get along with myself.
- I: I'm asking because it can happen that one identifies one's own body as a source of {of problems} so that one wants to put some distance between self and the body which is the source of {of suffering} of suffering maybe ... but I think it's different for everybody.
- G: I think so. It depends on the extent to which you accept the illness. I think that, often there are people who truly reject it, especially when they are going through difficult times. I'll tell you the truth, there was a time when I was going through a difficult time because, every day I was unwell, there was something every day. So I met a psychologist but she said there were no really big problems, I was just feeling down.
- I: and this was ... at the beginning?
- G: yes, long ago, but then ... maybe that's what encouraged me to react. Since the I started on the way up.
- I: and what about your work with the support group ... how do you see it, is this one of the factors that help you feel better?
- G: yes, yes yes, undoubtedly because you feel useful. Instead of just staying at home, without four walls, you feel useful ... to other people who have the same problems as you.
- I: there's a sense of community ...
- G: yes there is amongst ourselves. After not seeing each other for a long time ... even today, it's a chance to ... for the meeting we have in the afternoon, it was a chance to see each other again after a long time, because it's not often that we can all meet but because of this we can get together and really ... there's true affection ... maybe because we all share the same sorrow.
- I: do you feel ... do you feel more understood by people who suffer like you?
- G: ye, sure. Especially initially, people near you, apart from my husband and my children, but those outside didn't really understand, the illness. Because maybe I was in pain and the day before, on the phone "how are you" "I'm really unwell" and then the next day they'd see me, as if nothing had happened. Maybe they thought "she's taking us for a ride" but no, it's the nature of rheumatic diseases ... difficult to understand ... one day you're in pain, the next you're well.
- I: it's maybe the idea, the stereotype of people with illness who should be in bed, unable to move, constantly {yes yes, it's true}.

G: for example, last November I met with some former colleagues, I hadn't seen them in a long time because I stopped working after having my second child. Anyway, then they talked to my sister, we all worked together, and they said to her "my God, poor Gina, with those hands" but that's nothing. They imagine God know what because of my deformed hands. Well they didn't say anything to me but this was the impact, whilst initially there were still no deformities and maybe you were in pain but the next day nothing but instead ... and you had to take very strong medication to be able to function.

I: so there was this paradoxical situation, so that maybe before there were no deformities but you were suffering a lot {it wasn't understood}, it wasn't understood, and then perhaps you see the physical signs but the suffering {is less} is less but people think it's worse because they see the signs.

G: yes, it's true.

I: ok thank you for your help. Is there anything else you'd like to add that maybe I haven't asked?

G: no, I think I'm coping well with my illness <LAUGHS> even if now is when the truly big problems begin.

I: why?

G: because it begins to affect the liver, the kidneys, the heart, the eyes, it the other side <LAUGHS>

I: always to do with RA?

G: yes, the drugs, they're good on one side but bad on the other. I've been taking them for twenty-two years.

I: [inaudible]

G: yes.

I: thank you.

G: not at all.

4.b Marta

- Interviewer: the first question, I just wanted to ask you if you wanted to tell me about your experience of illness. When did it begin, for example ...?
- Marta: I began when I was fifty-eight it, I had never had any illness in my life so I considered myself lucky, because I had never been ill, and suddenly, from a minor pain, from a finger, a whole succession of ... this pathology was born, RA.
- I: mhm mhm.
- M: and, erm, little by little it got to my hands, and feet. Diagnosing it wasn't easy because I'm ... my tests are seronegative, I mean, they didn't show anything, and so further tests were carried out to find out what it might be ... which maybe didn't involve RA. Then in the end it was diagnosed and now I'm living with the consequences because within four years my hands and feet were compromised, and they had to be operated.
- I: and you said ... you were saying it began with a finger?
- M: yes, a finger.
- I: what kind of ...
- M: I was diagnosed a simple, by the orthopaedist, a very simple tendonitis, erm, so I didn't think much of it. but then, later, I had problems in my hands, burnings, erm, at night I had very intense pains in my hands. Then my foot began to swell and the ankle, and more. Things like these.
- I: and were they all ... I mean ... at the ankle and so, was the first manifestation always painful, or was it a case of swelling first then pain?
- M: no no ... with the hands it was painful, because obviously the carpal tunnel becomes totally compromised and inflamed so it would be painful, the hands were, especially at night. These burnings, unbearable, and some swelling too.
- I: so the pains were burnings?
- M: yes, burning and then swelling, then ... then one ankle began to swell, then the other, and so ...
- I: and what about the first one, that initial problem you had in your finger ... what type of pain was it?
- M: well it hurt. It hurt ... this thumb, so I went to the orthopaedist asking why I had this pain, and he told me "it's a ..."
- [portion of recording missing owing to damaged tape]
- M: it could, it could be, of course I don't know about these things, and I'm not saying that, <LAUGHS> but ... this stuck in my mind clearly and everything possible was done and in the end they told me "no, you've got nothing else". Also from a neurological point of view I went to [name of the hospital] and they did a lumbar [x-ray?].

- I: the lumbar⁴³ ...
- M: all. And all was fine, the nervous system was fine, physically ... so I was advised to follow rheumatologic therapies.
- I: and during all that period ... and even in this one, was your pain continuous? Or maybe ... not ...?
- M: well, to begin with I was bludgeoned with anti-inflammatories. Cortisone, at the beginning. And so, naturally, the burnings I felt in my hands kind of abated, more or less. Well, I can't say ... even in my feet, walking was difficult because with the joints having become deformed they create problems ... the joints become stiff and walking becomes difficult and I had to do something. Even though my hands were straight, my feet were straight, normal <LAUGHS> and so I got pain from these deformities that stiffen your joints. And naturally the movements of the hands, the feet, the pain is a pain, at least in my case, it's not a pain where you go "oh my God, oh my God I'm hurting, I'll take a painkiller right away" but it's something that stays with you the whole day, because more than a pain it's a stiffening, a ... a difficulty in ... you can't close your hand properly, you can't ... so you always have this tension ... in your muscles, the joints ...
- I: is this sensation you're describing something that you feel, that you feel even when you're not moving, and you're sitting, doing nothing, when you're at rest. Or is it something that comes on when you attempt to make a movement?
- M: sometimes even when I'm doing nothing, when I'm at rest, some pains come on when you're at rest. But obviously rest helps. For example yesterday I told myself I was stupid because I carried a bag {mhm mhm} I go shopping and stupidly, even only from the car to the, the thing, instead of carrying by the handles as you normally do I carried it on my forearm. And this morning I'm all ... it must be where the nerve is and ... it got ... and I said "I can't carry absolutely anything, not even a bag on my forearm", and so ... I did ... <LAUGS>.
- I: so at present ... generally now, for example right now, as we speak, have you got any pains?
- M: well, then obviously one can get use to a state which is not normal ... in terms of pain, now I don't have any but there always is, for example in my ankles, that sensation of stiffening that ... well I may move a foot because it feels like there's something that constricts me, so maybe say I'm there, sitting, with no problems, I have to move my foot because I feel something, more than intense pain in my case it is a sensation of stiffening, which maybe doesn't bother you as much as pain but still ...
- I: how would you say that having RA influence your life, how did it modify it?
- M: well, it did. I've always enjoyed running, walking, before I became ill. In June 97, twenty days earlier, I went for a walk in the mountains. And in fact I blamed this.

⁴³ Rachicentesis, or "lumbar puncture", introduction of a hollow needle into the subarachnoid space of the spinal canal, usually between the fourth and fifth lumbar vertebrae, usually performed for diagnostic purposes.

I: mhm mhm.

M: I went to two thousand metres, well from one thousand I went to two and came back. At one point I had to stop and go back, leave the group <LAUGHS> I went back on my own because I couldn't take it anymore, I made an effort but couldn't. Maybe I wasn't used to walking that much anymore, but I was well, like I said I was a healthy person with a desire to do things and naturally my life changed in the sense that I can't say anymore "tomorrow I'll go, go on a trip". Tomorrow I'll see how I feel, if I can do it. like this morning, I had an appointment to see a friend, but to be honest I didn't feel to good. Even if had been urgent ... there's one thing, I can't really plan my life, that's it, I can't plan my life, and naturally this changes many things.

I: everything is more ...

M: how can you say ...

I: unpredictable.

M: what really helps me these days is being able to drive.

I: mhm mhm.

M: because since I can't walk much, obviously, not being able to walk much, being still able to drive <LAUGHS> helps me really a lot.

I: so you can drive?

M: yes.

I: without any problems?

M: none. And being able to go, say, to the supermarket, do my own shopping even if my walking isn't good ... it makes me feel fulfilled. There have been times when I've had to be housebound for two months at a time, because I had been operated and couldn't drive, I felt like I was a serious case. Because I couldn't go around, I would say "what if I go out, walk a bit, and then get tired?". I'm scared of using public transport.

I: why?

M: because I had only one hand I could use.

I: I see.

M: I can't function ... go <LAUGHS> with just one hand, I didn't think I could do it, so ...

I: would you still have problems using public transport?

M: not so much now, with two hands ...

I: because before you could only use one?

M: yes, because I had surgery on one hand, and so, being able to drive really did help me a lot, really.

I: because you didn't depend on anybody?

M: yes, sure. Also because with the type of illness we have ... I'd always have to ask my husband to take to do tests, to the GP, do the bureaucratic things that are needed, there's always something.

I: sure.

M: so there are forms to fill, to be given insoles I have to see the orthopaedist, are you kidding me? A man <LAUGHS> would have to ...

I: he'd have to always be available.

M: I always tell my husband that he's lucky I took my license thirty years ago.

I: sure <LAUGHS>.

M: when he didn't want me to. He'd say "why do you need a license?"

I: but instead it proved useful.

M: typical chauvinist of old <LAUGHS>

I: whereas now <LAUGHS>. You did the right thing.

M: sure, sure.

I: compared to other pains unrelated to the illness, that you felt or may have felt in the past, how would you compare them? I mean everybody has ... I don't know maybe a bruise because of a fall, a scalding, I mean what are these pains like, compared to a pain caused by the illness?

M: well, physically, one falls down and manages the pain. This kind of pain goes away, one overcomes it, but in this type of illness there's no going back. I mean, you think "ok, this is how I'm feeling, but what about tomorrow? Will I still be able to drive? Still be able to ...?".

I: mhm mhm.

M: I mean, it's very limiting, it's more serious than other things, it's chronic, let's be honest about it. then one can manage in different ways. In my life I've had many sorrows, quite big ones, I lost two children, soon after giving birth ...

I: yes.

M: so serious things.

I: mhm mhm.

M: but physically and mentally you overcome them, I mean. Certainly, if it had happened to me to become ill with RA when I lost the children and I was thirty, I think my life would have been much worse. I feel quite good overall. When I hear about these women who became ill in their twenties or thirties, I feel ... their lives have been ruined by this illness.

I: ok. Thanks a lot.

M: [inaudible].

I: is there anything you'd like to add?

M: <LAUGHS> no, nothing, I hope your research can be of help <LAUGHS>.

I: I hope so too, many many thanks.

5.b Sandra

- Interviewer: ok, would you like to begin by telling me a bit, in general terms, about your experience, when it started?
- Sandra: right, I'm thirty-two, I became ill in 1983, I was eleven I've been ill for twenty-one years. So, I began ... I was in middle school [*scuola media*] and I had ... I was listless, one might say. I began to have fevers, pains, but the fever wasn't continuous, I had an intermittent low fever so it didn't always look like I was unwell. Then one time my arm would hurt, then the sole of my foot and the pains would move around. Until one day I went to the doctor's and ... that day my temperature was 39C, it was very high. Since that time, nothing, practically I kept getting worse.
- I: ... these pains you were talking about, in your foot or arm, what kind of pains were they, can you remember them?
- S: well I find it difficult to remember, because the moment I'm fine again I delete everything from my mind, the pain I feel, but the moment when even only a finger hurts the sensation of pain I've felt resurfaces. Let's say ... it was a very intense pain, I wasn't able to put the foot down or use a hand. But let's say that ... more than anything it manifested itself with me getting a temperature ... when I have a relapse I just can't move any more. My joints are blocked, with strong pains in my hip joints, and the shoulders too, and let's say that I need help to do anything. Getting up, getting dressed, washing, even to have breakfast, to lift up my bowl of milk.
- I: so they're very ...
- S: very strong, when I'm going through an acute phase. Because when I had the latest relapse, in 1997, when it [the illness] manifested itself with pains and fever, I practically ... I mean now I am ... I'm ok. The pains are minor, just in one hand, where I began in 97, and ... but they are very manageable. Let's say I've always been treated with lots of cortisone, I can't say if twenty years ago this was what treatment was like, because when I hear other people, now they don't give you as much as I was given. I really took a lot of cortisone, I was given several *boli* of cortisone.
- I: what are they?
- S: *boli* are doses of cortisone administered intravenously, of methylprednisolone. They are administered over three days, a dose per day, and ... their purpose is ... to halt the illness. Sometimes I've had to have them administered consecutively, because ... because I was not responding to the drugs. They also gave me immunosuppressants, that I took for many years, and nothing, with the immunosuppressants than I was able to decrease the dose of cortisone, to take the minimum dose. I haven't had many relapses, in my illness. The ones I've had have been very strong.
- I: the diagnosis ... when did you get it ... you told me it was that time you had ...
- S: we are talking lupus, not RA.
- I: so your diagnosis is of lupus.
- S: yes, I was given it right away. I am ... let's say that ...

I: after this time ... after this time, you were telling me that you'd experienced ... first several pains than the fever, which was very high and you'd been to see a doctor.

S: right.

I: and that's when you received a diagnosis.

S: the diagnosis came, practically, after two months in which I, from April... no after a month because from April I had to stay in bed until May, end of May, I was taken into hospital and they immediately diagnosed the illness, because the following day, well I got the butterfly-shaped erythema, as well as the pains, as well as 40-41C temperature. I can't recall exactly how it went, only that then yes, there ... they made an immediate diagnosis because of the erythema, there were the cells [inaudible] that was ... the test once used to ascertain this type of illness, there were the antibodies, very high, the ESR was very high [erythrocyte sedimentation rate], yes ...

I: what is the ESR?

S: well, practically it's used to determine the level of inflammation.

I: oh, I see.

S: and nothing, these various test results. The pains. The pains are very intense when I go through an acute phase.

I: what type of pains are they? Are they ... how would you describe them?

S: well, they are pains you initially feel under the skin. They're neither in the bone nor in the muscle, or they can be distinct, or in the bones, or the muscles. It's an unpleasant sensation, a sensation that makes you feel restless. A ... something that precedes the onset of pain proper. Then, at least the ones I feel, it's really a pain, an intense pain, dull, a really strong one. I can't find an appropriate term ... pains that won't let you ... mhm ... lead a normal life, but even the most mundane things like writing, washing, getting dressed.

I: but are they, when you have these pains, are they there only if you try to do something ...

S: I can't ...

I: or even if you're still, not moving, like that ...

S: even if I'm still, yes, not moving, yes. Yes, yes even if I don't move the pain is still there. So maybe I'm not able to stand up or ... say ... but once I'm on my feet, slowly, I can stand. But it's not always easy, and I always need to be assisted. Then others I can't describe them, to be honest.

I: so they're not like ... because at times I imagine them similar to burning sensations but ...

S: mhm, that's an initial phase of the pain, before the acute pain. It's a ... I call it ... it's the phase before I get the pain proper, yes, that phase of burning, yes. I truly feel pain in the joints. I mean I can really feel all the joints ... one by one.

I: so you have an initial phase with ... where ... which precedes the acute phase ... and this dull pain you described before, is it part of the acute phase?

- S: precisely. It's really a very intense pain that will not allow you to lead a normal life, the daily activities one does, yes.
- I: erm, how would you say ... that it has ... what effect has the illness had on you, the pain?
- S: the illness? The pain not that much, because, aside from the acute phases, then it's very manageable. Consequently after having plugged it with medication you can, you can still ... do your own things, you can. As far as the illness is concerned ... well ... how can I say ... how can I explain? Every choice I've made, every choice I've made in my life has always been influenced by the illness, because it's always been there, ever since I was a child, and everything has always been ... a problem. A problem going to the seaside, a problem going out with my friends, a problem ... everything. Still, and I'm married, there are problems. Every choice has ... has had a consequence, because the illness developed when I was little and we grew up together. Consequently ... it's been a parallel journey.
- I: yes, it really started ...
- S: when I was eleven.
- I: can you remember what life was like before becoming ill?
- S: honestly, I had never had a temperature, never an illness, never ... anything, nothing at all, I had only had chicken pox, when I was three, and then nothing else. Until the age of eleven, then ... then there have been very serious consequences because of the therapies. I got spinal osteoporosis, where the vertebrae collapsed. I was in cast ... and I have an osteochondritis in my knee.
- I: osteochondritis?
- S: osteochondritis. Very rare ... [inaudible] not much written about it <LAUGHS>.
- I: what, what is ...?
- S: practically the bone dries up and then becomes brittle. This is what it is in short. They perforated my knee with an arthroscopy, so that the blood can bring oxygen to the bone ... although ... they tell me it's not much help. I ... at times it happened ... after several years to have very strong pains in my knees so much so I couldn't put my feet down. It happened while I was on holiday <LAUGHS> I didn't know what to do. They explained to me that the only thing was rest, when it felt like it would go, there were no tablets, no cream. Nothing, because they don't even know much about it themselves. Then other problems ... ok, my social life ... let's say it isn't ... it also depends a lot on one's personality. Let's say that since I got married ... my true personality truly emerged, consequently I was able to fight it better. Before I would not fight as much, but, never say never, even because since I got married ... I had a relapse last time a year before getting married, consequently since I got married I haven't had other relapses, so I'm not in a bad way. I speak positively of my lived experience of being ill, when I have a relapse, don't talk to me about my illness, because it's a thing that doesn't belong to me. I really tend to disassociate from it.
- I: when you are experiencing a relapse?
- S: yes, yes, right ... it's only been since I started coming to the group that I've been able to talk about my illness, before you'd see me, you wouldn't notice I was ill because

you can't tell, and I would never had told you. Not out of a desire to hide, more because of a feeling of inferiority.

- I: with others?
- S: yes, right. I don't know whether that's right or wrong, it's the way I am, very emotive, like this ... this is the truth. But let's say that little by little I'm trying to overcome it. to ... to become more self-confident.
- I: however, you were telling me that when you're experiencing a relapse ...
- S: yes <LAUGHS> we'll talk about it when I'm unwell again, because that's the way I've always reacted, I can't, I mean ... I'm unwell, leave me alone, when I'm well again we can talk about it.
- I: now, I don't know, might be difficult to say, but do you think this is a kind of strategy to ... to remove oneself {it's a refusal} to overcome ...
- S: it's a rejection. It truly is a rejection of the illness because when you're suffering, you're undergoing heavy treatments, as well as ... as well as being physically unwell you really, so you have, you don't feel like doing anything anymore because you're so absorbed by your pains, or by other problems that the illness gives you, that you don't feel like ... you don't feel like thinking of anything else. But anyway ... it really is a self-defence mechanism, erm, ... also because ... the drugs they give you are, very strong and they cause you mood swings, changes in physiognomy, and that's' something really heavy, it really does, a lot. Then I truly feel very different.
- I: from what you normally are?
- S: yes, I'm not myself anymore. I truly change, my personality changes, yes.
- I: and, what would you say ... how would you say your relationship with your own body has changed?
- S: ... tricky question!
- I: <LAUGHS>.
- S: erm ... my body. My body has been devastated consequently I don't have a good relationship with my body because, I tell you again, and you can ask around, ask doctors. The doses of cortisone that I took, unfortunately on my very young body, it really devastated it. luckily not many of us have been so devastated, but ... it happened, amen, what can we do? I don't look at myself much <LAUGHS>.
- I: you don't look at yourself much?
- S: yes <LAUGHS> [inaudible].
- I: <LAUGHS> it's interesting the relationship that illness {yes} ... the posture we assume vis-à-vis ... our body, isn't it?
- S: that's right, even though ... I have my husband who loves me and all that, well [inaudible] but ... if I dig deep inside me ... it's all very difficult.
- I: and do you find ... well ... now I am talking to you but ... do you find it difficult to talk about your illness? Earlier you said you find it difficult especially during a

relapse ... more than when you're not in pain. But, what I mean, is it difficult to describe what happens to you? Is it difficult?

S: to me it's difficult, yes very, also because I can't always find appropriate terms because, ok, it's physical pain, but it can be different types of pain. There's tension pain. Or I'm unwell every month to be honest, before the menstrual cycle I feel very unwell. I have an acute phase of pain that takes my arms and shoulders until I get the cycle, then I'm perfectly well, who knows why. Not even doctors know but this is also a problem I experience, so when I have these strong pains I say "oh god, what's happening?" but then I think about it, look at the calendar then ... ok "let's wait until such and such day" and then, when I see I'm better, then I don't worry any more, otherwise I'd start to worry, yes.

I: and obviously, given you became ill so early you can't really tell if they're pains that ... normally connected to ...

S: erm, I don't think so because ... I don't think so because ... I mean it's not only about ... the renal area or the back, they're really pains connected to the tension, as if, as if I ... I don't know ... if I tensed all up and had, had these pains, you see ... muscular pains, mainly.

I: so, when you experience a pain not related to the illness, like a fall, or a burning ... erm {if you knew how often <LAUGHS> anything, how ... how do you experience it, I mean has the way in which you experience changed?

S: well, now you can't see it anymore, I had a burning here on my hand, I had a blister but "who cares" what does one more scar matter? <LAUGHS> honestly, it's not a big problem. The only thing that would bother me is if the face ... if I developed something on my face <LAUGHS> "have mercy, at least spare my face", yes, the rest, I don't really care.

I: but, is there, a type of pain not related to the illness ...

S: well, to give you an example, the other day my balcony was wet and whilst turning I hit the corner of one of the windows. I'm still hurting <LAUGHS> because I really hit it hard, but ... it's different, erm, it's not the same pain, it's very different, you can recognise it.

I: but do you think {it's a bruise} have experience illness related pain, do you see other types of pain differently?

S: well, perhaps I don't care as much, I care less. Even if lately, when I'm in pain because of the illness, I try to pick myself up, because I always tell myself "heck Sandra, you must carry on, you must make it, do it today because you don't know what tomorrow will be like". Yes, lately I tend to tell myself these kind of things.

I: to conclude, if I asked you another question, probably a difficult one {ok let's try} in general ... what is pain?

S: what is pain? Physical pain? Or psychological pain? {well, the first you think of} the most ...? The one which is foremost in my mind is ... erm ... psychological pain, the one that's heavy to bear. That's the heaviest for me. To be able to face ... with more serenity ... maybe I'd also be able to better face physical pain. Although I can assure

you that until and unless I'm completely blocked I carry on, I keep on working, I do the dusting [inaudible] when I can't take it any more it's because I've reached the limit, the end of the line. That's how it's been so far.

I: what do you do?

S: I ... I'm a secretary in a firm ... I work in the shipping office but for a year now, I was in the archive before, physically archiving, and maybe that's why the hands were affected the last time I had a relapse ... because in the past seven years I've used my hands a lot and I have ... lifted weights, doing this kind of work, yes.

I: are you still working full-time at present?

S: no, no, no ... initially ... I've been working for ten years, initially I asked to go part-time, six hours, because having never worked before, I couldn't tell if I'd have been able to work eight hours. When I got married my mum was the one who had to do the housework for me, I couldn't work at home too, because when I got home at four I was so tired I couldn't do anything. Not because I didn't want to <LAUGHS> I was tired. So I requested to work less and now I work part-time, four hours per day, so that in the afternoon I can do things at home. So now ... I can more or less manage on my own. I'm not saying I don't get any help, there are things for which I need to be helped {but you manage} yes, I can do my things, without help.

I: well, thank you very much. Is there anything you'd like to add?

S: not sure ...

I: ok.

S: is this enough?

S: yes, really good. Many thanks.

6.b Veronica

- Interviewer: nothing, could you please tell me a bit about your experience, when ...
- Veronica: when it began?
- I: yes when it began, how it did ...
- V: well, I was 17, I did athletics professionally, and ... distance running, 800 metres, I started having these pains, and to cut a long story short, instead of ending up on the track I ended up at the <LAUGHS> hospital].
- I: <LAUGHS> another race.
- V: another race, which lasted an entire life.
- I: and these pains you felt initially, where did you feel them?
- V: in my hands and mostly in my feet, and in fact my coach would say to me I was putting on an act, in order not to make an effort, because he wanted me to ... in those days women didn't do distance running, so on top of the normal training, he would make me train for distance running, and it was there, in my foot joint, in a different way, that I began experiencing, these pains, and I've had them ever since.
- I: in your feet, initially?
- V: in my feet, and hands but the hands weren't ... in my feet, it wasn't continuous they were pains that would be felt after training, but, I've had these pains for 17, 25 years – well – almost ... almost eight years, without ... nobody recognising my illness, because my illness was seronegative, so the blood tests you couldn't, you couldn't detect anything. I had good muscular tone, strong because I was doing athletics, no hardening, no outward sign, so that one doctor even told me it was psychosomatic and that I had to go elsewhere to be treated. Then however, I began getting tumefactions and ... in the meantime my GP wanted me to come here, to see Professor B., who's no longer here, he was the consultant in rheumatology and he diagnosed RA. He draw me a graph where he explained that my life would always be accompanied by this illness, that I would have highs and lows, moments of ... mhm ... relapse and moments of remission, but that each time the relapse would be more acute and that during the remission I would have felt less well than the previous time.
- I: pardon me, how old did you say you were when the problem began?
- V: well, forty years ago ... forty-one, this year I turn fifty-eight in August, and I was ... let's say ... I was seventeen.
- I: and after how many years did you get a diagnosis?
- V: I was twenty-five, after about eight ... seven eight, seven and years and a half eight years.
- I: that's when you knew for sure you had RA. Listen, these pains you felt at initially, first in your feet, then you said ... in your hands, what, what ... if you had to describe them, what kind of pains were they?

- V: it's been such along time ... well ... it was a pain ... let me think, in my hand I remember one afternoon it was an acute pain, fixed, erm, that ... as it appeared it went, but it lasted the whole afternoon, oh yes, come to think of it I also got it in my groin, even that one, they were all acute pains but fixed, they were not alternating in intensity, more and less intense, they were fixed whilst those in my feet came on when I walked, it wasn't really pain, erm, you see ... for example I got a pain in my hand that I felt even with my hand at rest, the one in my feet I would always feel it after training and they were, almost, pains, a burning a ... erm I remember once my coach we were doing the relay race, he had the baton in his hand, to pull my leg, I don't think he meant any harm, he took the baton and ... he hit the sole of one of my feet where it hurt, it was a terrible pain, acute very intense, then he stopped teasing me because I must have, probably, must have been transfigured by pain, because, it was such a strong pain, but ... never mind.
- I: but there were still no signs, I mean visible ones, there weren't ...
- V: no. and by the way I hade very good hands, so much so that many would tell me "you've got the hands of a pianist".
- I: <LAUGHS> I was going to say it myself, yes.
- V: indeed, so ..., erm ... they would tell me "move your hands" ... and I would move them, I would do everything they asked, they would say "no, there's no RA here" and I told you, the legs, they were a nice pair of legs with good muscular tone because, doing distance running, I would run every day, kilometres upon kilometres, so ... mhm ... it could be thought of, something ... <LAUGHS> psychosomatic, but instead it was ...
- I: and then, how did the situation change?
- V: well ... {after diagnosis ... as time went by ...?} well, with time, I've always had a slow progressing but aggressive form of RA, meaning that, I ... I can't recall, but I could have experience them but ... I erase, I mean if I'm in pain now, in fifteen minutes if I'm not in pain any more I forget ... the pain, it's a defence mechanism , erm, I think, I think I never had pains like some say that, that you can't bear them. I have pains, for example at present my hands are hurting ... but, I have ... they're bearable pains, rarely have I had pains that were so strong that ... that I couldn't even communicate with others and to need to isolate myself, because when I've had them, normally I shut off, I need to wrap up in myself, and ... and get my strength back, and then it passes and ... at times I even fall asleep on the pain, because ... it helps me concentrate, yes if it isn't a particularly intense pain, but if it is a pain typical of my illness, which is there, still ... I focus on the place that's hurting, the limb, and ... afterwards if I'm by myself, calm, I can even fall asleep on my pain.
- I: and this thing ... is it a technique you've developed independently {yes} something that ...
- V: no, no, no no, I did it all by myself {I see} little by little I did ... I don't know if, I wouldn't even say I made myself do it, it came naturally to behave like this.
- I: so, this, this isolating yourself it to, to better face ...
- V: to isolate the pain and to overcome faster the crisis, because, even with all the operations I've had, this is my 18th, I realised that if I stay calm, don't communicate with others and concentrate, the pain is les ... less intense. If instead I have to speak

because ... maybe because I need something, then the pain becomes stronger, takes time to control it again, but there are moments when the pain is definitely stronger.

- I: I hope <LAUGHS> you're not feeling pain now ...
- V: no, no, these pains are easy to tolerate, it's my hand ... when it goes up it hurts a bit but, no no, don't worry, no <LAUGHS> I would say so.
- I: so, why are you in hospital at the moment?
- V: because I've had an operation, I have a knee replacement, the second leg because I have had one for the other one two years ago, and then ...
- I: and ... the replacement, is it to help the knee function again?
- V: that's right, because I had a knock knee, quite a lot, and ... {meaning ... protruding?} yes, yes, practically, my hip was moving inwards ... and from the knee to the foot ... well it pointed outwards and it was ... I had problems moving, I found it difficult to walk.
- I: and did it hurt?
- V: well it did. Until it got completely deformed and then it became a mechanical pain, in the sense that if I didn't move, making no effort, I didn't feel it and, and I can say I could live normally at home. But it was enough to go out for a little walk and I could be sure the next day it would hurt. But it's a mechanical pain, not due to the illness. I mean it's the parts that now are worn out, because of rubbing against each other that's inflamed them ... and the next day ...
- I: and what ... what type of pain would this give you ... I mean, was it a burning or what?
- V: well, ok, if it swells up, then ... it's a sensation of heat, a burning, a pain ... and hot, it burns. If instead, but rarely because usually my knee problems have been caused by the liquid that formed, the synovial joint that would come out, and so all this liquid formed, if not it was only a pain ... when moving. So if I remained sitting, still, I had no pain but the moment I moved my leg I had, I had the pain caused by the rubbing, but not ... never unbearable pains, rarely have I had them.
- I: and so, what was the progression of the illness after the diagnosis?
- V: well, I have, ok ... I must go back in time, forty years <LAUGHS> no, [name of daughter and name of son] I had already had them, luckily because then they told me it was better not to have children, and the diagnosis... ok, I have had, for example, erm ... when my wrists became blocked, I have had fixed, continuous pains and in the end ... the wrists ... and all the bones, in the metacarpus became ... they became almost consolidated so you see, what I can move is this [shows hand movement]. Pain is constant. In the sense that more or less intense I've always had it, I've told you it's progressive but slow ... so that, erm ... it's never been that kind of pain that didn't allow me to live, to ... go to school, but still I had it, with me. It's always been a companion of mine, yes <LAUGHS> of forty years. Last year I turned fifty-seven, RA turned forty. I told it "com on, do me a favour, make me younger. You keep the fifty-seven ... <LAUGHS>. But it kept its forty years.

- I: and now, at this moment are you ... are you in pain while we're talking?
- V: yes, but I, it's a burning, not a pain, I have it in my knee where they operated. I have it going up, by the place where the knee bends I have it. but there's something, if it happens that I have a pain in one foot, or a hand, a shoulder, I have had strong ... well, constant more than strong, in the cervical vertebrae, so much so that I had a dislocation of the [inaudible] so they had to operate, and ... I accumulate pains, so ... the one I feel the most is the strongest. The others, I don't even realise I have them. I realise ... you see now I've made this movement [shows movement] my elbow hurts. It hurt, it's a mechanical pain because you see the elbow too is deformed. And I felt it [the pain] ... otherwise I wouldn't have realised I had a pain in, I mean when using a joint, if the joint is painful, if I don't feel it it's because there's something else more painful, and so when I move I realise that there's a pain in the joint ... it hurts. It's pains accumulating.
- I: and ... given you've lived so long with, erm, with these types of pains ... when it happens, I don't know, a pain which is not connected to your illness, for example if you bump into something, a corner ... a burning with an iron, anything, do you ... do you experience them differently?
- V: no, it's still pain. It's still a pain so I immediately resort to the defence mechanism.
- I: which is the isolation you were telling me before?
- V: isolation or concentration and ... with isolation, I've done it rarely when I was really suffering, but I can concentrate and, to ... I'm not saying to isolate because the pain I have it and I feel it, but, if for example, when I'm sitting here, and my knee hurts, if only I can turn the TV on and watch something, I can take my mind off pain. The pain is still there, I feel it, but it's no longer unbearable as it was a moment before. I need to do something to forget it. Anyway the defence mechanism against pain is ... wherever it may be coming from ... it's always the same, I think that by now it's become automatic ... this mechanism, this defence, I think.
- I: well, thank you very much *Signora*, I'm really grateful.
- V: not at all.
- I: is there anything you'd like to say, anything you'd like to add?
- V: no, because, well there's something important and that is ... but I've told you, it's the memory thing, in the sense that, that too is probably a defence mechanism, and ... but something that doesn't help me when I talk to doctors because ... "how are you feeling?", if at that moment I ... [interruption] if at that moment I don't have, any pains, but maybe I have felt so unwell as to call the doctor and say "I need to be seen" ... <LAUGHS> at that moment I feel like answering that I'm well because, I have erased all that has {that's passed} yes, right and that I then put to one side.
- I: thank you very much.
- V: not at all.

7.b Fabio

- Interviewer: what type of problem did you experience?
- Fabio: well, my problem is a discal protrusion. Erm ... that could be compared to ... like a herniated disc, more or less.
- I: this, when did this happen [inaudible]?
- F: this happened, well the operation was done in December 2002. Early December 2002.
- I: ok.
- F: and this problem started to be felt about a year earlier, it began to be felt.
- I: and how did it manifest itself?
- F: well, I must say that this type of problem, mhm ... before the operation, I had experienced years before. About seven eight years before, that miraculously it had gone as it had come on. It lasted a few months, well no, I would say ... maybe a year, and I lived with it not very well. But, since that was a particular time in my life so I didn't ... I put up, so to speak, with the pain. And then, miraculously it disappeared. Miraculously and luckily. Years later, probably because of a change in my job, of ward⁴⁴ type, so with much heavier work, the pain came back. As it had disappeared it reappeared. Initially, as a bother, so a nuisance, something, ehm, like the dripping of the tap.
- I: mhm mhm
- F: something like that, that you'd perceived, continuously, fastidiously, but that wouldn't ... when I say fastidious I mean it wouldn't let me ... to make movements that had been hitherto normal. But let's say it caused me some disadvantages. And then, little by little, as well as this sensation pain began to appear.
- I: what type of pain?
- F: of the type ... initially like cramps, not too intense. Then, erm, the intensity increased. These very strong cramps, like a muscle being violently pulled. As if somebody were pulling you and so you'd feel, not really pangs, because there was no apex in the pain, but something like ... like a burning, like needles, stinging from inside.
- I: and what makes you describe them first like an ache, something bothersome, then pain?
- F: well, it's that at first, I mean, the ache you could more or less erase it by engaging in other activities, concentrating on other things you'd put it to one side. But with the pain, well, you could put it to one side but then all of a sudden you'd feel it, it was

⁴⁴ Meaning: "hospital ward"; at the time of the narrated episode as well as the time when he was interviewed, Fabio was working as a professional nurse for the Italian National Health Service (SSN).

there. But also because even with the simplest moves, aside from being blocked, yes the pain would reappear. I mean, you'd keep it under control, but if you made a movement just like of the ordinary, like getting up from a chair quickly, or bending over or helping a patient with physiotherapy, or to somebody we had in the ward, it would force you to make these unusual movements and so the pain would reappear. It's not that it would come on in an acute way, but still, it would reappear, you'd feel it more. Because the movements would make you feel it more distinctly [inaudible].

- I: so, between the ache and the pain the difference was in the degree with which it interfered in your daily activities. Was it this that, is it this [inaudible] the determinant fact that made the former an ache and the latter pain?
- F: erm, yes when ... let's say it was more a psychological thing. In the sense that an ache is easier to put to one side. You feel it but, let's say, you can manage it. whilst a pain, erm, but let me repeat, I consider myself to have a very high pain threshold. So, erm, for me it's more effective, so to speak, to focus and things other than pain rather than taking painkillers. In fact I did take painkillers, very many, and the never helped. I mean, I was never helped by the painkillers. I followed a therapy for quite some time, prescribed by the doctor, with painkillers, erm, cortisone, and other stuff, but it never ... it never helped. Nothing at all. In the sense that the pain was there and wouldn't move, that's it.
- I: but if you had, if you'd had to describe ... the type of sensation you felt during that phase that you were calling an ache, was it the same or similar to that caused by pain, only less intense, or was it different? You [inaudible] spoke, of muscles being pulled, burning ...
- F: well, when I say "ache", think, an ache is something that hinders you, that stops you, erm, keeps you from doing certain things. And this ache, erm, I don't know ... it could be compared to a common ailment, like a low-intensity headache. Something which is there, which bothers you, but that you can manage.
- I: but so it was still ...
- F: whereas when an ache becomes a pain {yes} and what I mean by pain is this intensity, these cramps, these intense burnings in the muscles.
- I: but what I mean is, in the ache phase, would you still get these cramps and burnings, only at a lower intensity? Or was it an entirely different thing?
- F: no, they were there but less intense.
- I: I see. So it was [inaudible].
- F: yes an ache is, erm, initially it was an ache, it didn't give you pain. I mean, it was something you'd feel that began to set inside your body. Then pain added itself to this ache.
- I: mhm mhm.
- F: and then it became, erm, pain. Pain which of course still maintained ache-like qualities, because the ache, the nuisance caused by the ache is in the end more psychological than physical.

I: mhm mhm.

F: it would cause, at least to me, a mental stress.

I: mhm mhm.

F: I mean, it, it'd give me, it would cause me more problems the stress than ... than pain itself.

I: mhm mhm.

F: also because the pain wasn't something that would go up and down [in intensity]. It was constant, I mean a constant pain.

I: mhm mhm.

F: a constant pain of the same intensity.

I: which was always there.

F: which was always there. So, the fact of saying "I'll go to bed and rest" wasn't enough. I mean it was there, erm, when I fell asleep, this pain was there. Then I'd wake up and it would return. And so the nights, they would become, well bad, erm, I repeat, it was an unnerving thing, stressful, more than the pain itself.

I: it was ... that was the effect that pain had on your life, on your activities in general?

F: yes, on my activities. Yes, because being a person, I'm obviously talking about myself, being an active person this was an obstacle.

I: mhm mhm.

F: and therefore it had a very negative psychological effect.

I: mhm mhm.

F: therefore debilitating. So if I have to quantify ... the physical and psychological effects, let's say that to me physical pain was much more manageable, whereas the stress caused me many more problems.

I: mhm mhm.

F: I mean, the stress was more unbearable than the pain. And even if I realised that my pain threshold was high, physical pain was easier to bear than the stress this would cause me. It would give me more problems.

I: mhm mhm. And how did this change after the operation?

F: after the operation ... let's say that the operation had become a hope. A hope to start living fully again, to engage in my activities. But it wasn't so. Precisely because I'm very active, the days of convalescence following the operation, and by the way – it wasn't an invasive procedure that messed you up and left you scars, it was done with a laparoscopy – I didn't follow my doctor's instructions as I should have and I began my activities again, before it was time and so ... the result was negative, only half a success. In the sense that, whilst before it was constant, now occasionally the pain reappears, suddenly. So it doesn't appear gradually, so you feel it's coming on. It just appear, and that's it.

I: in terms of intensity, is it the same as it was before the operation, or is it different?

F: erm, not, it's ...

I: I mean, if you had to describe this type of pain to somebody who's never heard you talking about it before, how would you describe it?

F: well, let's say that in terms of intensity it's lower, if we're talking about the intensity.

I: and in terms of quality?

F: from, well ... from ten, if before the pain, if before the operation it was ... let's say nine.

I: mhm mhm.

F: now the pain is four, the fastidiousness is nine. In the sense that for fastidiousness I mean ... as an example, like somebody who keeps pinching you, erm, always in the same place. Do you understand? On your chest, for example. These little pinches that are not painful, but they are fastidious. I mean ... somebody keep pinching you pinch pinch pinch, until you end up thinking of it as really troublesome, like ...

I: but something that still manages to interfere with your daily activities ...?

F: yes, sure, yes. Yes because, I repeat, being a person who does a myriad of things, erm, I mean, this would hinder me. Meaning that, quite apart from my job, which I try do at the best of my abilities, other things ...

I: and does it still hinder you?

F: and it still hinders me. In the winter, for example, I practice sport, I sky, and this ... anyway whether I sky or not the pain is still there, so I'd rather sky.

I: mhm mhm.

F: in this sense. But obviously yes, you're skiing but you're not really enjoying going down fast, without a care in the world, happily. I also have an activity that lasts the whole year, of fitness in the gym ... and so this causes me ... actually I have to say I feel some relief in the absence of gravity, so swimming.

I: mhm mhm.

F: when I swim I don't feel anything. But I don't really enjoy swimming, I find it boring. So yes, I do swim, for a while, but then ...

I: well, earlier I asked you to think of an image, to create an image to represent this pain, the pain you've experienced with an image. Can you repeat it to me?

F: well, the image is a workman in the street, one of those roadside worksites, where a workman is using a pneumatic drill, yes and I ...

I: and are you the street?

F: erm, no, not really ...

I: are you the person nearby who hears this loud noise?

F: yes, more than the street I am ... the one who hears this deafening noise, unremitting, which, erm, which causes you all those problems and consequences ...

I: mhm mhm.

F: so, something that you quantify, that you assign a maximum value to. Because this drill, this noise, erm, always there, which goes on and on ... I mean I see it, I see it, that's how I've seen the pain, in that sense, more than something utterly catastrophic.

I: mhm mhm.

F: something like this.

I: so pain ... as image of noise, in a sense [inaudible]?

F: like noise, like movement, I mean seeing this workman that's holding this drill, and everything shakes, so ...

I: and it distracts you, it keeps you from ...

F: exactly.

I: it enters into your life.

F: exactly, it stops you from continuing it, and you apply strength to control this pneumatic drill, and you need increasing strength to bear it, to hold it in place, more strength than if you just let it go.

I: mhm mhm.

F: it's like "ok, let's see who's stronger".

I: mhm mhm.

F: and so, this is what wore me out, wore out my daily life, which had now become a war. In the sense that I refused this thing, I kept refusing it because ... well maybe a factor is that you realise you're getting older and don't accept it, don't accept certain things, although pain can happen also to a twenty-year old man, in case of an accident, or if he breaks a leg.

I: and now what is it, a radio playing too loud?

F: now ... no, let's say when this thing is there, when the pain returns, with the stress, because it was the stress ...

I: mhm mhm.

F: so, erm, there's a psychological factor coming in, I mean the fear of, of living the same experience as before.

I: mhm mhm.

F: so to be unable to move, to feel blocked, even for a stupid thing like getting into a car.

I: so more than, more than what what's actually happening to you, it's what's possible, the possibility of reliving the experience?

F: right. That's right. More than the pain that comes back. Because for example, sometimes I'm walking in the street, going on a walk ... easily, and suddenly your leg gets stuck because you have this pang that comes on ...

I: mhm mhm.

F: suddenly.

I: mhm mhm.

F: and so, as well as the pain you think "heck, why now" I mean ...

I: mhm mhm.

F: it's something that wears you out, psychologically, more about that than about pain.

I: mhm mhm.

F: because if it was just the pain and nothing else, one could say "ok" ...

I: mhm mhm.

F: if you have ... if you have a toothache you take a painkiller and it goes, yes, or if you know you have to have an operation, say [inaudible], I mean you know it's going to have an end.

I: mhm mhm.

F: with a toothache, but not in this case. Because discal protrusions, anything to do with the spine, it stays.

I: mhm mhm.

F: this is it, I mean.

I: thank you.

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