



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Pain Experience and the Imagined Researcher

Citation for published version:

Smith, MV 2008, 'Pain Experience and the Imagined Researcher' *Sociology of Health & Illness*, vol. 30, no. 7, pp. 992-1006. DOI: 10.1111/j.1467-9566.2008.01096.x

Digital Object Identifier (DOI):

[10.1111/j.1467-9566.2008.01096.x](https://doi.org/10.1111/j.1467-9566.2008.01096.x)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Sociology of Health & Illness

Publisher Rights Statement:

© Smith, M. (2008). Pain Experience and the Imagined Researcher. *Sociology of Health & Illness*, 30(7), 992-1006. 10.1111/j.1467-9566.2008.01096.x

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Pain Experience and the Imagined Researcher

Marion V. Smith
School of Health in Social Science
University of Edinburgh

Abstract

Little attention has been paid to what happens communicatively when members of the general population attempt to complete a postal survey. The questions – here, on the experience of pain – encapsulate health researchers' views of useful indicators of the scope of pain experience, hence displaying an 'official' representation of experienced pain, limitation, and disability. The respondent faces the double task of aligning their personal experience with this representation in a way that is meaningful and true both to their own experience and to the perceived demands of the questionnaire. For this to succeed, context is often crucial. The paper explores sources and indications of tension in this endeavour as part of a communicative process. Beginning from the observation that respondents frequently write unsolicited comments on their questionnaires, the paper proposes that the need for communication beyond the requested tick in the box treats the questionnaire as an attempt at dialogue with a figure I call 'the imagined researcher'. The paper discusses the communicative task that confronts respondents and the implications of 'the imagined researcher' for the research process.

Keywords: Communication; surveys; methodology; pain; fibromyalgia, marginalia

7914 words

Introduction

This paper explores indications of tension in the way respondents answer questions in two pain surveys. Instead of taking the questionnaires simply as instruments which attempt to measure aspects of pain, disability and limitation, the analysis here takes the questionnaire as a 'communicative floor', and considers the indications of tension as part of a communicative process. By 'communicative floor' I mean a space or opportunity for dialogue that is created between participants by their orientation to each other and to their shared topic(s) (cf. Sacks et al. (1974). The receipt of a postal questionnaire can be seen as a summons or request for communication, and the completion and return of the questionnaire as a relevant response. The paper explores the ways in which this highly specialised type of communicative floor, specifically in the context of communication about pain experience, makes particular demands on respondents and raises particular kinds of problems. These effects are indicated by some respondents' attempts to communicate directly with an authoritative figure behind the questionnaire by writing comments in the margins and in various ways departing from instructions on the completion of the questionnaire. The principal issue here is not simply a matter of the construction of questions or the contexts of use (cf. Barroso and Sandelowski, 2001), but crucially one of communication (cf. Clayton et al. 1999) and the transformation of experience into a specialised format.

Issues around pain and communication are of enduring interest and topicality. As there are no unique physiological indicators of pain, the fact that someone is suffering can only be approached through body language, grunts and groans, and spoken/written language. It is language that transforms private experience into the demand for services or presentation of the problem to health care professionals and friends alike. It is on language, in this case survey questions and responses, that we rely in order to gather information on e.g. the distribution of chronic pain in the

population. It is language that forms the bridge between unpleasant personal bodily experience and the social world. Hence language is a critical form of social action and the catalyst for pain as a socio-cultural experience (Smith 1998). Yet pain's resistance to language, it has been argued, is central to what it is (Scarry 1985; Morris 1991); and Frank (2001) eloquently makes the case that suffering similarly resists expression. What sorts of problems may arise, then, when respondents are asked to communicate their experience within the limited capacities of the fixed choice questionnaire? The health survey reduces the possibility of communication to a most frugal level in the sound and established interests of clarity, precision, and to aid understanding of patterns and frequencies across defined populations.

Survey researchers' purposes are satisfied by statistical tests that demonstrate adequate levels of validity and reliability in amassed responses to surveys. But at the personal level of experience of living with pain and disability, it is hard to acquire data – other than through the costly and time-consuming process of conducting semi-structured interviews alongside the survey (thereby diminishing one advantage of survey research) – which would inform or reassure us that the tick-box procedure makes sense to respondents as a representation of their suffering and difficulties, and that it has a validity that *they* can recognise. There is no formal way to reassure the researcher that respondents are satisfied with *what* and *how* they have been able to communicate. There is, however, one indicator of respondents' reactions to the questions that could also serve as an unsolicited and spontaneous source of further information about their experience. I refer here to addenda and annotations that are made around the response boxes on many questionnaires. The fact that such comments are made at all could be taken as an indication of strain within the working of the questionnaire. Presumably it is only because the questions cannot be answered in a straightforward manner that respondents feel the need to comment on or qualify their answers.

For some researchers (interestingly, both quantitative and qualitative) these addenda are not data but rather an indicator of trouble:

These comments are not data; they are simply an indication that the researcher should begin again by conducting a solid, appropriate qualitative study. (Morse 2005:584)

This implies a focus solely on the questions rather than one that seeks to include the marginalists as producers of comments in the margins. Two questions follow: first, whether these comments *can* be treated as data, and secondly whether they are merely a *simple* indication of inadequate preparation or problematic question design. I suggest rather that we should pay attention to such phenomena and allow ourselves to consider more deeply their significance. In this paper, I explore the nature of a communicative event that takes the form of a task requiring the attenuation of personal experience into a limited range of questions and answers.

It is not my intention to focus here on the formulation of questions or the range of choice (cf. Mallinson, 2002). This is, however, necessarily implicated in the discussion that follows. Rather, this paper focuses on the analysis of annotations at two levels. First, how far are some of the problems to do with the nature of questions, the nature of pain, or the interaction of both? The signs of strain may be purely to do with the representation of pain experience in the form of a check-list of boxes. Secondly, a distinctive aspect of the argument presented here is closer consideration of what the respondents are doing when they break the convention and write in the margins of the survey forms, and for whom they may be doing it. In the discussion below I call this person 'the imagined researcher'.

The empirical basis of this discussion is a small exploration and analysis of unsolicited comments made by respondents to two large-scale medical surveys about the experience of fibromyalgia and knee pain. These were postal surveys, completed anonymously by 3000 sufferers of fibromyalgia contacted through support groups in the first case; and by 8995 members of the general population over the age of 50 years and belonging to three GP practices in the second case. Two hundred forms selected at random (100 from each survey) were scrutinised for any addition made by the respondent beyond those requested in the instructions. Although the majority had no such additions, 44% of the fibromyalgia forms had some kind of additional comment or information provided, and 33% of the knee pain forms. Clearly, a large minority of respondents were moved to communicate beyond requirements. This has been reported by others: for example, Clayton et al (1999) found that 25% of respondents to a questionnaire on health promotion and quality of life in multiple sclerosis (MS) added extensive qualitative comments. However, as this paper is not intended as a full report of my investigations, some of the findings will be reported here only to illuminate the discussion of the issues outlined above.

The Questionnaires

Fibromyalgia is characterized by widespread pain and (most importantly for some researchers) the discovery on examination of 'tender points', specific anatomic sites that respond painfully to touch. Often, the sufferer was not aware of these sites before. About 80-90% of fibromyalgia (henceforth, FM) sufferers are women. There are multiple other symptoms associated with the pain, in particular stiffness and fatigue, and sufferers have very little recourse to any form of relief. There appears to be no underlying pathology. FM is a 'new' condition insofar as it has only been diagnosed since the 1980s. Its diagnosis is still contentious, not systematically applied across practitioners, and sometimes not recognised as a unique clinical entity

(Okifuji and Turk 1999; Wessely and Hotopf 1999; Dadabhoy and Clauw 2005; Mease 2005; Katz, Wolfe and Michaud 2006).

The questionnaire in this study (henceforth, FMQ) presents itself to the user as a survey of sufferers' experiences of fibromyalgia. However, the range of possible experience is of course predetermined by the questionnaire. The FMQ is set out in three sections on background information; experience of fibromyalgia (including a manikin on which painful sites are to be recorded); and general health and activities. This third section of the questionnaire notes in the introductory instructions that respondents are welcome to "make any of [their] own comments if [they] like", but by each individual question in section 3, as elsewhere, instructions are precise, e.g. "Please tick one box only"; "Please answer Yes or No to each question". This questionnaire, despite the invitation at the head of section 3, and like many others, does not appear to cater for, or expect, any response other than ticked boxes or brief responses to closed questions (e.g. "What is your job?").

The knee pain questionnaire (henceforth, KPQ) has five sections. It presents itself as an assessment of the need for health services, and asks all respondents to fill in the first four sections, and only those with, or who have had, knee pain, to fill in the final section. The sections comprise a manikin (on which respondents are asked to record aches or pains); general health and activity questions (identical to FMQ); a further range of questions about feelings (e.g. "I feel restless as if I have to be on the move"); and background information. This last section introduces the focus on knee pain via two questions ("Have you ever injured your knee badly enough to see a doctor about it?"; "Have you had pain in the last year in or around the knee?"). Those who have experienced knee pain in the last year are then requested to move on to the final section which asks where the pain is (i.e. in which knee, or both), on

how many days they have had it over the preceding year, and whom they have consulted; and a range of questions on how much pain they have under different conditions (e.g. walking, standing), how much joint stiffness they experience, and difficulty over a range of activities.ⁱ

In this questionnaire each question is followed by an instruction (e.g. “Please put a cross in one box on each line”), but as well as this there is a general instruction at the beginning of the questionnaire which records that all answers should be marked by a cross in the appropriate box. Written responses (e.g. to occupation) are to be given in block capitals, and short vertical lines (thus providing a space for each individual letter) subdivide the lines where they are to be written.ⁱⁱ Nothing invites the respondent to supplement their responses by further comments.

Under these restrictive and directive conditions, what makes so many people (a third to two fifths of respondents) decide to ‘break out’ of the format and supply additional information? The parameters of this specialised ‘communicative floor’ are very clear. So why do they transgress the convention? This is not a consideration that can be taken lightly: the convention is powerful, given the instructions by each question and the standard layout of the questionnaires. This is an issue to which I shall return.

Communicating through questionnaires

When sufferers are confronted with a questionnaire that presents them with a range of questions and a limited number of possible responses to each one, the task they encounter is a double one. Each question has to be understood in the context of the questionnaire *and* in the context of their personal experience. Taking the example of general health, both questionnaires start by asking whether in general the

respondent's health is excellent, very good, good, fair, or poor. Five people made comments at this point on the knee pain questionnaire, and eight on the fibromyalgia questionnaire. These are given in Table 1 below.

Table 1.

Knee Pain annotations:		Fibromyalgia annotations:	
Box ticked:	Comment:	Box ticked:	Comment:
1: Good	Goodish	1: Good	Apart from FMS/MPS
2: Good	non insulin diabetic	2: Good	other than FMS
3: Good	except for aches and pains	3: Good	i.e. good apart from fibromyalgia. I rarely get colds or other infections
4: Poor	I have hiatus hernia, diverical colitus (sic) at the moment, I have just had a lot of x-rays and tests. The doctor thought it was cancer there is something, but I have got to have all again in 4 months	4: Good	I count my blessings. I know it could be much worse, I try to maintain a positive attitude.
5: Poor	Rheumatoid arthritis, has a wheelchair blind in one eye, just see a little in the other My husband is almost housebound. (Written by wife on husband's behalf.)	5: Fair	I have answered this question based on my overall health including FM.
		6: Fair	I do not know any difference you accept how you feel as normal
		7: Poor	(Including FMS)
		8: Poor	Not good and bad days – but bad and worse days

The scope of this question is clearly under-determined. Whether or not those who simply ticked a box were aware of this is impossible to sayⁱⁱⁱ. Most of the annotations on the FMQ make it explicit as to whether they have rated their general health including their FM or excluding their FM. But this hides a deeper question that is brought out by some of the other responses. What is 'health' (cf. Seedhouse 1986, Blaxter 1995)? This is a double-edged question: in the context of the questionnaire,

is the scope of 'health' locally defined, so that respondents should answer about aspects of health that are not dealt with in other sections of the questionnaire, or is it a general question about experienced well-being? In the latter case, is it a relative condition (e.g. healthy or unhealthy for someone who spends their days in a wheelchair) or does it tend more towards an ideal state? Does 'health' refer specifically to 'illness' or 'disease'? and in which case should 'aches and pains' not be taken into account? The very familiarity and fossilised nature of the phrase 'aches and pains' has a trivialising force, which may have to be borne out behaviourally, even if experientially they are not trivial. Perhaps 'health' refers to your usual state, a point from which you never or rarely go up, though downward episodes can always occur (cf. Lowton and Gabe 2003). This would be the 'normality' that one comes to accept (as in response 6, FMQ) and might incorporate being confined to a wheelchair and blind in one eye (response 5, KPQ). Does the question imply an implicit comparison with others? Is 'Poor' checked for this last respondent from a sense of self, or from a sense of others? It is clear that the 'poor' general health of respondent 4, KPQ is a different kind of 'poor' general health than that suffered by respondent 5, KPQ. The FM respondent who accepts how she feels as 'normal' refers to a potential difference within *herself* that would inform her that her health could be better or worse. The respondent who 'counts her blessings' and checks 'good' (response 4, FMQ) either has experienced much worse herself, or refers to her knowledge of others' suffering. She suggests her answer is informed by her commitment to a 'positive attitude'.

These few comments open up an ill-defined microcosm where words and concepts tie in poorly with personal experience. This is a language issue; but there is also the problem of pain. As Jackson (1994, 202) notes, "Any chronic pain whose underlying pathology is not totally clear ... confounds the common-sense notions of disease and health". How can we begin to unpick this?

In the terms of the communicative context of the questionnaire, general health presumably should be rated without taking account of the specific condition because that is dealt with in a separate section elsewhere in the questionnaire (although no instructions clarify this issue). However, in terms of experience, how can respondents divide themselves into a part that suffers from fibromyalgia or knee pain (that has to be managed and taken account of in all aspects of daily life), and another part that can be assessed separately, albeit on a fuzzy parameter? In such a dilemma, one can provide a 'best guess' answer, or one can attempt to make the answer truly meaningful by providing a context or trace which shows what lies behind that answer. By these means, an FM sufferer can rate their health as good on the grounds that they "rarely get colds or other infections": they make explicit their own criterion of health in order to meet the requirements of a question in a particular context and make it coincide meaningfully with their own daily pain. Clayton et al. (1999) report that their sufferers of MS clearly felt the need to provide a context for their answers, in terms of past or current circumstances or events. These comments appear to be longer and more detailed than the majority of those on the FMQ and KPQ. The further question here, however, is why take the trouble to provide the trace, or why is there a need for commentary? Perhaps there is a sense in which it is this that enables the respondent to tick the box. Personal context is necessary for any one box to become a reasonable answer, so it therefore becomes necessary to their answer for that information to be written on the form at the precise point of communicative trouble. The convention must be transgressed in order for meaningful communication to take place.

Where a comment refers to a specific question, it may make better sense to a respondent to record their message where the issue arises, rather than to use a free text comment box at the end of the questionnaire. No comment box was included on

either the FMQ or KPQ, but Garcia et al. (2004) report fairly substantial usage on medical careers surveys (on average, 40%) and a maternity care survey (43%), and Ong et al. (2006) report 80% on a low back pain survey. In such cases, the imagined researcher has a more official or bureaucratic presence within the questionnaire and the opportunity for dialogue is more developed, albeit within circumscribed limits. Garcia et al (2004) found that few comments related to one ticked box on a specific question, but did give more depth on some topics covered by the questionnaire as well as identifying new issues and providing feedback on the research process. Although such comments are invited as part of the formal structure of the questionnaire, and presumably are more likely to be admitted as 'data', Garcia et al. (2004) raise a number of points about how such data are to be analysed.

Question 3 in the general health section asks respondents about activities they might undertake in a typical day, and how much they are limited in carrying them out (a lot; a little; not at all). Ten activities or groups of activities are listed. Five people provided annotations on this question on the KPQ, and ten on the FMQ. On the KPQ, the comments qualified either the question or the selected answer. For the former, in one of the questions that listed a group of activities, the respondent underlined just one of them, presumably indicating that she was answering the question on this activity alone. Perhaps she could not attempt the others. For another question, about bathing and dressing oneself, the respondent indicated that she could dress herself, but not bathe alone. For those who qualified their answers, one woman recorded that she was not limited in 'Walking more than a mile' if it is a flat walk. This response was also recorded on the FMQ for 'Walking 100 yards'. Three responses (one KPQ, 2 FMQ) record that their ability to do an activity varies. The remainder of comments on the FMQ indicate that some activities are possible if they are "done taking time", or done "with pain", or done "with help". Several activities are ticked as 'limited a lot', but beside them the respondent has recorded

that the activity is “impossible”, or they are “never able”, “unable”, or “do not” do it. These take up the remainder of the comments for this question. These responses, particularly those on the FMQ, open up a realm of disability that the questions themselves do not touch. In the context of the questionnaire, the categories cover a reasonably representative range of normal daily activities such as climbing stairs, bending, walking and vacuum cleaning. Yet these apparently simple categories do not translate unproblematically into the social context of restricted lives. For accurate communication to be effected, the questions or answers have to be adapted. Do these respondents take the trouble to increase the accuracy of the question and/or the answers for their own satisfaction, or do they believe that the researcher who receives their questionnaire will appreciate greater precision?

A further brief example from the general health section takes us further into the life-world of the FM sufferer. The question asks how much physical health or emotional problems interfere with normal social activities, and receives two tart responses:

“I cannot sit down or stand up still for long at a time (i.e. half hour). This is a major constraint on my lifestyle.” (Ticks ‘Quite a bit’)

“The question hardly applies. Unchanged. Social activities are normally rare.” (Ticks ‘Not at all’).

Again we have a sense of the slippage of comparative standards that people use to answer these questions. Long-term conditions develop their own ‘normality’ within which people exist. Some appear to acknowledge that ‘normality’, like the second respondent above who claims that her ‘normal social activities’ are not affected at all, while others (e.g. the first above) retain the implicit contrast with what could be. The whole idea of ‘normal’ activities in the context of the long-term FM sufferer is puzzling and contradictory. Comments such as these supplementing an apparently straightforward choice of box carry a sense of protest or exasperation, focused at this moment on the ineptness of the question.

Writing for the imagined researcher

There are conflicting processes of meaning-making at work here. The research instrument constructs FM or knee pain in line with a specialised body of knowledge that has determined the form of the survey, whereas the respondents' body of knowledge comes from their experience. What they have to attempt is a construction of their experience in terms of the questions. Writing on the form itself not only shows us this process in action, but also implies that there is someone who *can arbitrate between comment and box, and complete this translation for them in terms of the goals of the questionnaire*. The imagined researcher, therefore, is someone who is actively engaged in the questionnaire as a turn-taking floor rather than an endpoint, and who can *understand* and hence is the mechanism for successful communication. The respondent appears to conjure up a communicative partner who can receive the concern that the tick in the box may be insufficiently informative or actually misleading. As someone who *wants* to receive information about personal experience of pain or difficulty, this (potentially caring or influential) imagined researcher needs data that are accurate and make sense, and it may be in sufferers' interests to supply it. There is also a compelling sense of respondents' eagerness to be truly helpful. This was also noted by Clayton et al. (1999), where respondents expressed their wish to make a positive contribution to an effort to improve future care and understanding. Such respondents have experience that someone wants to know about, and they are prepared to take the trouble to point out where the questions or answer choices do not match that experience. The irony is that they may achieve little more than to slow down data entry. The respondent, therefore, sees the filling in of the questionnaire as a communicative task, whereas the researcher can usually take a strictly limited interest in annotations, and in the main

will enter all reasonable-looking ticks into statistical analysis. The tick in the box has a different symbolic status.

I turn now to the section of the FMQ that asks specifically for information on respondents' experience of FM. The FM section has nineteen questions, six of which cover issues of onset (timescale), diagnosis and consultation, whether relatives have similar symptoms, and events that may have triggered the condition. The remaining questions deal with the location of aches and pains, symptoms, other medical conditions, and a further range of questions about feelings and limitations on activities.

I shall deal with the six 'background information' questions first. Most of the comments that have been added attempt to make their answer more precise than the choice of boxes allows. For example, under the question "Who first diagnosed you as having fibromyalgia?", four people have ticked the 'Specialist' box, and added 'Rheumatologist'. Under "When did your pain start?", two people have ticked 'More than 10 years ago' (the longest time period) then added a date, '1975', '1963'. Others have ticked two boxes, and indicated that the more recent box shows when they suffered a marked increase in the severity of their problems. The most notable comments occur under question 3, "Who have you been to see about your symptoms?". This appears to be a very straightforward question that does not obviously need any qualification or elaboration. There are twelve healthcare specialisms to choose from (and more than one box may be ticked), plus space for "others, please specify". Beyond the qualifying comments such as 'plastic' added to "Surgeon", and 'cranial' added to "Osteopath", respondents have added comments as shown in Table 2.

Table 2.

Box ticked:	Comment:
1. GP	He told me it was not such a thing as Fibromyalgia in spite of there being a pamphlet about it in the waiting room.
2. Others	Occupational Therapist who was a waste of time just had me in tears.
3. Others	I attend C_ Hospital regularly for rehabilitation (also pain clinic at _ District General Hospital)
4. GP and Rheumatologist	Had to fight to get my GP to let me see He said it was a waste of time. It was. They diagnose you then discharge you to care of GP. There is no chance to try other treatments or be referred on.
5. Others	Specialist in ME, FMS, and CFS! (they do exist!)
6. Others	Urologist – also get urinary problems (cystitis)
7. Others	Self-referral to NHS incontinence advisor for IBS and IC. Both her and the NHS Aromatherapist helped me.
8. Others	Orthopaedic; healer 1979 to learn relaxation, meditation and healing.

Alongside this list it is worth considering two further comments that were appended to the “Myself” box under question 4, “Who first diagnosed you as having fibromyalgia?”:

9.	After my friend showed me an article on FM saying it sounded like the way I felt. Then I discussed it with my doctor.
10.	I specifically asked if I had this illness.

From reading through these comments, it is clear that there are troubling issues surrounding the diagnosis of FM. In the FM sample, this question received more annotations than any other. This suggests it touched a raw nerve: an apparently straightforward question aroused a far more complicated set of experiences than a straightforward answer could convey. First, there is a concern that diagnosis *does take place*. Comment 1 shows a mismatch between what the sufferer thinks she has got, and what the GP thinks. Further, such a conflict of views (the sufferer has joined a FM support group, so she has acted on her self-diagnosis) can lead to patients feeling that their problems are not acknowledged, either sufficiently seriously, or even

at all, if they do not end up with a diagnosis that they can recognise or trust in themselves. The pamphlet in the waiting room need not, of course, have any bearing on what the patient may have, but the comment hints that this patient was informed about the symptoms of FM and that the GP was not. Other comments compound this sense that sufferers need to be proactive in order to be diagnosed: it is not a simple or even complicated process of recognition. Thus comments 9 and 10 show that both these sufferers took the diagnosis to their GP themselves. Comment 7 mentions “Self-referral” and comment 4 asserts that she “had to fight”. This is clearly experienced as contentious ground. However, once made, the diagnosis need not herald greater satisfaction. As comment 4 shows, the consultant’s diagnosis simply led back to the GP’s surgery. There is a sense here that diagnosis is meaningless if nothing follows. This is borne out by comment 2, whose experience of the occupational therapist led only to fruitless distress. Alongside the ‘blind alley’ of diagnosis is a feeling that somewhere there must be a treatment or a specialist that can help: it must be perplexing to run into seeming incomprehension. Comment 4 refers to the lack of opportunity to try other referrals or treatments. Is this an impasse created by a lack of availability, or by a deficit in expertise? Comment 5 suggests that there are indeed appropriate specialists, but perhaps that it is difficult to find them. She even suggests that the administrators of the FMQ may not know of their existence: the parenthetic exclamation is insistently pedagogical. Augmenting this sense that there is no ‘traditional’ or ‘standard’ pathway to health for FM sufferers is the list of ‘alternative’-style treatments that we can compile from comments 3, 7 and 8: relaxation, meditation, healing, aromatherapy, and the pain clinic. This deepens the suspicion that there is little specialist interest in musculoskeletal pain. Comment 5’s exclamation marks draw attention to her protest.

A further problem in the diagnosis of FM is suggested by comments 6 and 7. Why, in a question about consultation for FM symptoms, do they refer to cystitis, IBS and

IC? Hovering here is the issue of which symptoms belong to which condition, and in what sense are they not all part of the same thing as manifestations of disease within one body. The checklist of FM symptoms on the questionnaire numbers 24 items, and there is space for others. What are the boundaries of this condition, and how can some symptoms be separated out and attributed to other conditions? Such questions blur our focus on the separation of symptoms into a dependable classification system for diseases. Ultimately, what is FM?

Finally, what does come over quite strongly in several of these comments is the respondents' resentment at the treatment they have received. Comments 1, 2 and 4 use formulations such as "not such a thing", "waste of time" and "had me in tears". These people are already suffering a mysterious and painful condition that is not readily treatable. As time goes on and such unsatisfactory and distressing experiences start to accumulate, what does this illness become?

The addenda here appear to be specifically linked to the experience of FM. In terms of the two questions posed at the outset of this discussion, these signs of strain do not seem to me to be connected either to the nature of questions, nor simply to the nature of pain. Those who have written comments are supplementing their answers, but they are not adjusting the meanings or scope of questions or responses as hitherto. There clearly is real strain here, but in the diagnostic process. In some sense, the commentators feel compelled to give further information even though it is not required or invited by the format. Again, they engage an imagined researcher and extend the range of the questionnaire in a direction that to these people at least is significant.

On the checklist of 24 symptoms mentioned above, respondents make changes that emphasise what is worst (three ticks to a box rather than one), narrow down a

symptom (e.g. deleting “mouth” in “Dry eyes and mouth”), or expanding a symptom (e.g. “and number” added to “Word mix-ups”). The list of symptoms is impressively extended under the “other” box: the sheer diversity and quantity is arresting. It returns us to the central enigma of what FM is. We should note some respondents’ concern to give more accuracy or detail than the questionnaire requests. Given the contentious issues around diagnosis noted above, do these people merely wish to express their experience more accurately than the format allows, or do they feel this more as an obligation, to really inform the researcher what FM is like? In the space left for other symptoms, three respondents have expressed themselves figuratively:

1. “muscles feel as if they beaten with cricket bats, joints feel as if they have been blown up by a syringe with sticky glue.”
2. “in the morning when I awake I feel as though a 10 ton truck has run over me.”
3. “painful tremor travels all down left side like machine gun fire.”

Instead of just naming a state in which they find themselves, e.g. sore muscles, painful tremor, these three people have sought to convey through simile how this actually feels to them (cf. Soderberg and Norberg 1995:58). A painful tremor may indeed be disturbing, but “like machine gun fire” conveys a sense of violence, a fear of damage and the unremitting nature of the experience. A straightforward description remains as someone else’s experience which, as a separate person, we cannot apprehend. A vivid simile, however, induces in the reader a synaesthetic appreciation of that experience. Similarly we can imaginatively encompass the night-time visitation of the 10 ton truck. This works to convey a sense of the weightiness of the body, the impossibility of movement, and the utter lack of refreshment from rest. Likewise the size and weight of the cricket bat evoke the intensity and indiscriminacy of the damage inflicted. This is contrasted by the precision of the syringe (why not a bicycle pump for instance?), and we gain a sense of the widespread and the localised contradictions of the experience. Overall, these similes convey

overwhelmingly the experience of violence done to the body, a violence from which they cannot protect themselves and which leaves no visual mark.

Most comments on the remaining questions briefly help to contextualise engagement with activities. Thus meals are prepared “with help”, or cars can be driven but “only locally”; other activities are followed by “pain and confusion after”. One person noted by her answers, “I have domestic help and an automatic transmission car to ease strain”. Does it count as “always” being able to do an activity, if you always have help and could not manage without it? Or should you, under such circumstances, tick “never” or “occasionally” if you cannot do it unaided? There is no guidance on such questions about the circumstances under which the respondent copes. Should their answer reflect their unaided ability, or their management strategy? If this is the dilemma, then a brief comment provides the context for the imagined researcher, so that they will know how to ‘take’ the information offered.

Concluding discussion

These comments are an invitation for researchers to “listen” into living with pain and disability; on FM pain in particular; and on difficulties in answering some questions. The forced choice format of these questionnaires is a severe communicative restriction. Of course, this is also the essential strength of the well-designed survey. But where information is supplied about ambiguity in questions or about pain experience, then it may well be helpful for these communications to be more fully received. Under these circumstances, the structure of the questionnaire then becomes enabling in terms of outcome, rather than simply constraining. Clayton et al. (1999, 521) refer to information received in this way as “serendipitous”, but acknowledge a responsibility for researchers to treat it as qualitative data and to

“address and disseminate” it. They note that there is much to be learned about the experience of chronic illness.

The instructions on how to fill in the questionnaire are explicit and the majority comply. That the researcher is expecting to receive clean sheets except for ticked boxes (and the occasional word or two for e.g. job title) is clear^{iv}. Under such circumstances the normative pressure is towards responding as intended and performing as requested. Schumann and Presser (1981, 298-9) note “the form of the question places an enormous constraint upon respondents. One of the clearest findings ... is the extent to which people ... accept the framework of questions and try earnestly to work within that framework”. With that in mind, what we see in these comments may be the tip of the iceberg. We also need to be aware that what lies behind a single ticked box - the range of experience, the contexts of that experience, and the decisions that informed that tick – is diverse. FM patients “are not homogenous, and we need to pay attention to the individual differences” (Okifuji and Turk 1999:242). There is a considerable hinterland that the comments considered in this paper go some way to sketching out.

The communicative relationship that is set in motion by the arrival of the questionnaire is a double one. First, respondents must engage with a tool, a series of questions. This demands a task of translation, that of experience into the linguistic categories provided. This in itself is not straightforward, and epistemologically is a constructivist task servicing a positivist tool. Felt experience is being translated into check boxes. These compress and neatly encapsulate experience that is amorphous, complex and may have different priorities and significances. It tidies up limitation and suffering rather than seeking to grasp it at a level of phenomenological attunement. Compare, for example, the metaphors for pain and the information gleaned from the ticked boxes. This isn't simply that more space for more text gives

us more information. Our understanding is different in kind. Here experiential knowledge is being recast as a new form of knowledge that will be put to uses, one of which is to create an account of the experience of fibromyalgia. This is a further translation. In essence, experience is sifted into linguistic boxes which are then translated into numerical scores before finally being accounted for in a third translation into different linguistic terms. Furthermore, the numerical scores and/or linguistic account will be put to other uses according to the aims of the research project. All these stages of translation (threaten to) undermine the connection between the real experience of fibromyalgia and the outputs or uses of the research. It seems to me that what we risk finding under these conditions is the overall structure of the questionnaire: arguably it is the questionnaire respondents are likely to recognise in a research report rather than a satisfactory representation of their experience. In short, the communicative floor opened up by the arrival of the questionnaire is not a space for direct communication but the starting point of a lengthy process of translation of experience into different sorts of packages.

The communicative floor demanded by a questionnaire is didactic and mechanical.^v The questions are presented so that the reader is 'taught' instantly how to answer. The process of selecting a box to tick, a point to mark, should be a mechanical translation of experience into a new form of representation. This demands an objectivist stance where knowledge can be located and engineered into a new recordable form. But the invoked presence of the imagined researcher is partly a manifestation of the stresses undergone to achieve this, and partly a misconstrual of the floor as dialogic and organic. The engagement with the imagined researcher shows the experience of communicating pain in the language of the boxes as requiring dialogue: cautions, caveats, qualifications and explanations.

By breaking out of the dual constraints (what information to present and in what form) respondents act as though they can communicate more freely *and* that there is somebody with whom communication can be engaged. In other words, the communicative task implies a communicator – the imagined researcher – whom the marginalists attempt to reach by going behind the questions they are trying to answer (cf. Clayton et al. (1999, 521) who report that “One of the unexpected findings was realizing that participants saw themselves in dialogue with the researcher”). The comments can be seen as an attempt to turn a somewhat passive process into a more dynamic, participatory one and hence an invitation to the imagined researcher to become actively involved rather than simply record the tick. Where the respondents cannot comfortably ‘fit’ their experience to a category, they explain, protest, or display the problem for the imagined researcher’s information or arbitration, and this suggests one clear role for the imagined researcher beyond being the receiver of unsolicited information. In a sense they are the ‘dictionary’ in their ability to authoritatively exchange one token for another in a different communicative system. As the originator of the questionnaire and implicated in the laying out of the parameters of pain and limitation, they should know how to incorporate information that does not correspond with a box - or at least have the anomaly pointed out to them.

One possible role for the imagined researcher is as the provider of a therapeutic intervention. Clayton et al. (1999) received comments which expressed gratitude for the opportunity to think about their lives and experience of MS and to confront lifestyles and feelings. There was no sense of the FMQ or KPQ as ‘therapeutic’, but rather an overall impression of constraint, and this suggests a further and less propitious role for the imagined researcher. It should not be forgotten that the health survey is essentially a levelling exercise. This is not just because it sets out the questions and answers. By presenting itself as an investigative tool from hospital or

academic departments it is in itself an authoritative communication. Its structure conveys to the respondent an educative display of categories of pain, limitation and disability, and indicates what is of significance, interest, or use. The imagined researcher is not simply a potentially beneficent gatherer of information, but also an authority on what counts. The respondent's pain experience is structured by the questionnaire; the act of filling in the questionnaire legitimates the representation denoted by the questionnaire. Respondents who seek to overcome this can be suppressed not simply because their intervention is set aside, but also because they are 'wrong' to attempt it under the specified communicative conditions. They have in a sense spoiled their paper by writing out of the box, and their response (their 'vote') no longer 'counts' in the survey. Respondents' comments are saying "You won't know it by asking like this", "I can't make my experience fit here" or "This is what you need to know". The danger, beyond this information not being received, is that those who just tick the boxes despite difficulties may feel that *their ability to answer* is inadequate, not the instrument.

Finally, I suggest that the mismatch in communicative aims between respondents and survey researchers embodied in the imagined researcher is particularly poignant in painful conditions where medical understanding is not well developed. It has been said that pain's resistance to language is central to what it is (Scarry 1985), but also that suffering "is the unspeakable, as opposed to what can be spoken" (Frank 2001:355). Pain, and the results of pain in terms of daily restrictions and changed relationships – forms of suffering – are hard to communicate, and the data discussed here underscore their amorphous, nebulous and dominating presence, the particularity of individual experience, and constricted lives. It is problematic in its communication, yet important to communicate, as appropriate treatment cannot be obtained by maintaining silence. Hence the imagined researcher may be conjured more strongly by the FMQ than the KPQ, because of the relative lack of support,

treatment and understanding of medically unexplained conditions. This argument would hold true for the rich information added to the margins of Clayton et al's (1999) survey of MS. Further, in their discussion of Garcia et al's (2004) unrepresentative sample of respondents who wrote in the comment boxes, Ong et al. (2006) show that those who used a comment box in their own research can be representative. It seems to me that this stems from the subject-matter of the questionnaires: Ong et al (2006) were researching low back pain consulters. Low back pain (also not well understood) is more likely to stimulate comments about negative than positive experience; but experiences of medical careers and childbirth are more likely to be both positive and negative. It seems likely that the desire to communicate with an imagined researcher is mediated by the subject-matter of the questionnaire.

I started with the premise that a postal questionnaire can be seen as a specialised example of a communicative floor, where sender and responder are orienting to a particular shared topic. How far has this held true? On the one hand Morse (2005) sees uninvited commentary as a problem in the research process, and on the other Clayton et al. (1999) see it as a genuine orientation to the shared topic. It then becomes the researchers' responsibility to receive and disseminate such information. Is there methodological space for the listening imagined researcher?

Survey research is carried out in a conventional way for conventional purposes often using 'bolt-on' sections of questionnaires that were originally constructed and validated under different research conditions years ago (cf. Barroso and Sandelowski, 2001). This is not a plea for qualitative rather than quantitative research but for two reassessments. The first of these is a concern with uncritical adoption of validated questionnaires and the acontextual character of their use. The second concerns the need to understand the basis of communication, particularly in a highly charged area such as pain experience. In many fields and for various

purposes this may not be so problematic, but when undertaking research in contentious and obdurate areas the relationship between data and different knowledges can be murky. The relationship between people's experience, the significance they see in that experience, and the data that will be created need critical alignment with the kind of communicative process that is being offered to respondents. A questionnaire concerning (especially ill-understood) painful experience may be an example of what C. Wright Mills (1959) termed 'atomized empiricism', a style of research that never really gets to grips with the relationship between the data and the phenomenon. Attending to marginalia is a move towards this relationship as well as towards a more collaborative style of survey research, opening the process up to a more inclusive and participatory stance.

Marginalia may not be data in many people's books, but they are a more genuine product of the questionnaire than (at least) some ticks.

Acknowledgements.

I would like to thank many people who have commented on this work. My interest in this area started when I worked in the Primary Care Sciences Research Centre, Keele University (Smith, 2001) and I would like to acknowledge the support of colleagues there, particularly Julius Sim, Pauline Ong and Jane Richardson, and also at that time Joanna Latimer. For the current paper I would like to thank Liz Bondi, Bernie Carter, Arthur Frank, Richard Freeman, Kath Melia, Richard Sparks and two anonymous referees for their close reading, comments and encouragement.

ⁱ The second (KPQ) and third (FMQ) sections are the Short Form 36 (SF-36), a validated general measure of health-related quality of life. Section 3 (KPQ) is the Hospital Anxiety and Depression Scale (HADS), a validated measure of psychological well-being. The second part of section 5 (KPQ) is the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC), a validated assessment tool for hip and knee osteoarthritis. The two questions on knee pain in section 4 and the first part of section 5 (again, KPQ) are the Knee Pain Screening Tool (KNEST) (see Jinks et al 2001).

ⁱⁱ This is for Teleform data entry.

ⁱⁱⁱ This question did prompt several phone calls to the project researcher, asking whether they should include their FM or not (J. Richardson, personal communication). It is clear that these respondents took the answering of the question very seriously.

iv Some respondents apologise for 'messaging up' their forms by writing comments (B.Carter, personal communication).

References

- Barroso, J. and Sandelowski, M. (2001) In the field with the Beck Depression Inventory, *Qualitative Health Research*, 11, 4, 491-504
- Blaxter, M. (1995) *Health and Lifestyles*, 2nd edn. Tavistock/Routledge: London.
- Clayton, D.K., Rogers, S. and Stuijbergen, A. (1999) Answers to unasked questions: writing in the margins. *Research in Nursing & Health*, 22, 512-22.
- Dadabhoy, D. and Clauw, D.J. (2005) Fibromyalgia: progress in diagnosis and treatment, *Current Pain and Headache Reports*, 9, 6, 399-404.
- Frank, A. (2001) Can we research suffering? *Qualitative Health Research*, 11, 3, 353-62.
- Garcia, J., Evans, J. and Reshaw, M. (2004) "Is there anything else you would like to tell us" – Methodological issues in the use of free-text comments from postal surveys. *Quantity & Quality*, 38, 113-25.
- Jackson, J. (1994) Chronic pain and the tension between the body as subject and object. In Csordas, T.J. (ed.) *Embodiment and Experience*. Cambridge University Press: Cambridge. pp 201-28.
- Jinks, C., Lewis, M., Ong, B.N. and Croft, P. (2001) A brief screening tool for knee pain in primary care. 1. Validity and reliability. *Rheumatology*, 40, 528-36.
- Katz, R.S., Wolfe, F. and Michaud, K. (2006) Fibromyalgia diagnosis: a comparison of clinical, survey, and American College of Rheumatology criteria, *Arthritis & Rheumatism*, 54, 1, 169-76.
- Lowton, K. and Gabe, J. (2003) Life on a slippery slope: perceptions of health in adults with cystic fibrosis. *Sociology of Health and Illness*, 25, 289-319.

-
- Mallinson, S. (2002) Listening to respondents: A qualitative assessment of the Short-Form 36 Health Status Questionnaire. *Social Science and Medicine*, 54: 11-21.
- Mayou, R. and Sharpe, M. (1997) Treating medically unexplained symptoms. *British Medical Journal*, 315, 561-2.
- Mease, P. (2005) Fibromyagia syndrome: review of clinical presentation, pathogenesis, outcome measures, and treatment, *Journal of Rheumatology – Supplement*, 75, 6-21.
- Mills, C. W. (1959) *The Sociological Imagination*. Oxford: Oxford University Press.
- Morris, D.B. (1991) *The Culture of Pain*. University of California Press: Berkeley.
- Morse, J. (2005) Evolving trends in qualitative research: advances in mixed-method design. *Qualitative Health Research*, 15, 583-5.
- Ong, B.N., Dunn, K.M. and Croft, P. (2006) "Since you're asking ...": Free text commentaries in an epidemiological study of low back pain consulters in primary care. *Quantity & Quality*, 40, 651-9.
- Okifuji, A. and Turk, D.C. (1999) Fibromyalgia: search for mechanisms and effective treatments. In Gatchel, R.J. and Turk, D.C. (eds) *Psychosocial Factors in Pain. Critical Perspectives*. Guilford Press: New York. pp 227-46.
- Raspe, H. and Croft, P. (1995) Fibromyalgia. *Bailliere's Clinical Rheumatology*, 9, 599-614.
- Sacks, H., Schegloff, E.A. and Jefferson, G. (1974) A simplest systematics for the organisation of turn-taking in conversation. *Language*, 50, 696-735.
- Scarry, E. (1985) *The Body in Pain: the Making and Unmaking of the World*. Oxford University Press: New York.
- Schumann, H. and Presser, S. (1996) *Questions and Answers in Attitude Surveys. Experiments on Question Form, Wording, and Context*. Sage: Thousand Oaks.
- Seedhouse, D. (1986) *Health: the Foundations for Achievement*. Chichester: Wiley.
- Smith, M.V. (1998) Talking about pain. In Carter, B. (ed.) *Perspectives on Pain: Mapping the Territory*. Arnold: London. pp 26-45.
- Smith, M.V. (2001) Communication and health surveys. Unpublished paper presented to Primary Care Sciences Research Centre, Keele University.
- Soderberg, S. and Norberg, A. (1995) Metaphorical language among fibromyalgia patients. *Scandinavian Journal of Caring Sciences*, 9, 55-9.

Vale, A. (1998) Fibromyalgia and pain. In Carter, B. (ed.) *Perspectives on Pain: Mapping the Territory*. Arnold: London. pp 264-77.

Wessely, S. and Hotopf, M. (1999) Is fibromyalgia a distinct clinical entity? Historical and epidemiological evidence. *Bailliere's Clinical Rheumatology*, 13, 427-36.