Meron, Tikva (2014) The meaning of advance directives in the lives of people with advanced long term conditions. PhD thesis, University of Nottingham.

THE MEANING OF ADVANCE DIRECTIVES

IN THE LIVES OF PEOPLE WITH

ADVANCED LONG TERM CONDITIONS

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Thesis submitted to the University of Nottingham

for the degree of Doctor of Philosophy

May 2014

ABSTRACT

Background

In the context of present medical developments, many health conditions such as cancer that were once relatively acute and quickly led to death are being increasingly transformed into long term conditions (LTCs). Many people living with LTCs experience difficult and complex symptoms, which often increase distress and frequently lead to a long experience of suffering. There is prognostic uncertainty in many LTCs, particularly regarding the trajectory towards dying and death. The final phase of illness is frequently associated with a loss of capacity in care decision making.

From a social perspective, health consumers today are more aware of their right to make decisions regarding their healthcare. This awareness seems to have influenced the creation of advance directives (ADs) as one possible strategy for dealing with medical advancements and prognostic uncertainty, and their implications.

Advance directives are tools that people can utilise to state their treatment preferences and to inform treatment decisions, should they lose the capacity to make such decisions. They are usually used to restrict life-prolonging medical treatments such as non-resuscitation, but may include palliative treatments to reduce symptom burden. Advance directives have been legalised in various countries around the world, yet in many countries they are either not legal or not applied. Advance directives are criticised mainly for being inefficient in helping to make end-of-life (EoL) decisions for incapacitated people in most real-life events.

Israel, the setting for this study, is considered a medically developed country although it does not necessarily have rich resources. One special characteristic distinguishing Israel from most developed (western) countries is that religious and state laws are interrelated in a complex way. Controversies between religious and state laws may restrict the implementation of modern values and ideas, such as a desire not to prolong life when suffering is considerable, or granting an equal value to the quality and the sanctity of life. Advance directives have been legal in Israel since 2005.

Aim and objectives of the study

To examine from a variety of perspectives, i.e. patients, relatives and health care providers (HCPs), the experiences, beliefs and practices associated with the use of ADs in Israel, with a view to understanding their role in the lives of patients with palliative care needs towards the end of life.

The objectives of this study were: (1) To learn from people with LTCs who are nearing death about the experiences, beliefs, values, and needs that led them to make ADs; (2) To discover what influenced changes in the content of people's ADs over time; (3) To identify the expectations patients have regarding their AD; (4) To explore the extent to which these expectations are met by their formal and informal carers during the delivery of care towards and at the end of life; (5) To examine the potential contribution that ADs have in the palliative care of people with LTCs, from the perspective of their family carers and physicians; (6) To examine HCPs' knowledge, attitudes and experiences relating to ADs, as well as their perceived role in the process of making ADs.

Methods

The study was conducted in Israel between January and September 2011. It used a mixed methods design which involved two phases: One phase, using a qualitative approach, took the form of patient-centred case studies (8 cases), ideally comprising a patient with an LTC, a relative and a physician. It used face-to-face semi-structured interviews that were analysed by comparing and contrasting findings within and between cases. Twenty seven interviews were held, including 10 patients, 9 relatives, 7 physicians and a Rabbi. The other phase examined HCPs' knowledge, attitudes and experiences regarding ADs using a questionnaire prepared and used by Schiff and her colleagues in 2006, which was adapted to the current study with permission. The final sample (N=72) of HCPs who care for people with LTCs comprised: 57 nurses (79%), 8 physicians (11%), and 7 social workers (10%). Statistical analysis was descriptive, using SPSS version 17.

Findings

All the patient-participants expressed a great desire to make autonomous choices. Making an AD was one aspect of this philosophy. They all shared a desire to actively control their EoL. Yet they provided many examples suggesting that their autonomy was 'relational' and that they often made decisions based on relationships with others around them.

Some relatives expressed fear that they might make mistakes when enacting the patient's wishes; most relatives reported feeling a moral obligation to become future decision makers for the patient. Analysis revealed conflicting commitments to self and to the 'other', from the perspective of the patient and of the relative alike, and indicated that the needs of patients and those of relatives grow apart as death approaches, when patients want to 'be released from suffering' through death and relatives have an emotional need to keep the patients alive for as long as possible.

Physicians, both in the survey and in the interviews, maintained that forgoing active treatments contradicted their medical education and the moral professional commitment to save and preserve life, and therefore was difficult to respect. The relationship between physicians and relatives regarding patients' ADs often appeared to be problematic. Most of the non-spouse relatives did not know and did not communicate with physicians, whether in acute hospital settings or in family-physicians' surgeries in towns. In rural community settings on the other hand, physicians and patients' relatives reported having had significant and repeated discussions.

The findings of the survey of HCPs and interviews with physicians showed relatively positive attitudes toward the concept of ADs, and also some experience of helping create ADs as well as using them toward EoL, apparently with positive outcomes. Yet difficulties, barriers and criticisms were also evident in both the qualitative and quantitative phases.

Discussion

In general, the data from this study enabled the development of a better understanding that ADs reflect a multitude of steps that are distinct but linked, as in a 'relay': the maturation of the idea in the patient's mind; the process of making an AD document; the sharing of this idea with relatives; the sharing of the idea with HCPs; and discussing the patient's wishes with all three stakeholders. The findings revealed that each of the steps in the 'AD-relay' is hard to achieve in its own right, and is also

related to and dependent on the other steps. Therefore if any one step is not managed well, this jeopardises the whole process. In addition, the difficulties and barriers that HCPs raise may hinder them from discussing ADs with patients and relatives and limit the possibility of using ADs in EoL care of patients with LTCs.

Conclusion

This study provides a voice to a small group of people who may have different needs and perspectives from those of the majority of the population. It suggests that people who want to make ADs are determined to control their lives and EoL, and perhaps require unique solutions in addition to the ones available in most countries in the world today.

The findings suggest that health care providers, who are responsible for the medical care of people with LTCs in Israel, are expected to initiate ACP-communication regarding EoL preferences as appropriate. This needs to occur when there is still enough time to prepare ahead for EoL decisions. When patients and relatives do present an AD document, it should always trigger discussion with HCPs about its content and meaning for the patient, and the document must be included in the patient's medical record. Yet findings indicate that many HCPs are ill-equipped to engage in ACP communication, and often avoid it.

The majority of the public is not aware of the possibility of ADs or their legal status and therefore cannot make an informed decision whether or not to use ADs. Policy makers will need to help to fully educate HCPs about ADs, as well as the public, and to equip HCPs with reasonable communication skills to regularly perform ACP.

ACKNOWLEDGEMENTS

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CHAPTER 1: INTRODUCTION

The thesis presented here reflects an investigation of experiences, beliefs and practices associated with the use of advance directives in Israel from a variety of perspectives, with a view to understanding their role in the lives of patients with palliative care needs towards the end of life (EoL). This investigation started at the end of 2009 and was completed in early 2014. The thesis focuses on 'advance directives' as one strategy by which to prepare in advance for the last phase of life, which may occur when mental capacity is heavily impaired and hinders the ability of individuals to make decisions regarding their own healthcare.

1.1 Long term conditions and their implications for end-of-life decision making

Illness patterns today are changing considerably from those perceived just a few decades ago, and healthcare systems are ill-equipped to deal with these changes (Nolte and McKee, 2008). Chronic conditions or long term conditions (LTCs) beyond specific illnesses are now being scrutinized by the World Health Organization, and cover a wide range of health problems and not only cancer, heart disease, diabetes and lung disease (World Health Organization, 2002). The wider definition includes some communicable diseases, such as HIV/AIDS, that have been transformed from fatal conditions into controllable health problems, allowing people to survive with them for many years. They also cover certain mental disorders such as depression and schizophrenia, or disabilities and impairments that are not classified as diseases such as blindness and musculoskeletal disorders (World Health Organization, 2002). The common trait of these conditions is that they all require an intricate and coordinated response from multiple health disciplines over an extended period of years and decades, with the aim of empowering patients to take as active a part as possible in their life and care (Nolte and McKee, 2008). For the purpose of this study however, I will refer to LTCs as meaning life-limiting conditions such as cancer, failure of crucial organs such as the lungs, heart, kidneys or liver, and various degenerative conditions of the neuro-muscular system.

Long term conditions are becoming a global health concern because the proportion of older people in the population is growing, further increasing the number of those with LTCs accumulated over their lifetime; quite often people live with multiple LTCs simultaneously; chronic conditions are becoming more difficult to manage as new drugs become available and interact with other medications to produce not only positive but often negative outcomes (Nolte and McKee, 2008). LTCs are also currently responsible for 60% of the global disease burden, and a considerable increase is forecast by 2020 (World Health Organization, 2002).

As a result, multiple LTCs may increase symptom burden and the experience of physical, emotional and spiritual suffering, which may be prolonged and may gradually transform into a lengthy and anguished dying. In addition to symptom burden, some LTCs, such as Alzheimer's disease, affect cognitive ability and gradually impede a patients' ability to take part in life and in their own health decision-making. This in turn adds ethical and emotional challenges for relatives and health care providers, who become responsible for these patients and need to make decisions in their best interests and on their behalf. Evaluations regarding Alzheimer's disease prevalence predict a global increase, for example an increase of 31-51% in various parts of Europe by 2020 (Nolte and McKee, 2008). Such a forecast indicates an increasing challenge and burden in the near future for relatives and for HCPs who are responsible for people with cognitive impairment. They call for initiatives that may help and support formal and informal carers, to enable them to best handle these challenges. One such initiative is the option of advance directives, which is the core of this thesis.

1.2 The Israeli context

1.2.1 Socio-demographic figures

Israel is the only country in the world with a Jewish majority. Of a total population of ~7.8 million in 2011, 5.9 million (75%) were Jews, and 1.61 million (20%) constituted a large Arab minority of whom 84% were Muslim, 7.8% Christian, and 8.1% Druze (Central Bureau of Statistics, 2013b). Most of

the remaining 5% of Israel's population had no religious affiliation according to the Ministry of Internal Affairs (Central Bureau of Statistics, 2013b). Jewish society is relatively secular, and around 43% of its population define themselves as 'secular', 38% as 'traditional' (meaning mildly religious), 10% as 'religious', and 9% as 'very religious'. Compared with this, the majority of the non-Jewish population is religious, with only 19% defining themselves as 'secular', 23% as 'not so religious' (equivalent to 'traditional'), and the remaining 50% as 'religious' and 8% as 'very religious' (Central Bureau of Statistics, 2013a). Israel is a democracy governed by secular law (based on the British legal foundations put in place under the British Mandate, 1917-1948).

1.2.2 Dual legal systems

One special characteristic distinguishing Israel from most developed countries is that religious laws (such as the Jewish 'Halacha') and state laws are interrelated in a complex way. Legislation on matters of values, such as life, dying and death, must reflect both religious philosophies and modern processes (such as medical treatments and procedures). Controversies between religious and state laws may restrict the implementation of modern values and ideas, such as a desire not to prolong life when suffering is considerable, or granting an equal value to the quality and the sanctity of life. Withdrawal of life-prolonging treatment is in complete conflict with religion (Cohen-Almagor and Shmueli, 2000), and withholding treatment is not allowed by any of the religious streams (Badarna, 2009).

1.2.3 Israel – health and palliative care

Israel is considered a medically developed country, although it does not necessarily have rich resources, with one of the highest life expectancies at birth in the world (World Health Organization, 2013d). There is no official data regarding the scale of long term conditions (LTCs) in Israel, but estimates indicate an increase in numbers. One of the strategies of care for LTCs is the palliative care (PC) concept that was originally developed and pioneered by the UK's Dame Cicely Saunders (Seymour, 2012). Palliative care is

mentioned here because it is expected to accompany the end-of-life of people with LTCs and to alleviate their suffering, and also because in Israel's 'Dying Patient Act' (DPA) palliative care and ADs are both included, and are related to each other. An expectation is expressed in the DPA that ADs will only be considered after exhausting palliative care measures to alleviate suffering and failing to achieve alleviation (The Dying Patient Act, 2005).

Palliative care (PC) related to the care of cancer patients started to develop in Israel in the 1980s, and has since developed further. In the UK, the promotion of palliative care has been embedded in policy, through the 'End of Life Care Strategy: Promoting high quality care for all adults at end of life' (Department of Health - UK, 2008). In Israel, the 'Dying Patient Act – 2005' (DPA) defines palliative care as a legal right that should be available to all patients with LTCs (The Dying Patient Act, 2005). In 2009 and based on the DPA, the Ministry of Health set a goal to extend PC to patients with all long term conditions (LTCs), both in the community and hospitals (Hozer Mankal, 2009). The Director General of the Israeli Ministry of Health published a circular regarding the operation of palliative care services in Israel, which was expected to be accomplished by the end of 2013 (Hozer Mankal, 2009). At that point in time (late 2009), palliative care was not well established and the DPA was not well known in the health care practice. There therefore seemed to be a unique opportunity to explore the meaning of ADs in the lives of people with palliative care needs, and the ways in which health care providers (HCPs) can and do work with these patients.

To add to the understanding of the Israeli context, it should be noted that by the end of 2013 the goal set by the Director General in 2009 is still far from accomplished, and resources are severely limited. Palliative care services are slowly being extended in Israel and include hospice at home for cancer patients in most areas, and a few hospice beds for cancer patients (less than 80 beds nationwide). Palliative care services for the elderly in geriatric hospitals are starting to develop as well (Bentur, Emanuel and Cherny, 2012).

1.3 The personal perspective

As a nurse in the oncology field I have accompanied thousands of patients through their illness trajectory, and frequently through their dying process as well. I often witnessed end-of-life suffering and its alleviation through pharmacological and other measures. Yet occasionally a patient's suffering could not be alleviated. This raised hesitations among my colleagues and me, as to the best way to handle the patient's situation. Such hesitations were further increased when patients or relatives did not allow open conversations, or when my fellow HCPs and I did not feel comfortable discussing their approaching death with patients, and therefore did not verify how they wanted us to respond to their suffering. Open communication was very rewarding, yet it was not easy to handle and was very rare. It was often unclear whether or not the patient realised that he or she was dying. Sometimes, and this was even more difficult, a patient would ask a question about the future and immediately express a need for reassurance that he or she would be able to get through this 'bad moment' and continue to live. Each experience of unclear, elusive, and ambivalent messages left me puzzled as to how best to handle the patient's care. I began to think that if people could write down their EoL wishes early enough, this would spare the embarrassment and help to fulfil their needs in a better way.

In a more personal tone, before I started this project I thought that everybody should write down their advance directives for end-of-life, while in good health. For many years I played with the idea of preparing my own advance directive for future care if I were to lose capacity, just in case I needed it one day. However, thinking is one thing and acting is another, and I never found the right moment to write out my advance directive. The right moment presented itself quite abruptly in a foreign place far away from home. A few weeks into my master's studies I had a bicycle accident one day on my way to the university. Luckily I was hardly injured physically, but I suddenly realised that within a second my life could be turned upside down, and I could become incapable of making any further decisions about my health care. At that moment I felt a strong need to prepare for such an unfortunate moment in the future. The experience shocked me, and after that moment of revelation I immediately prepared my own advance directive.

I shared my document with someone I hoped would be willing to provide my AD should I lose capacity in a foreign country, where I was on my own and without my relatives and friends, and a stranger to the local health care system. I also shared my AD with my brother, and was surprised by the emotional difficulty that he expressed during the conversation about my advance wishes for health care, should I be incapacitated. This was one of the main things that triggered my interest in exploring ADs as a social phenomenon, in understanding the meaning attributed to the act by people who prepare ADs, and their expectations of it. This starting point, combining both my professional and my personal experiences, influenced the way I approached the research, my interest in it, my questions, and my interpretation. This personal standpoint needs to remain clear throughout the reading of this thesis.

The thesis has however taken me on a journey that has influenced my perspective a great deal. It has added much to my knowledge, but also to my understanding of the complexity of ADs.

1.4 Thesis overview

The thesis is made up of eight chapters, a synopsis of the case studies involved, and five appendices. The first chapter will introduce ADs and the context of this study. The second chapter will look at the available literature relating to ADs, and at identified gaps leading to the issues that this study sets out to explore. Chapter 3 will describe the planned design and actual methods that were applied to conduct the research. After a synopsis of all the case studies, Chapters 4 to 7 describe and discuss the findings of my study. Chapter 8 provides an overview of the key findings and their contribution to the available knowledge, as well as their implications for future research, for policy and for practice. The formal English version of the legal Israeli 'Advance Medical Directive' document is attached as Appendix A; the ethical approval for this study is attached as Appendix B; the advert for this study in LILACH's[1] bulletin is attached as Appendix C; the patient-participants' information sheet is attached as Appendix D. The questionnaire that was used in phase 2 of this study as Appendix E was removed (see note under Appendix E).

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[1] LILACH in Hebrew is an acronym for 'living and dying with dignity'

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Illness, suffering and death have preoccupied humankind since the dawn of history. They were explained and managed by religions and they were attributed to the will of a God (or Gods), although explanation of death and what comes after it (Heaven or hell; reincarnation) have differed between religions, epochs, and locations.

It was not until the eighteenth century that non-religious views started to emerge and challenge religious views regarding illness and death (Barry and Yuill, 2011). During the twentieth century, some important social changes emerged which influenced society's views of illness, dying and death. They were related to new scientific knowledge, a decrease in the power of religion, and growing individualism.

Alongside social changes, medical developments in the last half century have greatly influenced illness, dying and death. Advance directives (ADs), are one of several social responses to the social and medical changes. This thesis focuses on ADs as a complex social phenomenon, by looking at them from the point of view of patients with long term conditions (LTCs) and other stakeholders around them. As a basic definition, I would briefly describe ADs as tools that people can utilise to state their treatment preferences, and that can be used to inform treatment decisions should they lose the capacity to make such decisions.

This chapter provides the contextual setting for the thesis. It starts by providing a background composed of some historical processes, some relevant definitions, and the conceptual framework underpinning this study. It then moves on to review the evidence around the main issues of this study, and subsequently points out gaps in the available evidence, which are relevant to this study.

2.2 Background

A historical overview regarding ADs, relevant definitions and a review of the available publications will provide the background for this chapter.

2.2.1 Historical overview - how did ADs come to exist?

In the brief historical overview below, the origin of ADs will be highlighted first, followed by an outline of contemporary shifts from the concept of an AD to the concept of *advance care planning* (ACP), as well as developments around ADs in Israel.

2.2.1.1 Medical developments

The development of medicine and associated life-prolonging technologies in resource-rich countries since the mid-twentieth century has led to increased longevity. The global '*average life expectancy at birth*' increased by six years between 1991 and 2011 (World Health Organization, 2013a). Long life may be complemented by good health but it also gives rise to a new phenomenon: longevity in sickness (Ayalon, 2003). Health conditions like cancer and (more recently) AIDS, that were once relatively acute and progressive, and which quickly led to death a few decades ago, have been increasingly transformed into LTCs[2]. People with LTCs such as heart failure, diabetes, stroke, cancer, Parkinson's disease and dementia, among other conditions, may now live for many years while ill. Moreover, the proportion of the population with long-term illness is globally increasing (World Health Organization, 2013b; World Health Organization, 2013c). For example, in 2010 it was reported that 15.4 million people were living with LTCs in England, and figures are expected to rise to 18 million by 2025 due to longevity combined with an unhealthy lifestyle (Department of Health - UK, 2010).

Modern medicine cannot as yet provide a cure for LTCs, but it can, in many cases, considerably slow the process of illness (Department of Health - UK, 2010; Thacher, 2004), and prolong the dying phase by months to years (Barry

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[2] LTCs - those 'conditions that cannot, at present, be cured, but can be controlled by medication and other therapies' (Department of Health - UK, 2012).

and Yuill, 2011). Additionally, physicians are trained to fight for life, and many find it more acceptable to be proactive (to resuscitate a patient, for example) rather than to abstain from life-saving actions (Bentur, 2008). For many patients with advanced illnesses, these two facts may result in a lengthy accumulation of physical symptoms typical to LTCs (Health and Human Services - USA, 2008; Thacher, 2004), which often increase emotional, social and spiritual distress, and frequently lead to the experience of suffering and a lingering process of dying (Chochinov, Krisjanson, Hack et al., 2006a; Henoch and Danielson, 2009). These changes have led to the development of ADs as one possible strategy to deal with medical advancements and their implications for the individual.

2.2.1.2 Social developments

Barry and Yuill (2011) identify social changes that began during the twentieth century and that seemed to have influenced the creation of ADs: *Medicalisation*, *Secularisation* and *Individualisation*.

1. *Medicalisation* of death and dying was influenced by the natural sciences, which were looking at phenomena related to living creatures as sequences of biological events. This meant an attempt to explain the cessation of life in scientific terms rather than in terms of divine powers.

2. *Secularisation* implied a different interpretation of life from that in the symbolic framework of religion. Without the religious preoccupation with resurrection and redemption of the soul, death became an event that was no longer attached to one's virtues or vices.

3. *Individualisation* emerged as the focus of interest shifted from the community, tribe or family to the individual. Human behaviour which was formerly dictated by culture and community gradually began to be questioned. Increasingly in the western world, individuals started to make their own decisions independently from norms and customs (Barry and Yuill, 2011). The freedom of individuals to choose how to behave also applied to health issues. Health consumers, led by consumers' rights movements, gradually became aware of their right to

choose between treatment options or to refuse treatments altogether under certain circumstances (Health and Human Services - USA, 2008).

The idea of limiting life-sustaining treatments stemmed from the above developments, which gave individuals the legitimization to take responsibility for their medical care. It took root in the 1970s in the United States of America (USA), and was probably first introduced to the wider American and international public with the controversial case of Karen Ann Quinlan[3] whose final part of life in a coma, depending on medical life-support, opened a discussion about dignity in dying.

The awareness of health consumers, which was depicted earlier in the chapter, triggered the development of 'social movements'[4] whose agenda was to improve dying and death (McInerney, 2006). In many countries these movements combined the words 'life' 'death' and 'dignity' within their names to create a message that dying can be dignified only if it can be controlled by the individual rather than by a medical authority (McInerney, 2006). These movements used individual court cases[5] and covered them extensively via the media, and they seem to have been quite influential, as is reflected by the legalisation of ADs in various countries globally.

Legal status was first afforded to the limitation of life-sustaining treatments in the USA in 1976, with the enactment of 'The California Natural Death Act – 1976'. This was the first attempt to reshape end-of-life (EoL) care through ADs (Health and Human Services - USA, 2008; Kendrick and Robinson, 2002). In the USA, legalization of ADs increasingly included other states and was finalized with the federal enactment of 'The Self Determination Act – 1991'

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[3] Karen Ann Quinlan – was 20 when she entered a comatose state apparently after taking alcohol with tranquilizers at a party in 1975. She was resuscitated and remained alive supported by mechanical ventilator. Her parents wanted to disconnect her from the life support to let her 'die with dignity' but the physicians and the court objected. A year later the New Jersey Supreme Court appointed Karen's father as her guardian. As legal guardian, her father decided to disconnect Karen's life-support system, yet Karen continued breathing independently. She remained comatose, breathing on her own and was fed for ten additional years, and died of pneumonia in 1985, at the age of 31 http://en.wikipedia.org/wiki/Karen_Ann_Quinlan.

[4] 'Social movement' – an informal group action which focuses on specific political or social issues, in order to carry out, resist or undo a social change.

[5] See also the cases of Nancy Cruzan (in 1983) http://en.wikipedia.org/wiki/Nancy_Cruzan and the case of Terri Schiavo (in 1990) http://en.wikipedia.org/wiki/Terry_Schiavo.

which comprised the whole of the USA and aimed to encourage competent adults to complete advance directives (Health and Human Services - USA, 2008). Similar processes occurred later in other countries such as the UK (Department of Health - UK, 2008); Israel (The Dying Patient Act, 2005); Germany (Wiesing, Jox, Hessler et al., 2010) and in some of the Canadian provinces (Library of Parliament - Canada, 2013).

In the late 1990s, state legislation in the USA focused on unwanted resuscitation of terminally-ill patients with the development of explicit 'Do Not Resuscitate' orders (DNR), and resulted in the creation of out-of-hospital DNR protocols in most states (Health and Human Services - USA, 2008). The development of legislation, as demonstrated, reflects a growing awareness of society to patients' autonomy regarding health, life and dying. Nevertheless, in the USA which is estimated as the leading country in this respect, only 18-30% of the entire population has ADs (Health and Human Services - USA, 2008) and this is by far higher than in any other country. The idea behind legalising and using ADs was to preserve patients' autonomy to decide for themselves about their own health care, by communicating to their relatives and health care providers (HCPs) their preferences for future care (in the event of incapacity). However, one of the greatest critiques of ADs is that they have failed to influence EoL care (Davison, Holley and Seymour, 2010). Critiques of ADs will be discussed in greater detail in a later section of this chapter. Yet the flaws of ADs did promote a search for better ways to maintain patients' autonomy.

2.2.1.3 Shifts from 'advance directives' to 'advance care planning'

Through investigation of failures to use ADs in EoL care in an effective way (The SUPPORT Principal Investigators, 1995) it became evident that in order to safeguard autonomy, individuals' needs and wishes have to be conveyed to others around them, such as relatives and HCPs, and this can only happen through communication rather than through instructive documents. Evidence that was gathered around ADs has emphasised how multifaceted individuals' wishes are, and has elucidated many aspects of complexity. It became clear that regardless of whether individuals do or do not decide to make any formal

wish for future medical care, they have the constant and on-going right to make decisions regarding their personal health care. This understanding shifted the focus from an emphasis on documents that cover possible future incapacity (such as ADs) to accentuating a much broader process of communication, which was named *advance care planning*, suggesting that throughout a long term condition, an on-going communication is required between patients, relatives and their HCPs, to constantly re-evaluate their changing needs (Davison et al., 2010).

2.2.1.4 Development of ADs in Israel

One special characteristic that makes Israel distinct from most developed countries is that religious and state laws are interrelated in a complex way, and therefore legislation on matters of dying and death must reflect both religious philosophies and the modern processes described above.

Advance directives emerged in Israel in the late 80s with the foundation of LILACH organisation that was aimed to promote the use and legalisation of ADs as means to promote dignity at EoL. The LILACH organisation prepared a format for ADs that was used by its members for advance statements of health care preferences when dying with mental incapacity. Two legal changes promoted the status of ADs in Israel: (1) The enactment of the Israeli *'Patient's Rights Act -1996' (World Association for Medical Law, undated)*, which promoted the concept of patients' autonomy and right to consent to or refuse medical treatment; and (2) the enactment of the Israeli *'Dying Patient Act-2005' (DPA)* that legally regulated ADs (Steinberg and Sprung, 2006). Further information regarding ADs in Israel is provided in Box 1.

Box 1: Additional information regarding ADs in Israel

In the Israeli 'Dying Patient Act – 2005' (DPA) ADs are defined differently from most western countries, in order to concur with religious obligation to preserve life.

The law orders that an exceptional request to prolong life should be respected even if it seems futile, unless it is harmful to the patient or others (Steinberg and Sprung, 2006) while other countries such as UK legalise only refusal of treatments (Davison et al., 2010).

The DPA forbids any shortening of life, because withdrawal of life-prolonging treatment is in absolute conflict with religion (Cohen-Almagor and Shmueli, 2000).

The DPA permits withholding treatments that are related to the LTC, but forbids withholding treatment of other pre-existing or new acute medical conditions, and forbids withholding nutrition and fluids until death is imminent (The Dying Patient Act, 2005).

It is important to emphasise that withholding treatments is unacceptable to some Judeo-Muslim religious streams (Badarna, 2009).

National AD-database

The DPA ordered the establishment of a national database for ADs under the auspice of the Ministry of Health. Only legal ADs forms are eligible to be kept in the national AD-database and they are accepted only when fully written (Steinberg and Sprung, 2006). This in itself is problematic, because in Israel currently most of the AD documents (~10,000) are held by the LILACH organisation ('Living and dying with Dignity' – Israel).

Advance directive documents

The DPA views the legal AD form differently from other forms such as LILACH's document. While the legal AD document is legally binding, different AD forms are only voluntary (Matsa, 2009).

The legal AD needs the signature of a nurse or a physician to certify that explanation regarding medical life-sustaining treatments has been provided and understood by the person who wishes to fill in an AD (Sne, 2009). If the person is already defined as a dying patient at the time of preparing an AD, the explaining authority has to be a senior physician.

Advance directive completion rate in Israel is extremely low (less than 0.2% of the population) in comparison to the given figures in the USA (18-30%) (Health and Human Services - USA, 2008) or even in the UK (~8%) (Alderson, 2010).

The legal form is considered by many to be complicated and less understandable to lay people.

In Israel (differently from the UK for instance), according to the DPA an individual can hold an AD and appoint a proxy decision maker for EoL decisions simultaneously. However, they need to specify which of the two will prevail in case of contradiction, otherwise the law specifies conditions in which either the one or the other document will prevail (see Appendix A, page 256).

People who have prepared a LILACH AD and later filled the legal AD form may actually possess more than one AD document.

Additional definitions

It is important to highlight and distinguish between ADs, a *proxy decision maker for EoL decisions*, and a *witness*, as follows:

Appointment of a *proxy decision maker for EoL decisions* - is a separate legal process and document from that of making an AD. The individual can limit and define for which

medical issues the proxy decision maker will be authorised to make decisions. More than one decision maker can be appointed, in case the primary one is unable to make decisions. The appointed decision maker has to sign their willingness to become the decision maker in due time (adapted from the DPA).

Witness is one of two persons who need to be present at the moment of filling in and signing an AD or a proxy decision maker. Witnesses approve that they know the individual who has filled in the document, or have identified that individual with an ID, and that to their best judgement the individual seems to be lucid and with no sign of pressure to formulate such documents. According to the DPA, a witness cannot be a potential heir or benefit financially from the death of the AD holder, and cannot be appointed simultaneously as a proxy decision maker for EoL decisions (see the official explanation in English in Appendix A, page 256).

To summarise the historical overview of this chapter, ADs seem to have emerged as one possible response to a shift in the course of many illnesses, towards chronic and slow declines which often prolong suffering and dying, and as an outcome of some social changes which placed much greater responsibility for life outcomes in the hands of individuals than ever before in history. Advance directives were aimed to reduce the suffering at EoL by taking personal control over decision-making during this period. Yet this tool is not an overall satisfactory response for all people and for all situations.

2.2.2 Working definitions around ADs

2.2.2.1 What are ADs, and what are they not?

There are usually two different types of advance statements related to health care: those which try to make advance decisions for specific (future) medical situations; and those which delegate the responsibility for future decision making to someone else. Usually, the former type is called an *advance directive* and the latter is called a *proxy decision maker* or *durable/lasting power of attorney* for health care (Health and Human Services - USA, 2008) among other terms. Some, such as Davison et al. (2010) for example, term these two types ADs, and divide ADs into *instructional* and *proxy directives* respectively*: Instructional directives*, meaning that they specify the individual's

preferences in specific medical circumstances; and *proxy directives*, which mean the appointment of a surrogate decision maker on behalf of the individual (Davison et al., 2010). Throughout this work I shall use the term *advance directives* (formerly called *living wills*) to refer to Davison et al.'s (2010) *instructional directives*. They are tools that people can use to state their treatment preferences in advance of their actual need (Health and Human Services - USA, 2008). They are generally referred to as:

> *'Instructions given by a capable person, often in written form, about their wishes for health care (treatment) and/or personal care in the event that they become incapable of giving informed consent' (Dunbrack, 2006: 25).*

They are sometimes called *advance medical directives*, emphasising that they are meant to define health care. In several countries ADs have legal status (examples: USA, UK, Canada, Israel), and they may usually be used to restrict treatment. There are a variety of possible restrictions, such as non-resuscitation or non-hospitalisation, which can be used in part or as a whole. Therefore specific treatment preferences (or restrictions) may be a part of ADs (see Figure 1, next page). The Israeli law permits the restraint of life-maintaining measures on behalf of an individual when four elements apply simultaneously: (1) They have an AD/surrogate decision maker, (2) they have lost mental capacity, (3) they face an advanced LTC, and (4) they are in considerable suffering even though palliative care measures are used (The Dying Patient Act, 2005).

Advance care planning is an overarching term that embraces both ADs and *proxy/surrogate decision maker* and is defined as:

> *'A process that involves on-going reflection, understanding, discussion, and communication amongst a patient, their family, and healthcare staff for the purpose of clarifying values, treatment preferences, and goals for EoL care. Advance care planning emphasizes not only decisions about whether to use a treatment but also practical arrangements, and includes attention to ethical, psychosocial, and spiritual*

> *issues which relate to starting, withholding, and stopping treatments' (Davison et al., 2010: 50).*

Attention is drawn to the fact that an outcome of ACP may be the formation of an AD, or the appointment of a surrogate decision maker, but it may also result in continuous oral statements without completing any formal document. Figure 1, below places the various definitions in relation to each other for better understanding of the terms that are used throughout this thesis.

Figure 1: Relationship between definitions
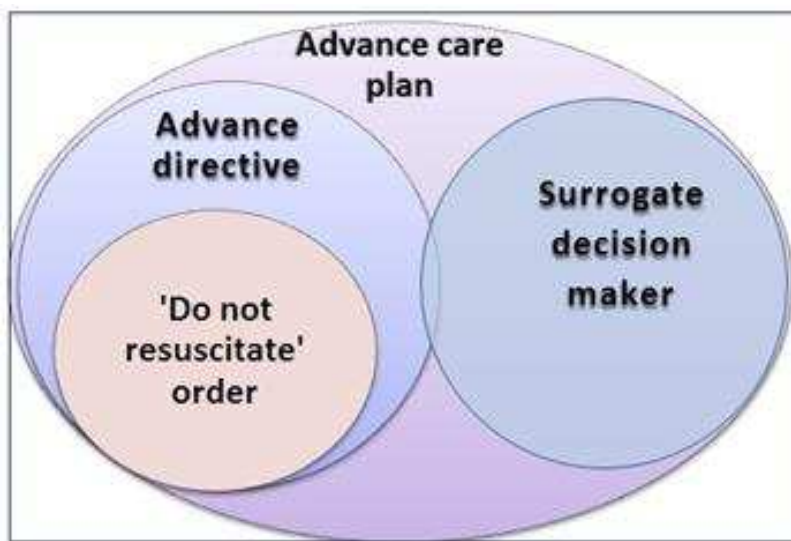
2.2.3 The conceptual framework regarding ADs

An advance directive, as a possibility, sits at a juncture of three major conceptual frameworks: *ethics,* which looks at 'what is morally right or wrong'; *law,* which looks at 'what is legally allowed or forbidden'; and *medicine,* which looks at 'what is practically available, possible and known'. In some places religion may add to or substitute for ethics or law (or both). Figure 2 (next page) aims to depict the above relationships.

Ethically - the medical ethical principle of *autonomy* now encourages and legitimises individuals to make independent decisions on their health; and an AD is a tool to prepare for the time when individuals may no longer be able to make decisions due to deprived capacity. Yet limiting health care by obeying ADs (which often means not prolonging a human life) has implications for a

religion which sanctifies life above any other value, and there are therefore communities, countries and cultures that do not view an AD as a legitimate concept or possibility.

Figure 2: The conceptual framework of ADs
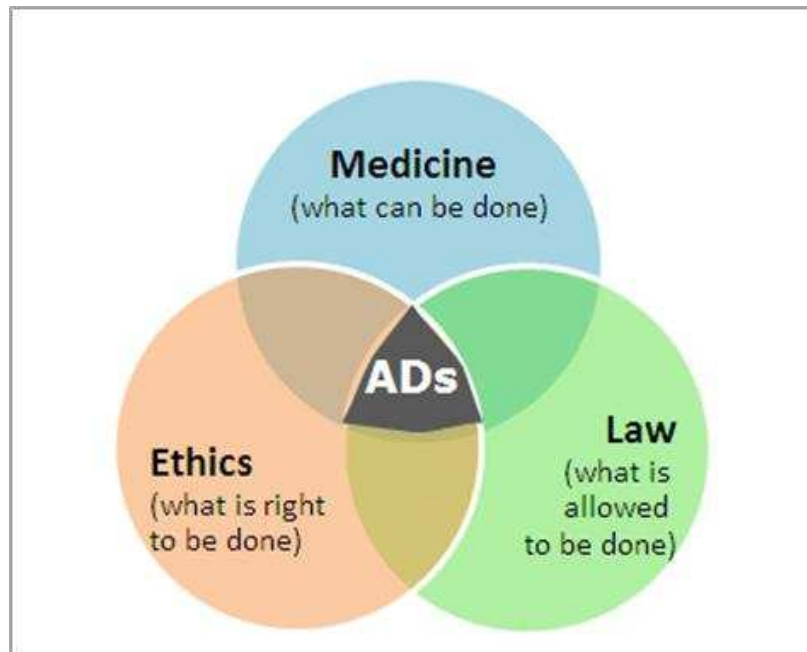
Legally – Advance directives, where legal, enable individuals' 'voices' to be heard when they are no longer able to express them, and they are binding for health care professionals as well as relatives. However, in most countries to date ADs are not legal and cannot therefore be applied there.

Medically – Advance directives are orders to restrict treatment or abstain from it altogether. This is contrary to the generally accepted medical teaching, to battle to preserve life at any time and at nearly any cost. Since the late 60s, medicine has become able to resuscitate people through cardio-pulmonary pharmacological and technological interventions, which are constantly improving. This ability only accentuates a tendency to view death as 'the enemy' and to keep fighting it actively and aggressively (Bentur, 2008; Schiff, Sacares, Snook et al., 2006). The possibility of limiting medical care in a way which may restrain life is accepted very restrictedly in the medical field. The palliative care concept, which emphasises improving quality of life over length of life with an LTC when symptoms become burdensome to patients, has not become rooted as a care concept, even in medical fields which are frequently

exposed to LTCs (such as neurology, kidney, lung or heart services). It is more common in the oncology (cancer) field, but not without flaws.

It is therefore not surprising that ADs are debated by ethicists, health care professionals, jurists, clergy and policy makers. In this discussion I will focus mainly on studies that highlight controversy around ADs. I will briefly mention some legal and religious aspects relating to ADs, but most of the debated issues will be related to medical ethics.

2.2.3.1 Controversies around ADs

It appears appropriate to start debating ADs by using an example from the USA, which was the first country to regulate ADs. The American government has shown an interest in promoting the use of ADs since the late 70s as a tool to preserve patients' autonomy, not only when patients have capacity but also when they lose it. In a report presented to the American Congress in 2008 by the American Ministry of Health, the committee in charge of the report stated that:

> *'The Committee believes that through the execution of advance directives... individuals can better protect their right to express their wishes about end-of-life care and have those wishes respected. The Committee directs the Secretary to conduct a study to determine the best way to promote the use of advance directives among competent adults... and provide recommendations to Congress on changes to Federal law needed to ensure appropriate use of advance directives'. (Health and Human Services - USA, 2008: v).*

Yet the fact that most of the American population does not comply with the seemingly 'humanistic' aim of the American government (and other governments) to promote ADs as a further step to individuals' autonomy, needs to draw attention and to allow questioning. I will use the above quote to elucidate some of the most prominent debates regarding ADs.

'The committee believes…'

Obviously, if an AD was a suitable strategy for all to preserve people's rights for self-determination, most or all of the population would wish to have an AD. Yet 18-30% have ADs in the USA, and far fewer than 10% in all other countries where ADs are legal (less than 1% in Israel), so perhaps not everyone shares the same beliefs regarding the importance of having ADs. Indeed, while some social movements try to preserve the right to control the process of dying, others give voice to the sanctity of life and oppose any abstinence from treatment (Kendrick and Robinson, 2002). It is suggested that consumers' movements may represent a smaller public than the impression provided through the media. At least three systematic reviews (Bravo, Dubois and Wagneur, 2008; Durbin, Fish, Bachman et al., 2010; Patel, Sinuff and Cook, 2004) were identified to look at the effectiveness of education and training of people regarding ADs, on AD-completion. Meta analyses show that even when people are educated and trained about ADs to maximise outcomes, with multiple resources and repeatedly, the maximum effect that was reported was 45.6% (in Bravo et al., 2008), and the minimum effect that was reported was an increase of only 0.9% (regarding AD completion) (in Durbin et al., 2010). This variance supports the suggestion that not everyone places importance on making an AD (Davison et al., 2010). Even those who believe that creating ADs is important do not always follow their belief with actions, giving many reasons for this but implying that action has been delayed due to internal ambiguities or other priorities (Horne, 2011; Jezewski and Meeker, 2005). Some people feel threatened and overwhelmed by talking and thinking about dying (Jezewski and Meeker, 2005).

'Through the execution of advance directives'

There is rarely good correlation between medical situations that are expressed in ADs, which are neatly separated from each other, and reality, which presents itself in many ways and with interrelated health issues in various degrees of complexity and severity. Therefore, ADs are rarely able to serve as exact guidance for health care (Davison et al., 2010). For example, the findings of Cohen-Mansfield and Lipson (2008) show that even when a high prevalence of ADs was available, in a nursing home setting, the directives themselves had a limited role in affecting treatments, mainly because most

situations (43 out of 64 cases) were inapplicable, because they varied too much from the written directives. Few other situations were related to relatives' changes of mind that physicians felt unable to overrule. The rigidity of legal AD forms often limits the possibility of using them as guidance when the time comes to execute them.

'Individuals can better protect their right to express their wishes about end-of-life care'

As I discussed elsewhere (Meron, 2013), ADs raise the ethical dilemma of 'two personalities', the former *healthy* and the latter *incompetent* (Kendrick and Robinson, 2002; Quante, 1999). When ADs are considered, the moral question that emerges is: who is the individual whose right we aim to protect? Is it the personality who made the ADs, or the one now living without capacity? The same body of a certain 'John Doe' seems to belong to two different personalities at different times, and the suffering of the two personalities may vary a great deal. Therefore, a commitment to protect people's wishes about EoL care is not simple and not easily ascertained.

'Individuals can better have their wishes respected'

A seminal prospective controlled clinical trial (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)) was conducted during 1992-1993 in five teaching hospitals in the USA, looking at outcomes of care at EoL (The SUPPORT Principal Investigators, 1995). It was aimed at improving end-of-life decision making and reducing the frequency of a mechanically-supported, painful, and prolonged process of dying. It included 4,804 patients, each of whom had at least one out of nine kinds of life-threatening diagnoses. The intervention included intensive and laborious efforts to provide enhanced information, counselling and support, informing physicians about patients' prognoses, and informing patients about possibilities and tools that could be used to express their wishes for EoL care (Murphy, Kreling, Kathryn et al., 2000). Yet no significant difference was found between intervention and control in outcome measures such as the timing of DNR orders, length of hospital days in ICU, pain control, and physicians' awareness of patients' ADs (The SUPPORT Principal Investigators, 1995).

Another aspect of respect for wishes, and one of the main controversies surrounding ADs, remains their trustworthiness in view of people's change of priorities, as has been researched by many (Barber, 1999; Carmel and Mutran, 1999; Ditto, Jacobson, Smucker et al., 2006; Weissman, Haas, Fowler et al., 1999). For example, it was found that elderly participants tended to change their preferences in response to hospitalisation in an acute setting. This suggested that decisions are dependent on context and that people's perceptions after experiencing a situation in which they are ill may differ from their original perceptions while healthy (Ditto et al., 2006). People may change their perceptions in different phases of illness as well, after experiencing new symptoms or further losing capability. People may adjust to their decline in ways that they cannot anticipate. The ethical dilemma is therefore whether an AD that was written at a certain moment is applicable at another time.

Furthermore, in order to execute ADs, the directives need to be known to others in addition to their makers. There is evidence that many patients do not share their ADs with their HCPs, which may hinder the possibility of respecting their wishes in due time (Becker, Jaspers, King et al., 2010; Covinsky, Fuller, Yaffe et al., 2000; Douglas and Brown, 2002; Justin, 1990; Sulmasy, Terry, C.S. et al., 1998). It is also evident that ADs are often inaccessible to health care providers when they are needed (Cohen-Mansfield and Lipson, 2008).

Additional dilemmas regarding ADs have been discussed more extensively elsewhere (Meron, 2013) and will just be mentioned here:

- Balancing between autonomy (of the individual) and social justice (public welfare).
- Balancing between the autonomy of the patient and that of their relatives (see also discussion in chapter 5).
- Balancing between futility and sanctity of life.

Two important barriers to promoting ADs which are interrelated need to be highlighted:

- Much of the population is unaware or does not know enough about the availability of ADs to actually seek ways of creating them (Bentur, 2008).

- Many health care professionals are unable to provide much information about ADs (Bentur, 2008), or think that patients do not want to discuss their EoL wishes (Davison et al., 2010).

These two barriers create a vicious circle, because as long as HCPs ignore information about ADs, there is no chance that they will discuss the latter with patients. Patients in turn will come across the option of making ADs only coincidentally in such reality.

To conclude the conceptual framework, there is a need to reconcile three very different conceptual frameworks simultaneously in order to enable ADs to exist (Figure 2, page 17). Also, clearly, there are many areas to explore regarding individual and social experiences at EoL. Without these there will be no simple answers to the American Congress' mission, 'to determine the best way to promote the use of advance directives among competent adults' (Health and Human Services - USA, 2008: v) and there will be no easily-found recommendations for legal changes that may ensure the appropriate use of ADs. An AD is not only a tool, but also represents values and world views. Arguments for and against ADs still occupy many philosophers, legal counsellors, ethicists, religious leaders, policy makers, health care professionals and public opinion, and these debates lie at the background to this study, and will continue long after its conclusion.

2.2.4 The extent of publication surrounding ADs – a summary of the available literature

There is an abundance of evidence related to ADs; therefore the next section presents a focused review of evidence which is most closely related to the scope of the present study. The process of searching for literature will be described first, as well as major issues investigated in relation to ADs in the past four decades, along with exemplary studies of each issue.

In an extensive search for evidence around ADs, held between 2009 and 2013, the searched terms were: 'advance directive*', 'living will*' 'advance medical directive*' and 'advance health-care directive*' in major sub-headings and titles, excluding psychiatric ADs and ADs related to mercy-killing

(euthanasia and assisted death). Data bases included: *Cinahl; Medline; Web of science; ASSIA*; as well as free searches through reference lists of journals and papers.

The aim of the search was to map out the available evidence, to follow up the development of research and understanding around the phenomenon called 'advance directive', and to identify gaps that I would hope to address with the current study.

The search yielded over 3,500 results throughout the period of the doctorate, with a high proportion of duplication, as well as high prevalence of non-research publications, comprising: opinions ('pros' and 'cons'); suggestions, policy and guidelines; legal aspects; critiques, philosophy, ethics and religion. Most of the publications were in English, but they included many other languages as well (but in a much lesser amount) from all continents and many countries, which probably reflect world-wide interest in ADs. Therefore it is not easy to provide a definite number for the studies screened and read for use in this thesis. However, hundreds of papers were read during this period, mostly but not exclusively in English[6].

An analysis of the results yielded regarding ADs showed that the first publication was in 1977, a year after the first legislation on ADs in the USA (in California). Between 1977 and 1990, 1-25 publications appeared each year. Since 1991 (after the enactment of the 'Patient Self Determination Act'), at least 50-100 publications appeared globally every year. After screening the publications and separating research out from the rest to focus on the available evidence, it was obvious that the papers covered a whole range of issues. The main issues can be categorised into seven broad categories:

1. Needs, knowledge, attitudes, experiences or behaviours of various stakeholders (the general public; patients; HCPs; relatives).
2. Correlations between AD holders' (or potential holders') expressed wishes, and their relatives' or HCPs' estimate of their wishes.
3. Barriers to ADs.
4. Effects of education (regarding AD communication) on AD holders, relatives and HCPs.

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[6] I read French and Hebrew fluently (T.M.)

5. Statistics of AD use.
6. Social, religious and cultural aspects of ADs.
7. Outcomes of ADs.

Table 1 (next page) summarises the major categories and issues covered by research to date, with three cited references, from the available evidence, of each issue covered, although for most issues more studies exist. The chosen examples are meant mainly to show the breadth and variety of evidence.

The evidence is varied in terms of condition of health (healthy and/or ill participants); illness (sampling people with specific LTCs such as cancer or lung disease and/or a variety of LTCs); age (specific age groups or all adults); settings (community, acute hospitals, nursing homes and/or hospices) and methods (using qualitative and/or quantitative methods, including RCTs).

2.3 Focused overview of research perspectives

Due to the wealth of evidence regarding ADs, this section will focus on evidence related to two issues chosen from the available evidence mapped in Table 1 (next page): needs, knowledge, attitudes and experiences of patients with LTCs and of HCPs, who are all central figures in this study.

2.3.1 Perspectives and experiences of patients with LTCs regarding ADs

When the search for published research literature was narrowed down to patients' perspectives, 45 papers were identified; the first was dated 1989, up to the most recent in 2013. Most studies were conducted in the USA; a few had been conducted in European or Asian countries or were multi-national. Many of them were examining how to influence AD-completion rates in various ways. They included mainly surveys or closed-ended interviews; a few were document reviews (especially when critically ill patients were sought after) (example: Batchelor et al., 1992). Only the study by Haisfield et al. (1994) was qualitative, using focus groups of cancer patients to learn about their needs regarding ADs (Haisfield et al., 1994).

Table 1: The main issues covered by research regarding ADs

The major categories of evidence	The researched issue	Examples of studies	
Needs, knowledge, attitudes and experiences of various stakeholders regarding ADs	Needs, knowledge, attitudes and experiences of the public	Hague and Moody, 1993 Sessanna and Jezewski, 2008	Matzo and Hijjazi, 2008
	Needs, knowledge, attitudes and experiences of patients*	Nolan and Bruder, 1997 Hechter et al., 1999	Jackson et al., 2009
	Needs, knowledge, attitudes and experiences of proxies	Moorman et al., 2009 Khodyakov and Carr 2009	Caron, 2005
	Knowledge, attitudes and experiences of health care professionals*	Gramelspacher et al., 1993 Lipson et al., 2004	Bentur, 2008
	Knowledge, attitudes and experiences of managerial bodies or policy makers	Black and Fauske, 2007 Golden et al., 2011	Krok et al., 2011
Correlations between patients' wishes for EoL care, and others' estimates of patients' wishes	Correlations between patients' wishes and relatives' estimates of patients' wishes	Sulmasy et al., 1998 Zettel-Watson et al., 2008	Barrio-Cantalejo et al., 2009
	Correlations between patients' wishes and health care professionals' estimates of patients' wishes	Druley et al., 1993 Fischer et al., 1998	Coppola et al., 2001
Outcomes	Outcomes of ADs in EoL care	The SUPPORT principal investigators, 1995	Hammes et al., 2012 Dobbins , 2007

The major categories of evidence	The researched issue	Examples of studies	
Barriers to ADs	Communication barriers regarding ADs	Tulsky et al., 1998 Weiner and Cole, 2004	Ko and Lee, 2009
	Changes in people's EoL wishes over time	Emanuel et al., 1994; Carmel and Mutran, 1999;	Froman and Owen, 2005
Influences of education on ADs	The influence of education and training about ADs on patients	Bravo et al., 2008 Cugliari et al, 1999	Detering et al., 2010 (RCT)
	The influence of education and training about ADs on health care professionals	DesRosiers and Navin, 1997; Merckaert et al., 2005;	Butow, 2008
Statistics of ADs	AD-completion rates and how to improve them	DeLaGarza et al., 2001; Payne et al,. 2010	Waite et al, 2013
Cultural, social and religious aspects regarding ADs	Religious aspects of ADs	Isaac et al., 2003; Pearce et al., 2006;	Curlin et al., 2008
	Cultural aspects of ADs	McAdam et al., 2005 (Filipino minority in USA) Sittisombut et al., 2005 (men and women in Thailand); Ivo et al., 2012 (comparison of patients in China, Korea and Japan)	

* The issues that are discussed in greater detail

Most of the studies included patients during their general practitioners' (GPs') visits (example: Sloan, 1990), or community-dwelling elderly. At least four studies related to nursing-home residents (example: McAuley et al., 2003); three to outpatients (example: Sam et al., 1993); and five to hospitalised patients in various wards (medical, intensive care, cardiac, surgical wards and even emergency departments) (example: Angelos et al., 1999) which did not necessarily indicate an LTC. In nine studies it was clearly indicated that patients had LTCs.

In most of the 45 studies there was a mixture of different illnesses (such as HIV, cancer, lung, or kidney illnesses) (example: Gilligan et al., 1995), and/or various stages of illness (example: Salmond et al., 2005). In many studies the percentage of AD holders among the participants was mentioned (example: Sulmasy et al., 1998). This was usually done to compare numbers before and after interventions to increase AD completion rates. Yet only seven studies were found to focus on patients with ADs, trying to identify their views, behaviours, and/or the outcomes of their ADs, with or without comparing them with other people (example: Teno et al., 1998). This variance makes it hard to analyse the evidence, because comparisons of largely different settings and participants can hardly be significant. I will therefore present the literature as it relates to the following subtopics that I find most relevant to this thesis: knowledge of ADs; reasons and motivations for making an AD; assistance and sharing the fact of having an AD; and cultural influences on ADs.

2.3.1.1 Patients' knowledge of ADs

Several studies elucidated lack of knowledge and misinterpretations among patients who had an AD. The definition of an AD and the implications of specific life-sustaining procedures (such as cardio-pulmonary resuscitation or mechanical ventilation), is not always well understood by patients (Douglas and Brown, 2002; Jacobson, White, Battin et al., 1994; Nishimura, Mueller, Evenson et al., 2007; Upadya, Muralidharan, Thorevska et al., 2002; Zronek, Daly and Lee, 1999). Some participants confuse ADs with testaments (Nishimura et al., 2007). Furthermore, in the study of Thorevska, Tilluckdharry, Tickoo et al. (2005) 37% of the patients, who had ADs, revoked them after receiving an explanation of treatments such as the above. This

finding is worrying, and supports the claim that people who make ADs often ignore the full meaning of the treatments they refuse. On the other hand, it strengthens the initiative in the Israeli DPA which mandates the signature, in the AD document, of a HCP who has provided an explanation of the treatment options that appear in the official AD form. This is one way of ensuring that the person who prepares an AD understands the different treatments that they will be refusing or demanding (see Box 1, page 12) (The Dying Patient Act, 2005).

2.3.1.2 Reasons and motivations for making an AD

Among the parameters associated with making an AD were: older age; having a terminal illness (Douglas and Brown, 2002; Sittisombut, Love and Sitthi-Amorn, 2005); and multiple hospitalisations (Douglas and Brown, 2002). Stated motivations of participants for having an AD were: to make EoL decisions easier for relatives; to abstain from life-support measures (Douglas and Brown, 2002; Duke, Thompson and Hastie, 2007); to provide choices for relatives; to reduce potential conflicts and guilt of relatives; to expose patients' wishes to their relatives; and to improve the odds that those wishes will eventually be fulfilled (Douglas and Brown, 2002). Advance directives reflected patients' need to take part in decision-making regarding their own care (Justin, 1990; Pautex, Herrmann and Zulian, 2008). Having said that, Sahm, Will and Hommel (2005b) examined AD holders' views regarding how binding ADs should be. Interestingly, many participants preferred ADs to be considered by relatives and HCPs as guidance rather than as orders; they wished them to be examined in the context of the patients' actual situations, and not to be too rigidly fulfilled 'by the letter' (Sahm et al., 2005b).

2.3.1.3 Assistance and sharing the fact of having an AD

One study was found in Germany, by Becker et al. (2010), which looked at resources used by patients to assist them in making an AD. It discovered that health care professionals are least used as resources, while lawyers and relatives are the most addressed (Becker et al., 2010). This finding is reinforced by descriptive data from other studies showing that patients share information about their AD with physicians much less than with relatives

(twofold to fourfold in different studies) (Becker et al., 2010; Douglas and Brown, 2002; Justin, 1990; Llovera, Mandel, Ryan et al., 1997; Sulmasy et al., 1998; Thorevska et al., 2005). This may partially explain the finding which appeared extensively, that HCPs are often unaware that their patients have an AD (Becker et al., 2010; Douglas and Brown, 2002; Justin, 1990; Sulmasy et al., 1998). In a more focused perspective, the Justin's study (1990) found that filling in an AD form was different when the patient was new to the GP's surgery from when the patient had known the GP for a longer time. The encounter around the AD stimulated less conversation for new patients than for the GPs' more veteran patients (Justin, 1990). This may suggest that sharing the fact of having an AD and the depth of the conversation regarding patients' EoL wishes may be related to patients' perceptions of their physicians' accessibility to such communication, which may depend upon a reliable relationship between both parties. On the other hand, it may be argued that physicians should explore the wishes of a patient who is new to them, and whose needs they know less well than those of a more veteran patient in their clinic.

In most studies that looked at the content of ADs or the expectations of their holders, participants preferred palliative care over life-prolonging measures (Nishimura et al., 2007; Sahm et al., 2005b; Sloan, 1990; Upadya et al., 2002). Nishimura et al. (2007) analysed retrospectively the AD documents of nearly 500 patients who had died in MD Anderson hospital, and found that people generally objected to life-support measures more as a general statement, without specifying which life-saving measure they objected to (Nishimura et al., 2007). This finding may strengthen the worrying finding that some of those who make an AD do not exactly understand what treatments they are refusing and the implications of their refusal (Thorevska et al., 2005), which may question the validity of an AD.

2.3.1.4 The predictability of patients' EoL wishes

One of the remaining critiques about ADs and their validity is that HCPs and surrogate decision makers are unable to "stand in the patient's shoes" and accurately predict or state these patients' preferences for EoL care. Some studies have tried to measure the accuracy of predictions by HCPs and surrogate decision makers of their patient/patient-relative's wishes for such

time as the patients' capacity was lost (Coppola, Ditto, Danks et al., 2001; Druley, Ditto, Moore et al., 1993; Sulmasy et al., 1998; Uhlmann, Pearlman and Cain, 1988; Zettel-Watson, Ditto, Danks et al., 2008). Some studies found that the correlation was no higher than that of pure chance (Uhlmann et al., 1988), while others found over 66% accuracy (Sulmasy et al., 1998; Zettel-Watson et al., 2008). Yet there is great variability between these studies in terms of illnesses, health conditions and age, among other factors, therefore these findings cannot be compared. Studies comparing the accuracy of HCPs' predictions and those of surrogates found higher accuracy with the surrogates (Coppola et al., 2001; Uhlmann et al., 1988). Gender difference was also found between women-surrogates and men-surrogates in couples, in favour of women, which was explained by women's higher sensitivity to their husbands than vice versa (Zettel-Watson et al., 2008). Another finding that was inconsistent, both with HCPs and surrogate decision makers, was the added effect of ADs on the accuracy of predictions. Barrio-Cantalejo, Molina-Ruiz, Simon-Lorda et al. (2009) found that an AD improved surrogates' accuracy, and that discussion on the AD further improved accuracy. However Sulmasy et al. (1998) did not find ADs to have a significant effect on the accuracy of surrogates' predictions of their patient-relatives' EoL wishes. Regarding HCPs, the most influential parameter on accuracy was their experience in performing discussions regarding life-sustaining treatments (Druley et al., 1993; Sulmasy et al., 1998).

To conclude, accuracy in predicting patients' EoL care wishes seems limited and problematic when considering surrogacy for EoL care, although communication improved the ability of others to grasp patients' wishes for their EoL care, especially when surrogates were women.

2.3.1.5 Attitudes and cultural differences in relation to ADs

Studies which looked at cultural issues related to ADs either compared countries (such as Ivo, Younsuck, Ho et al., 2012), who looked at Japan, China and Korea), or focused on minorities in a specific country, such as McAdam, Stotts, Padilla et al. (2005) who looked at Filipino-Americans. Some studies have elucidated cultural influences regarding EoL decisions (see Sittisombut et al., 2005; West and Hollis, 2012), while others found insignificant effects of ethnicity (Ko and Lee, 2009). To add to Ko and Lee's

(2009) perspective, some studies identified an effect of global "westernisation" (Ivo et al., 2012), and of "acculturation" of minorities, meaning their cultural merging into their new communities in new countries (McAdam et al., 2005). Although cultures are still influential in many countries, there seems to be a growing blur between cultures, and the effects of culture seem to be gradually diminishing in the face of modern "globalisation". This is not to say that cultural sensitivity is not important, but that sensitivity is likewise needed to prevent one from prejudicially looking at patients as obviously part of their "ethnic culture".

To summarise, the evidence concerning patients' perspectives includes both patients' motivations for making an AD and the content of their wishes. It shows a low level of knowledge regarding ADs, even among AD-holders; a low level of sharing ADs with relatives and HCPs; and low correlation between patients and their relatives and or HCPs in terms of patients' EoL preferences.

2.3.2 Health professionals' perspectives: A review of research

Health care professionals' perspectives included physicians, nurses and social workers. No work was identified regarding psychologists and ADs. Over 50 studies related at least in part to HCPs (29 included physicians, 33 included nurses, 5 included social workers, with some studies including more than one discipline). The studies were dated 1988 to 2012. Participants were often from community settings, i.e. nursing homes or GPs' surgeries; some were from acute hospital settings such as: departments of general medicine, intensive care units and surgical units; a few were oncology and/or hospice-related HCPs. Participants' exposure to EoL was varied.

Most studies were surveys, using mainly self-report or structured questionnaires. Yet there were a few qualitative studies (example: Lang-Welzenbach, Fasching and Vollmann, 2005) and some interventional studies, especially those which related to education regarding ADs (example: Thayer, 1997). The majority were conducted in the USA (38), others in Korea (2), Thailand (1), Germany (2), Sweden (1), Ireland (1), Austria (1), China (1), Canada (2) and Israel (3).

Professionals' perspectives showed three broad constituents: *Knowledge*, *attitudes* and *experience* (or behaviour), which were not always completely distinguishable from each other. The main themes of each of the three topics are listed in Table 2 (below) and some will be further elaborated on.

Table 2: Professionals' knowledge, attitudes and experience related to ADs – the main themes that appear in literature

Knowledge	Attitudes	Experience
• End-of-life care • Advance directives (ADs) • Documents of ADs • The related law • Available relevant resources • Supportive communication • State and professional policies	• Self-perception\personal traits • Professional role perception • Perception of own preparedness to discuss ADs • Attitudes towards ADs	• Communication • Inter-disciplinary collaboration & support • Previous experience with ADs • Knowing patients' wishes

2.3.2.1 Health care professionals' knowledge and knowledge needs

Knowledge was mostly related to ethical, legal and other aspects of care at end-of-life, and evidence elucidated barriers to and gaps in that knowledge (Bentur, 2008; Marchand, Fowler and Kokanovic, 2006; Richter, Eisemann and Zgonnikova, 2001). In order to overcome these barriers, participants in some studies expected that in medicine, nursing and social work, learning about end-of-life should be part of the basic curricula, as well as of continuous education (Bentur, 2008; Lipson, Hausman, Higgins et al., 2004; Thompson, Barbour and Schwartz, 2003). It was suggested by researchers that communication about advance care plans (ACPs), should be through experiential learning and not based only on theoretical knowledge (Bentur, 2008; Bergman-Evans, Kuhnel, McNitt et al., 2008; Kane, Hamlin and Hawkins, 2004; Lacey, 2006; Lipson et al., 2004). This is congruent with findings showing that experience promotes a positive attitude to ADs whereas

inexperience provokes an avoidance of the subject (Bentur, 2008; Lipson et al., 2004; Schiff et al., 2006). Another reported potential barrier to making or discussing ADs was lacking knowledge of formalities, such as: lack of familiarity with AD documents, with the signing procedure and with policies (Bentur, 2008; Lipson et al., 2004; Schiff et al., 2006).

2.3.2.2 Attitudes and views regarding ADs among health care professionals

Most studies used pre-prepared scenarios in self-reported questionnaires in order to discover professionals' attitudes (see Carmel, Werner and Ziedenberg, 2007; Kim and Lee, 2003; Richter et al., 2001; Thompson et al., 2003). Overall evidence shows more positive than negative attitudes towards ADs in studies. Advance directives are often described by HCPs as useful (term used in Bergman-Evans et al., 2008; Schiff et al., 2006; Sittisombut, Maxwell, Love et al., 2009) and more specifically in Israel they were positively described as 'legalisers' of 'do not resuscitate (DNR)' orders (Bentur, 2008). Advance directives are viewed by HCPs largely as promoters of conversation about EoL care, allowing patients' wishes to be honoured and helping to inform relatives of those wishes (Schiff et al., 2006; Steinhauser, Christakis, Clipp et al., 2000; Thompson et al., 2003). Some physicians prefer partly accurate or vague ADs rather than none at all because this guidance enables them to respect patients' wishes (Barbour, Schwartz and Thompson, 2003; Bentur, 2008).

Yet not all attitudes are favourable of ADs. A recent review of evidence regarding physicians' attitudes toward the concept of ADs shows that the main barriers to ADs as viewed by physicians were: **cultural,** where ADs were perceived foreign to the local culture, and where family is considered very influential on patients' health decisions (Sittisombut et al., 2009); **legal,** fear of litigation; **religious or moral,** where ADs were perceived as breaching the sanctity of life or as allowing euthanasia (Coleman, 2012). In addition, critiques of ADs include **ethical** aspects such as: deciding in health for a future state of illness, although the tendency of human beings is to change their minds (Bentur, 2008; Lipson et al., 2004; Schiff et al., 2006; Thompson et al., 2003). A reactive view to the latter critique suggested that AD forms

need to be re-evaluated periodically to concord better with patients' changing wishes (Bergman-Evans et al., 2008; Cohen-Mansfield and Lipson, 2008). Another critique of ADs was the potential coercion of patients by pressure from relatives, which was expressed by 75% of physicians in two studies (Schiff et al., 2006; Thompson et al., 2003).

Some of the studies asked about participants' attitudes towards personally holding ADs. In a Korean study, 90% of the nurses reported that they would have rejected life-sustaining treatments in the event similar to the scenario described in the questionnaire (Kim and Lee, 2003), and in one study in the USA, 36% of the nurses stated that they had made their own ADs (Lipson et al., 2004) which reflects a positive attitude toward the concept of ADs. Overall, there seems to be correlation between professionals' world views and their behaviour: accepting death as part of life was found to correlate with an openness to discuss patients' concerns (Black, 2007; Kim and Lee, 2003), whereas perceiving death as taboo was related to fear, anxiety and health care professionals' avoidance of communicating about ADs (Bentur, 2008; Black, 2007; Kane et al., 2004).

How physicians perceive their role regarding ADs?

Physicians' role perception regarding ADs extends from rejecting an active role related to ADs (Bentur, 2008; Coleman, 2012) to a perceived obligation to participate in them (Bergman-Evans et al., 2008; Cohen-Mansfield and Lipson, 2008). Some physicians maintain that their role is to focus on resuscitations and maintaining life, and not on refraining from treatment (Bentur, 2008). Others lack compliance with patient wishes due to a professional paternalistic culture (Coleman, 2012; Richter et al., 2001), which seems to be gradually fading away with the younger generation of physicians, when compared with the older generation (Richter et al., 2001). Another barrier to taking an active role in processes related to ADs is lack of confidence in communication skills; a sense of lack of guidelines which led HCPs to feel uncomfortable with AD conversations (Bentur, 2008); and hesitation to discuss ADs until patients raised the subject (Almack, Cox, Moghaddam et al., 2012). However, overall, most physicians reported giving priority to patients' EoL wishes and respecting patients' AD documents (Bentur, 2008; Carmel et al., 2007; Coleman, 2012; Schiff et al., 2006).

Nurses and social workers' role perception regarding ADs

Looking at nurses and social workers specifically, their perceived confidence in their own knowledge was a significant predictor of discussing ADs with patients (Lipson et al., 2004). In a qualitative study of nurses and social workers, the perceived role of nurses was to clearly depict details of the medical procedures that could be provided ('a tube down the throat') whereas the perceived role of social workers was to help find out the significance of decisions at end-of-life and how treatment could affect life (Black, 2006). In both professions there are HCPs who are involved in AD discussion in some places, and their involvement seems to be accepted by fellow-physicians (Bentur, 2008; Kane et al., 2004; Lacey, 2006). Yet it is not clear to what extent nurses and social workers take part in discussing and exposing patients to the option of ADs, and more specifically in Israel this information is missing.

2.3.2.3 Experience and behaviour regarding ADs

The experience of HCPs could be based on their own actions regarding ADs as well as on the way that ADs are handled by their colleagues in their professional setting. Findings of various studies have revealed that HCPs' experience with ADs was diverse in various studies. For example, 81% (583/719) of nurses in Ohio selected randomly from the registry of nurses said that they had experience with ADs (Lipson et al., 2004); 56% (454/811) of the UK geriatricians had cared for patients who had ADs and of those, 62% (280/454) had cared for patients while ADs took effect (Schiff et al., 2006). Looking at the few relevant studies in Israel (Bentur, 2008; Carmel et al., 2007), the exposure of HCPs to ADs is unknown and should be explored.

The initiation of discussion about ADs is one aspect of experience which varied in different studies. Some professionals initiate a discussion on ADs or see it as an opportunity to discuss ACP (Bergman-Evans et al., 2008; Black, 2006; Schiff et al., 2006; Thompson et al., 2003); others leave it mostly to the patients' initiative (Almack et al., 2012).

Some studies reveal that HCPs experience discussion of ADs as difficult, due to the heavy emotional burden related to bringing up the issue (Bentur, 2008; Bergman-Evans et al., 2008) and due to time constrains that hinder long

conversations (Bentur, 2008; Bergman-Evans et al., 2008; Black, 2006; Ryan and Jezewski, 2012; Schiff et al., 2006), even with physicians who view those conversations as valuable (Schiff et al., 2006).

Richter et al. (2001) found that role-perception also played a part in behaviour related to ADs. In non-authoritarian medical settings there was correlation between physicians' awareness of their patients' wishes, and the medical treatment they provided to these patients. Yet in more authoritarian medical settings, physicians are less likely to take account of their patients' wishes and tend to use much more invasive, high-technology life-sustaining measures. Among the countries investigated, non-authoritarian settings were found most prominently in Sweden, less in Germany and least in Russia (Richter et al., 2001).

Cohen-Mansfield and Lipson (2008) examined the impact of ADs on care in real EoL situations by comparing physicians' self-reports and summaries of actions with residents' documentation in a care home in the USA. The researchers suggested that complex issues such as withholding treatments and acute hospitalisation at EoL could better be examined in a real-life context. They discovered, for example, that at night time, physicians were 'on call' from a distance, and did not hold all the information regarding patients' ADs (Cohen-Mansfield and Lipson, 2008). It was the only study that I found where a variety of reasons for mismatch between directives and treatment decisions in real-life occurrences could be unveiled.

This section reviewed some of the evidence related to professionals' perspectives surrounding ADs, showing great variance of skills, experiences, knowledge and perceptions. Some of the findings were contradictory. There are some indications of gaps between different countries or disciplines which may be valuable for regional and global policy-makers and for the development of education strategies and programmes. Most of the studies are self-report ones, therefore a study such as that of Cohen-Mansfield and Lipson (2008) which compared actual occurrences with self-report, adds value to the understanding of barriers and problems of using ADs. The general impression from this overview is that there is an interaction and dependency between *knowledge*, *attitudes* and *behaviour*, each affecting the others.

2.4 Gaps in the available evidence relating to ADs

Most research focused on one target group; very few looked at the whole system and included all stakeholders. Only one study in Israel (Bentur, 2008) was found which looked directly into ADs, and it may serve as a probe to health care professionals' perspectives on ADs. In that study, Bentur (2008) recommended: a wider data collection, that will include other disciplines, and other medical specialisation related to LTCs; gathering more quantifiable data and moving further away in time from the enactment of the DPA, in order to learn about experience with and awareness of ADs, in a way that will enable education and policy to be informed.

It is important to understand the meaning of ADs for people with LTCs, through a variety of perspectives such as those of patients, family and HCPs, because all are fundamental to the execution of ADs. In Israel, in particular, no attempt has yet been made to view the phenomenon of ADs from such a variety of perspectives simultaneously: holders of ADs and relatives; perspectives of patients and of their professional carers; ADs made in health and in illness; looking at ADs as a process rather than an event.

There are four major lacunae in the available evidence: (1) researchers often use theoretical scenarios; (2) research rarely looks at people who are at their EoL; (3) most evidence is based on self-report questionnaires; (4) evidence regarding Israel is thin. The proposed research aims to fill this gap.

At this point in time, when palliative care is planned to span to all LTCs in Israel, and where ADs are legal, a unique opportunity has been presented to learn from the experience of people who have made ADs, and also to map out the knowledge and attitudes of HCPs who are supposed to educate, discuss, support and execute those ADs. I anticipated that the picture drawn from gathering the multitude of perspectives of all stakeholders may help to discover gaps that need to be filled in the near future in order to make ADs work in favour of individuals' best interests.

2.5 Overall aim of this study

The overall aim of this study was to examine from a variety of perspectives, i.e. patients, relatives and HCPs, the experiences, beliefs and practices associated with the use of ADs in Israel, with a view to understanding their role in the lives of patients with palliative care needs, towards the end of life.

2.5.1 Objectives

- To learn from people with LTC who are nearing death, the experiences, beliefs, values, and needs that led them to make ADs.
- To discover what influenced changes in the content of people's ADs over time.
- To identify the expectations patients have relating to their AD.
- To explore the extent to which these expectations are met by their formal and informal carers during the delivery of care towards and at the end of life.
- To examine the potential contribution that ADs have, in the palliative care of people with LTCs, from the perspective of their family carers and physicians.
- To examine HCPs' knowledge, attitudes and experiences relating to ADs, as well as their perceived role in the process of making ADs.

2.6 Conclusion

The above review of the literature has provided a historical view on the emergence of ADs, as well as an overview of the variety of publication around this issue. It also guided the reader through the available evidence, focusing mainly on patients' perspectives and those of HCPs, and pointed out some of the gaps that the present study aimed to fill. The next chapter will deal with methodological aspects and the design of the research itself.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter will describe the design of the research, which examined (from a variety of perspectives), the experiences, beliefs and practices associated with the use of advance directives (ADs) in Israel. In this chapter, the research question will be associated to both ontological and epistemological perspectives regarding the social world, as well as to suitable methodological concepts and research tools.

The study was planned as a mixed methods design in two phases. One (major) phase took the form of a patient-centred multiple-case study. The other (minor) was a survey of health care professionals (HCPs) who care for people with long term conditions (LTCs), about their professional experiences concerning ADs (Figure 3, below).

Figure 3: Overview of the study design
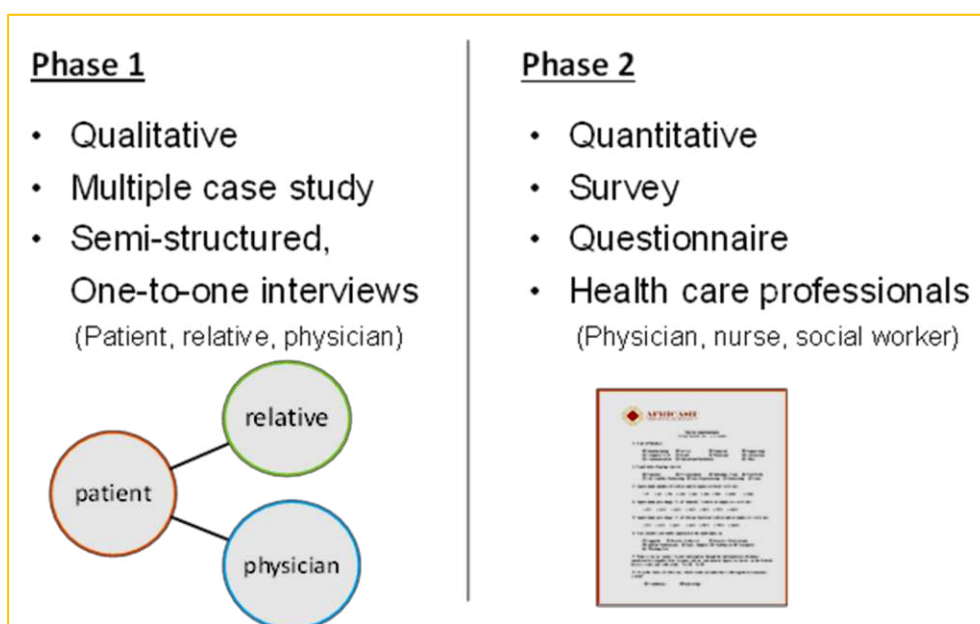
This chapter firstly addresses some basic philosophical questions, to set the theoretical grounds and legitimacy for my project. This is followed by a section describing the planned design and rationale for each of the two phases, supported by methodological literature. Data collection follows, focusing particularly on the various challenges and the decisions taken to address them. Final sections address issues of reflexivity and data-analysis strategies.

3.2 'Worldviews' for studying advance directives

Exploring the meaning of ADs in depth entails engaging in a phenomenon that exists, first and utmost, as an idea in people's minds; a set of values, thoughts and meanings that people hope will be influential in their real lives, toward end-of-life (EoL). Advance directives exist in people's minds, but they are also represented externally by legal and other documents, and more importantly they exist to guide behaviour and to act on health-related decisions in real life. Thus, an exploration of ADs stems from a theoretical perspective that accepts both the physical world and the inner mind as 'real' entities that interact with each other "in a single real world" (Maxwell, 2012: 16). As such, ADs are a social construction, and studying their meaning is best suited to research established on paradigms that are aimed to understand social life.

Creswell (2009) discusses four worldviews[7] to explain social research: *postpositivism, constructivism, advocacy/participatory* and *pragmatism*. *Pragmatism* is focused on research problems rather than on methods, and therefore is not committed to one specific theory or method. Such a liberal approach to research makes pragmatism suitable for mixed-methods research (Creswell, 2009). Pragmatists view the social world as based on social interaction, and therefore on interpretation that may not be 'objective' or 'true', but subjective and relative (Benton and Craib, 2001). Generally, this worldview represents my view that a single theory cannot give complete answers to the *ontological* question, 'What is there in the world?' in regard to ADs and to the *epistemological* question, 'How do we know what is there?' (Maxwell, 2012), especially due to the fact that '*there*' may refer to people's minds.

My study draws on elements from several philosophical worldviews because all provide partial, but none a completely acceptable framework to support it. In this respect I follow the pragmatic worldview, accepting that:

- An AD is a 'complex multifaceted social construction' (Creswell, 2009) that was not 'there' some decades ago, but was invented by human beings.
- Once constructed, this phenomenon becomes real, in the sense that it is a driving force to behaviour (Maxwell, 2012).

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[7] Also called *paradigms*, *ontologies* and otherwise by various researchers, meaning a general view about 'what is in the world' in order to guide ways to learn about it (Creswell, 2009; Maxwell, 2012). Some writers refer to both *ontologies* and *epistemologies* when they use this term.

- An interaction between varied perspectives on reality (or multiple realities) is so complex that it cannot represent one global truth (Maxwell, 2012).

- Although participants share their views honestly as being true to them at the moment of sharing, they are not absolute truths even then, but a summary of complex influencing factors within and outside of them. Paul Rock uses the term 'authenticity' (in Benton and Craib, 2001: 87) to describe such honest sharing.

- Social knowledge is relative to time, place and other influences, and is therefore local and mortal (Benton and Craib, 2001; Maxwell, 2012; Spencer, Ritchie, Lewis et al., 2003).

- People's experiences are varied and so are their values and preferences. Interpretations given to one event by two individuals can sometimes be contradictory (Brock, 1993). Human social life differs from natural facts in its unpredictability (Benton and Craib, 2001). Therefore, understanding complexity is based not only on accepting diversity but also on actively looking for it, rather than looking for categories, groups or "ideal types"[8] (Benton and Craib, 2001; Murphy and Dingwall, 2003; Walter, 1994).

- Interpretation is a legitimate research tool when looking to expand insight into a social phenomenon (Creswell, 2009; Maxwell, 2012; Stake, 1995), for example ADs, because such insight entails 'accessing the minds of others[9]'. In order to obtain a closer look at this phenomenon, good communication between the participants and the researcher is essential. Yet communication is subjected to a twofold transformation: the constructions made by the participant while trying to articulate emotions and thoughts to the researcher, and the inevitable interpretation of the researcher while trying to understand the participant's world (Murphy and Dingwall, 2003).

- Local realities may be un-generalizable (externally - to other settings, or internally – to others within the setting that did not participate in the research) (Maxwell, 2012), yet they are nevertheless evidence, and they can be used as a source for critique, insight and learning by others who are external to the particular setting, being aware of the similarities and differences between both the research setting and their own.

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[8] "Ideal types" – termed by Max Weber, meaning: shared characteristics that can construct a generalizing idea of a group based on common values and practical thoughts, disregarding emotions and traditions (socialsciencedictionary.com).

[9] 'Accessing the minds of others', i.e. accessing people's accounts, reflections, perspectives and thoughts.

The aim of phase one, which is the core of my project, is to expand the understanding about the variety of influences and motivations in going through the process of creating ADs, and to enlighten more aspects of 'cultural contiguity'[10] relating to EoL (Maxwell, 2012) by searching for diversity (Creswell, 2009). Phase two complements the first by showing the views regarding ADs in the health system, in the local setting of Israel today.

3.3 Methodology

There are several types of research designs which are relevant to my project's aim, most notably: *case study, phenomenology* and *mixed methods* (Creswell, 2009). The study used a pragmatic mixed-method design, combining a major qualitative phase using multiple case studies with a minor quantitative phase using a questionnaire. This type of mixed methods is often termed: "QUAL+quan"[11] (Morse, 2003).

Mixing methods in research is not new, but in the last few decades attempts have been made to establish the principles of what has become, as some would claim, the 'third paradigm' after the positivist and interpretive paradigms (Alpert, 2010). Pragmatists claim that social phenomena often hold simultaneously quantitative and qualitative traits, and therefore the methodology should be able to answer the research questions rather than reflect a specific paradigm rigidly (Alpert, 2010). My project was pragmatic, and to appropriately answer its questions I drew inspiration from several methodological perspectives: it is mostly influenced by a *phenomenological* interest in the topic under investigation and in-depth exploration of its meaning for individuals who created ADs, as well as for others around them (Cohen, Kahn and Steeves, 2000a); its key structure is *multiple-case study* design (in the qualitative spirit of Stake, 1995), trying to explore a common issue from a variety of perspectives (Payne, 2007). It also uses more than one strategy to collect data, which is viewed as promoting the understanding of complex phenomena, and thus answers the definition of a *mixed-method* design (Creswell, 2009; Newman, Ridenour, Newman et al., 2003). All three types

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[10] 'Cultural contiguity': Relationship that is "associated on solidarity of difference and complementarity rather than similarity" (Maxwell, 2012:54).

[11] '**QUAL**'=qualitative project; '**quan**'=quantitative project; '**+**' indicates that the projects are held simultaneously; uppercase indicates the major project (Morse, 2003).

support an understanding which leans on interpretation and on multiple realities; an understanding that is relative to time and place, and therefore prone to change. All of them allow the examination of complex phenomena, which is the intention of my study. Additionally, this study is centred on AD holders and as such may be able to give 'voice' to a pioneering minority which is not as yet identified as a group but which may be 'disenfranchised' even if not oppressed (Creswell, 2009: 9). Therefore this study may possess an underpinning *advocacy worldview* 'flavour' although it is not expressed in the methodology or the design (Creswell, 2009).

Mixing research methods aims to validate phenomena, by triangulating findings, but also to complement findings and information, and to expand knowledge that is accumulated from various sources (Alpert, 2010). The exploration of experiences, values and practices related to ADs is often better answered by qualitative research tools, which are frequently used in palliative care research (Payne, 2007). However, in the setting of my study, learning how ADs are viewed and understood by a larger sample of HCPs in Israel was viewed as complementary to an investigation around AD holders. The approaches were selected because they seemed appropriate for the specific aspects of investigation (Alpert, 2010; Creswell, 2009; Denscombe, 1998).

3.4 The methods of data collection

3.4.1 The design

The study was designed in two phases. One phase took the form of a patient-centred multiple-case study. The other was a survey of HCPs (see Figure 3, page 39). Due to the differences between the two phases, the planned design and the actual process of each of the two phases are described separately (see flow chart in Figure 4 next page). Following these, various challenges of the actual data collection and their resolutions will be discussed. Lastly, the data analysis of each phase is described:

Figure 4: Mapping the structure of the methods section of the chapter
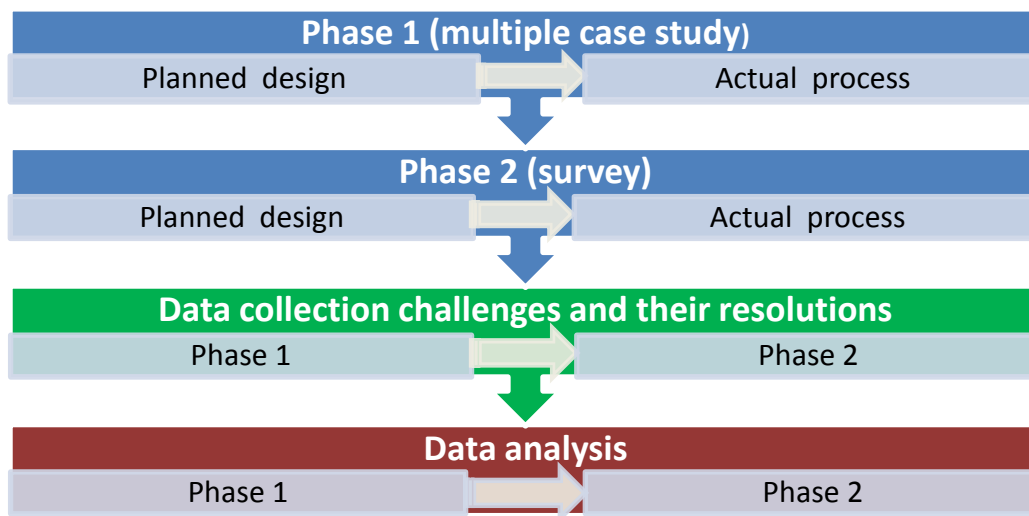
3.4.1.1 Phase 1 – Multiple-case study

3.4.1.1.1 The planned design

This phase engaged with patients' experiences, supported by additional input from others around them, and was aimed at giving an in-depth understanding of the use of ADs in palliative care. The plan was to encompass both the process over time (retrospectively) and the parties influenced by it. This was sought after by favouring in-depth interviews and by focusing on a small sample (Denscombe, 1998; Payne, 2007). In order to exploit what can be learnt about ADs at end of life and to maximise the perspectives, it seemed that by using a collective case study (CS) design, my study could refine conceptions about ADs that appear in the literature by revealing variability not previously recognised (Stake, 1995).

Setting

The study was conducted in Israel. With the advantage of the country's small size, there were no further geographical limitations.

Sampling

It was planned to include between 10 and 15 people with long term conditions (LTCs) who had created ADs, as central figures, and around each to include relevant stakeholders, preferably forming 10 CSs. The variation that was

sought after included religions, religiosity, ages, illnesses, and genders (Denscombe, 1998; Mason, 1996; Stake, 1995).

Inclusion criteria

Patient-participants had to fit all the criteria below:

- Being with capacity.
- Having made advance directives.
- Having a long term condition.
- Being at the end stage of their illness at the time of the interview.
- Being aware of their advanced stage of illness.
- Accepting audio-taping and the making of written notes during interviews.
- Signing a consent form.

Exclusion criteria[12]

- Having cognitive disability or extreme emotional distress.
- Being non-fluent in Hebrew[13].

Recruitment plan

Patient-participants – The LILACH[14] organisation provided me with access to potential patients by agreeing to publish my recruitment letter in the organisation's bulletin. The plan was to reach people who had made their ADs through 'LILACH', calling for those who met the inclusion criteria. If this option failed to recruit participants, I planned to approach patients' associations, such as 'ATLS' (the MND[15] patients' association in Israel).

Non-patient participants (other stakeholders) were envisioned to be nominated by the patient and to participate at their own consent.

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[12] Speech impairment that can make communication limited or difficult was not regarded as an absolute exclusion criterion, and was considered individually.

[13] Israel is a state of emigration, and many senior citizens speak Hebrew fluently as a first language, although it is not defined as their 'mother tongue'. Therefore the criterion for inclusion is **oral fluency** in Hebrew and not its being the **mother tongue**.

[14] LILACH - 'live and die with dignity association' in Israel, an association that has promoted the concept of ADs since 1987 and gives information and legal advice to its members, but also keeps a database of around 10,000 members' updated ADs.

[15] MND (motor neuron disease) is a degenerative condition, which causes gradual paralysis, from the lowest parts upwards. When it reaches the respiratory system the person attained can be kept alive only on mechanical life support.

3.4.1.1.2 The actual design

Recruitment

I used the LILACH bulletin at the end of December 2010. About a week later, on the 5th of January 2011, an overall 110 applications had been made. The dilemmas and challenges are discussed farther.

Actual inclusion and exclusion criteria

In reality there was a slight change in the inclusion and exclusion criteria. Due to time pressure at the time, it was agreed to add the antecedent of the willingness of the caller to nominate a family member and the physician. This would not guarantee the willingness of the latter to participate, but it could increase the chances of completing CSs. This criterion was applied to the last two patients recruited. One physician was on extended leave and could not be reached until the end of the data-collection period. Three other exceptions were:

- One participant was included not because of his LTC, which was stable, but because he was over 90 years old, and this seemed to be threatening his life expectancy more than his cancer.
- Being at the end stage of their illness at the time of the interview was retrospectively found to be inaccurate in one case. It was an advanced but stable illness, yet other reasons prevailed to keep the participant in the study.
- Accepting audio-taping and making written notes during interviews was rejected by one participant at the last moment, when the interview was about to start, and yet the participation was not officially excluded. I wrote notes during and after the interview, but compared with the audio-recorded ones, the data I have is limited and less accurate.

Sample

The achieved sample is presented in Table 3 (next page), and described below.

People with long term conditions who made ADs (labelled hereinafter as 'patients' or 'patient-participants'): Number of patient-participants included,

N=10 (6 women, 4 men). Age range: 59 - 90. Marital status: 2 widowed 1 single and 7 married. Variety of LTCs: Cancer (5 patients); renal insufficiency (2 patients); respiratory insufficiency (2 patients); cardiac insufficiency (1 patient); neurological degeneration (2 patients). Three of the patients had multiple LTCs.

Non-patient participants were nominated by the patients, and were included upon both the patient's and their own consent. The sample consisted of _relatives_ and _physicians_ and in one case a _Rabbi. Relatives_ (N=9: 4 children, 3 spouses and 1 cousin); _Physicians_ (N=7) included: four who were nominated by the patients (3 family physicians and 1 specialist physician) and three others who were recruited in other ways. The rational for recruiting physicians outside CSs was that four out of ten optional interviews were viewed as insufficient. Moreover, it was felt that the medical voice would be biased by the fact that the participating physicians were the ones who seemed more comfortable with discussing ADs and EoL issues, while the evidence of Bentur (2008) showed the discomfort of physicians in communicating with patients about these matters (Bentur, 2008). In order to give other 'voices' a chance, three medical managers were interviewed, from three different inpatient services caring for people with long term conditions, in a large hospital where I used to work. Thus, physicians who are based in another (inpatient) setting and are quite often exposed to EoL decisions shared their experiences regarding ADs. Similarly to the two patients who were not part of the CSs and contributed to the sample of patients, these interviews contributed to the sample of physicians.

During the primary conversations with applicants over the phone, neither nurses nor lawyers were identified as key figures. Before any interviews had started, cases were restructured to comprise: a patient, a relative and a physician (Figure 5, page 49).

Table 3: Case studies (CSs) – summary of participants' information (participants appear in pseudonyms)

	Participating figures	age	Profession\ occupation	education	LTC
CS1	Patient (Noa)*	>70	Education	B.A.	Multiple Sclerosis
	Husband (Ben)	>70	Administration	High school	
	Physician (Dr. Yahalom)	>50	Medicine - family physician (GP)	MD	
CS2	Patient (Meira)	>80	Engineering	BSc.	Renal failure
	Daughter (Lea)	>50	Academia	B.A.	
	(Physician)	----	Refused by the patient	--	
CS3	Patient (Naomi)	>50	Academia	PhD	COPD
	Cousin (Carol)	>60	Art	B.A.	
	Physician (Dr. Barda)	>60	Medicine - pneumologist	MD	
CS4	Patient (Yarden)	>60	Health care profession	B.O.T	Colon cancer
	Son (Yagil)	>30	Health care profession	academic	
	Husband (Koby)	>60	Administrative	High school	
	Rabbi (Nakdimon)	>50	Clergy	Rabbinical studies	
	GP (Dr. Shalom)	>40	Medicine - GP	academic	
CS5	Patient (Omri)	>80	Administration	Certificate	Multiple LTCs
	Daughter (Vicky)	>60	Education	M.A.	
	Physician	---	Refused	--	
CS6	Patient (Shelly)	>70	Health care profession	certificate	Colon cancer
	Son (Deckel)	>40	Business	B.A. +	
	Physician	---	Refused by the patient	--	
CS7	Patient (Dov)	>90	Agriculture	certificate	Prostate cancer + age
	Son (Yoni)	>50	Engineering	certificate	
	Physician (Dr. Paz)	>40	Medicine - GP	medicine	
CS8	Patient (Debby)	>60	Retired (printing)	High school	Renal cancer
	Husband (Alon)	>60	Retired (administration)	certificate	
	Physician	---	Was in a long leave	--	
Patient 9	Adam	>60	Agriculture	High school	MND
Patient 10	Ehud	>80	Health care profession	academic	Leukaemia + bladder cancer
Physician	Dr Agmon	>60	Medicine - neurology	medicine	
Physician	Dr Azriel	>60	Medicine – general medicine	medicine	
Physician	Dr Ash	>50	Medicine - nephrology	medicine	

* Died during the data collection period

Yet, in reality, there was inconsistency in the composition of cases, as can be seen in Table 3 (page 48). Of the eight case studies formed, three were formed according to the plan (comprising a patient, a relative and a physician); four included only a patient and a relative; one case included an additional participant such as a Rabbi, who was included due to the relevance of his involvement with the patient's AD.

Figure 5: Overview of the qualitative phase - 'multiple-case study' design

case studies, each comprised ideally with a patient, and nominated relative and physician
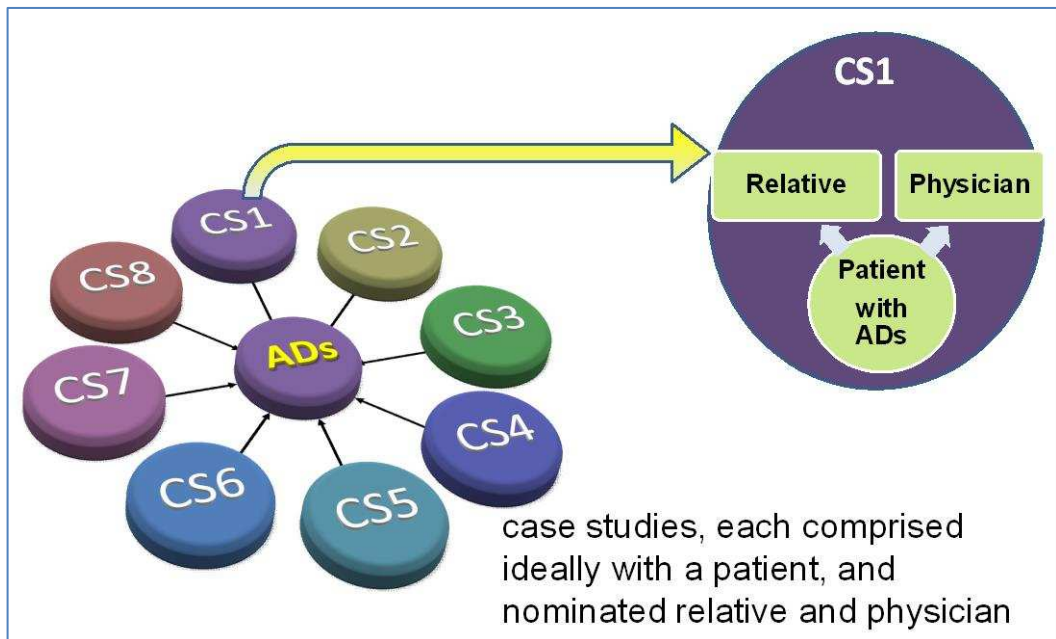
Interviews

Most interviews were one-to-one in-depth interviews. Two included the spouse of the participant, and are discussed later. All interviews were semi-structured, using open-ended questions, and all but one were audiotaped and transcribed verbatim. Most interviews took place at peoples' homes. Physicians were interviewed in their work places (except one home interview). One relative was interviewed in a café at her request.

The duration of the interviews with *patients* ranged from less than an hour to nearly three hours, mostly lasting over an hour and a half. Interview time with *relatives* ranged from between half-an-hour to two hours. The option for more than one interview was suggested to patients and to relatives, at the end of the interview, but was not realised. Interviews with *physicians* ranged from

half-an-hour to one hour. Interviewing physicians, who were generally very busy, demanded extreme flexibility.

Ethical approval

The study received the approval of the ethical committee in Israel (application number 0188-10 RMB, see Appendix B, page 284)[16].

Ethical issues were addressed and discussed with my supervisors and with participants at each and every meeting, to assure that all the ethical aspects that were planned were indeed protected. All the participants signed their consent to participate, before the interview started, and after having had stressed to them the option to refuse or stop the interview at any point, without needing to explain anything (see information sheet in Appendix D, page 286).

At the end of each interview with patients and with relatives, I suggested that if the content of the conversation had provoked any distress they should seek support. I also invited them to call me if they wanted to discuss any issues arising from speaking with me, so that I could signpost to support resources. This was addressed in the consent forms as well. At the end of interview, a few of the relatives disclosed to me that prior to the meeting they had been a bit nervous about meeting me to discuss ADs, but that the conversation, although not easy, had actually relieved the burden.

One participant was concerned that the refusal of his physician to participate would influence his participation or harm the research and this caused him unnecessary worry. I was able to reassure him that this would not occur. Other ethical issues that appeared during the field work are explained later.

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[16] The framework of Integrated Research Application System (IRAS) was used to prepare the ethical application.

3.4.1.2 Phase 2 – a survey

3.4.1.2.1 The planned design

Sampling

In this phase the sample criteria consisted of professionals who care for people with a variety of LTCs[17], in hospitals and in the community, including physicians, nurses, social workers and psychologists.

Recruitment

It was planned to approach nurses and physicians through professional specialist bodies, such as: 'Israeli Neurological Association'; 'Israel Heart Society'; 'Israeli Oncology Nursing Society'. This would enable an element of control over the number of surveys sent (N) and the percentage of completion. Social workers and psychologists who care for non-cancer patients with LTCs were planned to be recruited through 'TMICHA[18]' (the palliative care society in Israel). Otherwise, the plan was to recruit an identified list of HCPs who worked in the various institutions – both hospitals and community health services – with the help of key informants. The preliminary concept was that once a list was formed, the total number of questionnaires sent (N) would be known, to enable the calculation of response rates. The plan was to send the questionnaires by post to potential participants according to the lists provided, or to provide the questionnaires in pre-paid envelopes to professional bodies, to enable them to avoid revealing their members' lists to me. In both cases, the plan was to add another pre-paid return envelope.

Questionnaire

The questionnaire was based on one made by Schiff et al., used to determine geriatricians' experiences of and views about 'living wills' (ADs), and geriatricians' views on related legal changes in the Mental Capacity Act in the UK (Schiff et al., 2006). The questionnaire items were generally appropriate, it was designed, piloted and revised by Schiff et al. (2006), and permission was

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[17] Examples for LTCs considered: Cancer, neuro-degenerative conditions, organ failure (Renal /heart /lung).

[18] TMICHA - 'support' in Hebrew

granted from the researcher to adapt it to Hebrew and to the Israeli context. The adapted questionnaire included 47 items divided between 7 sections. It had three types of questions: (1) closed-ended with one (most applicable) answer; (2) closed-ended with the possibility of choosing all the applicable answers and adding options; (3) open ended questions. The questions covered knowledge, attitudes and experiences related to ADs.

Linguistic and cultural adaptation

Beaton, Bombardier, Guillemin et al. (2000) recommended an adaptation of both culture and language when a cross-cultural adaptation is required, and suggested four distinct processes: (1) translation from the original to the target language; (2) reverse translation from the target to the original language; (3) an evaluation of the similarity between the original and the reverse-translated outcome; and (4) pilot-testing of the translated questionnaire (see Figure 6, next page).

For maximum validity, Beaton et al. (2000) suggested that the processes of translation should be done by more than one translator whose first language is the target (and later the original) language, and that the versions should be compared and discussed to produce an agreed version called 'the pre-final version' that ought to be tested on 30-40 participants. These recommendations try to ensure accuracy when an identical questionnaire is desired, and where the psychometric properties of the questionnaire – whether a psychological test or scale – need to be maintained (Beaton et al., 2000). Yet my study used a questionnaire which addressed a different sample of participants from that in the original study (Schiff et al., 2006), and therefore could not be identical nor claim 'sameness'. I drew upon Schiff et al.'s questionnaire as a foundation and adapted it culturally and linguistically, and to a wider variety of health disciplines. I followed the three processes depicted above, but adapted them as appropriate in the specific context of my study. This adaptation will now be explained in greater detail.

Figure 6: Graphic representation of the stages of cross-cultural adaptation (Adapted from Beaton et al. (2000)).

Stage 1 Translation	• Translation to target language • Adaptation of terms to target setting • Adaptation of questions to target disciplines
Stage 2 Backward translation	• English first language • With no access to the original • Work from target language backwards • Create backward translation
Stage 3 evaluation	• Evaluation of the process • Comparison of original and backward translation
Stage 4 pretesting	• Focus group to test questionnaire • Refining and adding questions • Finalising the questionnaire • Probing the questionnaire

The English questionnaire was translated to Hebrew (the target language), and some items were changed to fit the Israeli and research settings. For example: the 'Mental Capacity Act' did not have an equivalent in the Israeli legal system and was replaced by 'The Dying Patient Act' which defined and legalised ADs. Also, questions about 'euthanasia' (the act of deliberately ending a person's life to relieve suffering) and 'physician-assisted suicide' (using a medical prescription of a lethal drug to end life) appeared to be drifting away from the research topic and were removed altogether; the list of religions needed to be adapted locally (the Church of England and Hinduism were replaced by Druze); religiosity was added and the names of organisations related to ADs in Israel replaced those applicable in UK. Another adaptation step related to the specific sample of my project. The original questionnaire was directed at physicians, while the target here included additional health care disciplines (nurses, social workers and psychologists).

A professional translator whose first language is English prepared the reverse translation from Hebrew to English (the original language), without having

access to the initial questionnaire. The reverse translation was appraised by experts in the field who reported that it achieved a similar concept, meaning, and fluency and that it would be able to achieve the same responses (Beaton et al., 2000). They affirmed that the meaning of the questions and proposed categories for answering them remained unchanged, although some of the wording was not identical.

The translated questionnaire was pilot tested on a group of multi-disciplinary HCPs who completed the questionnaire and then discussed it with me, critiquing it and suggesting how it could be further developed to enhance its validity. This was achieved through one focus-group discussion of psychologists and nurses (N=5) from oncology and neurology clinical fields; two one-to-one discussions (one with a physician (a pulmonologist) and another with a social worker from oncology); and one phone conversation with a physician (a neurologist). Their feedbacks helped with rewording and adding questions, as well as adding options for answers where it seemed appropriate.

I believe that with all the measures taken, the end result was a questionnaire that had greater validity than would have been possible had I constructed one entirely on my own, with the resources available in the framework of my doctoral research.

3.4.1.2.2 The actual design

Recruitment

In reality, the plan of using professional bodies proved to be unrealistic. Professional associations were reluctant to expose their members to surveys, apparently due to their abundance. It seems that physicians are inundated with surveys and do not respond to postal surveys. Two options were considered: one was to use professional links and engage senior nurses to give the questionnaire to their multi-disciplinary staff; the second was to use the occasion of a national multi-disciplinary conference on palliative care and survey this population. It was decided to use the second option because it was more feasible and provided an opportunity to access professionals from around Israel rather from one locality. Permission was granted by the conference committee, and it was agreed that the survey would be advertised

in the opening session, when all the participants were located in one hall. In the end, this opportunity was missed and participants were approached individually.

The sample

When I approached participants at the conference, I was not aware whether they were HCPs (although most of them were), and if so, which discipline they belonged to. The sample eventually included physicians, nurses and social workers; however, no psychologists filled in the questionnaire. I am not aware whether or not psychologists participated in this conference and if they did, how many took part. Eighty five participants were approached and of these, 77 completed the questionnaire. The detailed description of the sample appears in Chapter 7.

To conclude this section, I presented the planned design of phase 1 (multiple case studies) and how it was applied in reality, and also of phase 2 (the survey). The next section will highlight the challenges of my data collection, and their resolution.

3.4.2 Data collection process, challenges and resolutions

Regardless of how well a research is prepared, reality is rarely identical to the plan and there is sometimes a need to reconsider options and find suitable solutions along the way (Maxwell, 2012). In my study, several such junctures were crossed during the data-collection journey. Whenever a problem appeared, it required decisions and solutions. This section describes the challenges and dilemmas that were raised, and decisions that were made to deal with them optimally, based on research ethics and methodology literature, and with the guidance of my supervisors.

3.4.2.1 Reaching for participants – from nil to all, learning the value of patience

The first attempt to reach out for participants through the LILACH bulletin was made in July 2010 (Figure 7, next page). It was expected that people would read the announcement and make the first contact with me by phone or e-mail

shortly after. The plan was to start collecting data in September. However, by August, not a single call and/or e-mail had been received. Searching the bulletin in LILACH's website to find the advertisement about the study proved to be difficult. The original A4 format agreed upon with the LILACH committee[19] was missing. Instead, a short note measuring 5 x 5 centimetres, which was barely noticeable, appeared on page 23. It was assumed that the reason that there had been no applications at all was that the notice was not visible enough. Yet the bulletin was nonetheless viewed as the best vehicle to call for participants, and it was agreed to use it again. This time the original A4 format was used as a flyer that was attached to, but not part of the bulletin (see Appendix C, page 285).

Figure 7: Pre-interview timeline up to the successful outreach for participants

July 2010	September 2010	October-December 2010	End December 2010	January 2011
•first advert (LILACH bulletin)	•planned start of field work •decision making about advert	•preparing the second advert •preparing phase 2	•second advert (LILACH bulletin) •advert in LILACH's website	•phone calls & eMails (starting 05.01.11) •first interview (14.01.11)
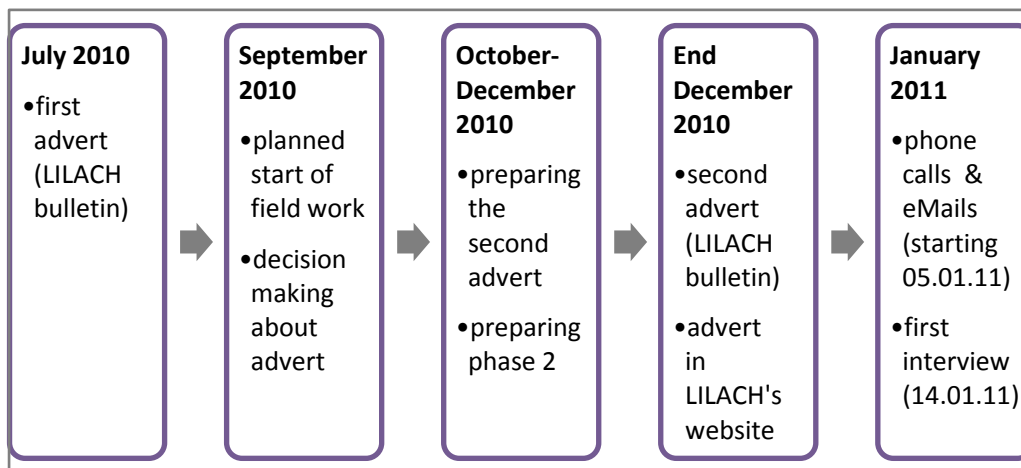
While reconsidering a repeat publication, the recruitment letter was reworded and piloted in order to make it more personal and to make the most of this second chance. The publication of the following bulletin was planned for the end of December 2010, nearly six months after the first attempt to advertise the project. The question was whether to use only the LILACH route, or to use other routes of publicity as well. The most problematic issue of all seemed to be the entrance of intermediate figures between the researcher and potential participants, which was mandatory when using the other sources. This interference was undesirable due to the sensitivity of the patients involved

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[19] The agreed A4 format included elements designed to promote confidence for readers: the aim of the project, the audience it addressed, the logo of the university and my photo.

(Addington-Hall, 2002). The worry was that due to their dependency on carers, ill people might be less able to protect their own interests than others, and might participate in research as a means of satisfying perceived expectations of those carers (Addington-Hall, 2002). To detach consent from the influence of carers or unintended pressure, the recruitment was made through the LILACH organisation, and by using an opt-in strategy, where the patient-participant who was interested approached me rather than vice-versa.

Eventually the LILACH bulletin was used a second time with the changes depicted above. This decision provoked anxieties about whether it would be successful and involved a period of waiting, but it proved to be effective. Following this second issue of the recruitment request, 110 individuals contacted me in all, mostly by telephone and some by e-mail

Due to the limitations of being a lone researcher, and the restricted schedule of PhD research, the time gap (over five months) between the two announcements (see Figure 7, page 56) could not be wasted on waiting. Instead, it was used to prepare the second phase of the study, the survey.

3.4.2.2 Significant phone calls

The reaction of callers is reported here because it was surprising and needed quick adjustment, and also because it called for an ethical consideration. In the planning of the study it was expected that the screening process of the applicants would entail short focused conversations. However, in reality calls typically lasted 30-45 minutes each. Conversations included answers to my questions for inclusion/exclusion and practical purposes. They also included additional information from the callers. I was looking for:

- Personal details (name, age, telephone numbers, and geographic location).
- Screening questions regarding ADs (whether or not they held them, and whether family members and/or a physician were involved).
- A general question about their condition of health, gently trying to understand the severity of illness when relevant.

Apart from answering the above screening questions, callers seemed open and interested in telling their stories. They shared personal and family stories, fears and expectations around health and life-threatening illness, disability and dignity at the end of life, quality of life and living wills. This content was initiated by the callers, which was interesting, moving and very informative. It helped the recruitment later and informed the interview schedule. One illuminating example of the interest of callers was a woman who called me on the second day of calls. She said that her husband had died ten days earlier, and that she was very interested in the research, and asked if she could participate a month later, to allow her some recuperation. The richness of material from the phone conversations would justify a thesis in itself. Yet, these calls were made prior to any formal process of informed consent, and the aim was to map out the callers for inclusion purposes. Without former consent they were not and could not be used as data. Therefore the calls were not recorded, but short notes were taken during conversations to help when making later decisions as to whom to include/exclude.

3.4.2.3 Sampling

Although the extent of applications allowed for purposive sampling, the whole sample was only partly dependent on the inclusion criteria, and variability could only be sought after in patient-participants. The non-patient participants depended on the patient's nomination and the consent of the nominee. This was challenging, because relatives and physicians were not as interested in taking part in my study as patient-participants. In addition, patient-participants were not always comfortable asking their relatives and physicians to take part.

Another challenge related to the desired number of CSs. The plan was to create ten CSs, because this number of cases was viewed as enabling diversity (Baker and Edwards, 2012). Qualitative research experts claim that the number depends on many factors (Baker and Edwards, 2012). The number was restricted by setting and by resources but was aimed: to enable sufficiently good evidence to be produced; to enable variety; to include the less reachable participants to minimise biases; and to enable depth (Baker and Edwards, 2012). Eventually, ten patients were interviewed, and 8 CSs were created, some of which were incomplete. Limited time resources and personal health factors imposed restraints on further recruitment. However,

steps were taken to exhaust all the options of collecting meaningful data, and to make changes in the design where possible to maximise the data sources and quality. The data that were collected were rich and varied, and enabled a considerable contribution to the understanding of ADs.

Making decisions about including or excluding patients in the study

The large amount of calls suggested a potential for purposive sampling. Therefore, callers were asked whether I could call them later, if needed, and they usually agreed. Healthy callers were thanked for their interest and support, and no further contact was made with them. Having over a hundred callers had both benefits and handicaps. The main drawback was that the only way to discover whether or not callers met the inclusion criteria in full was by conversing with all of them. Yet the efforts were worthwhile, because the breadth and the detailed conversations enabled a better choice to provide the desired variety.

Selection of patient-participants

The four callers, who seemed to be most terminally ill, were the first to be recruited. Their interviews were held between mid-January and mid-February. This first wave of participants served essentially as a pilot exercise, in the sense that this first wave enabled me to refine my on-going sampling framework and interview schedule before recruiting further cases. I took the time to learn about my skills as an interviewer from each interview. After interviewing the first four patients, I chose the next participants in order to create a multiplicity of illnesses, ages, and health conditions, aiming for a balanced representation of men and women. All the applicants were Jewish, although the plan was to represent people from various religions. Religiosity was not probed during phone calls, but three callers identified themselves as religious, and it was important to represent religious participants in the sample. One of the three had a metastatic cancer and was recruited. During her interview, I realised that her cancer had been stable for over five years, but this did not reduce her awareness of the potential threat to her life. Two other callers were identified as facing the last stage of their illness, and were included in the sample. From the six who potentially appeared the closest to

needing to use ADs, five were women. I focused on the group of male applicants for my next recruits, and selected two men in their 80s with a multitude of LTCs. The interviews revealed that one was extremely ill and frail, and although he managed to maintain independence, he could also be at the end of his life at any moment and was well aware of it. The other had refused any treatment for his dual malignancy (cancer) but described his quality of life as fair. A new participant was included because in the initial phone conversation he had described his age (90) as a daily threat to his life and well-being, a threat that guided his present life and related decisions. In the context of this project it seemed appropriate to relate to very old age as a risk factor for EoL issues and decisions, although old age is not an illness.

Two of the patient-participants were unique as they did not form a case study. One proposed that I interview his relatives after his death, because at the time of the interview they were described as totally denying the deterioration in his health and the threat to his life. He consented to the interview with the physician who had communicated with him about his illness and about the option of making ADs, but no further contact was made due to reasons of personal safety explained below. The other patient did not agree to include any of his family members or his physician in this project, saying that they were extremely busy and he did not feel comfortable asking them to spend time on my study. The content of both interviews is incorporated in my study even though they could not form larger CSs. They were added to the group of patient-participants.

Exclusion of patient-participants

Three callers were excluded during the screening calls, based on exclusion criteria listed earlier. One was a man in his late 30s who described himself as having complex physical, social, psychiatric and financial problems. Another was a woman in her 80s who told me that she had memory impairment. The third exclusion was of a woman whom did not perceive herself as cognitively impaired, yet had forgotten about her call to me even when I reminded her of the letter in LILACH's bulletin. She was convinced that someone must have called me without her permission and I had a strong feeling that she had memory or cognitive problems. A few weeks later, she called me again, not

remembering that we had already spoken. This only served to further justify my prior decision to exclude her.

3.4.2.4 Interviews

The aim of the project was to get as close as possible to the moment when ADs needed to be carried out (i.e. capacity would be lost as death became near). I wanted to look at ADs as a process along a period of time, rather than as a 'snapshot' of the 'here and now'. I planned to achieve this by asking questions retrospectively, about the earliest thoughts of ADs, up to the time of the interview when patients were aware that they were approaching death. When patients are no longer competent, their viewpoints can no longer be accessed through research; it was therefore hoped that if any patient participant lost capacity while data collection was in progress, their family members participating in my study would be willing to share their experiences in another interview. This could further develop the portrait of ADs and deepen the understanding of this phenomenon at the very end of life, which was less easy to time in my project. Actually, I had two opportunities to be informed about such moments. One patient-participant died during the data-collection period, and another participant was mechanically ventilated in the emergency department in one of her respiratory crises, contradictory to her ADs, and lived to tell the story. These examples appear in the findings chapters in greater detail.

Interview structure

In-depth semi-structured interviews are a means to gather the descriptions and interpretations of others about something that cannot be observed and is internal to individuals (Mason, 1996; Maxwell, 2012; Stake, 1995). Interviews are supported as a way of gathering qualitative data in palliative care in general, with sensitivity to problems such as breathlessness which may tire the patient or compromise clarity (Payne, 2007). People's thoughts and preferences regarding ADs could not be observed. Taking into consideration the fact that patient-participants and their relatives could be frail and exhausted my study was based on a single interview per participant, although at least two interviews are usually recommended (Cohen et al., 2000a).

Participants were offered a second interview if they wished, but none took up my offer.

As a result of both methodological literature and ethical considerations, a preliminary set of *etic* questions, based on previous literature, was prepared as an interview guide for each stakeholder, to guide the first steps of the research, and to perhaps stir up some *emic* issues belonging to those forming the case (Denscombe, 1998; Stake, 1995). The interview usually began with a question about the start: When did *patients* first think about making ADs; when was the first time that *relatives* heard about it; and when did *physicians* become aware of the patients' ADs. From this question on, every interview took a different path that was formed by the replies of each participant and the issues that they brought up. The interview guide's questions were used when I felt that the interview was approaching its end, and I wanted to be sure that I did not overlook something important which had not been discussed. Participants shared many life stories to explain their thoughts, fears, expectations and needs. However, sensitivity was used to let each interviewee recount their unique story as far as seemed relevant to the understanding of the context, and their sharing was only interrupted when they drifted too far away from the topic, and only at a natural break (Mason, 1996; Payne, 2007; Stake, 1995). Payne (2007) thinks that the degree of structure of an interview is related to its aim: whether to answer the researcher's (*etic*) agenda, or elicit the participant's (*emic*) agenda (Payne, 2007). The project was intended to discover participants' perspectives on a specific topic. The preliminary questions prepared for the qualitative phase were therefore used as probes to further identify each participant's *emic* issues regarding ADs. They were used flexibly, as triggers when needed, but only when necessary, and some were changed as the study progressed (Stake, 1995). However, sometimes a question was used to focus on ADs or to bring the interviewee back to expand further on a point that they had brought up, and about which I wanted to know more.

Participants' expressions and terms were used as means to create a common language and promote their ability to expand on issues that they had brought up and that needed to be further explored. Patients' *relatives* were invited to share their views and experiences with an ill relative who had made an AD, and how this had affected themselves, family life and their own priorities.

Physicians were interviewed about their experience of communicating with a patient/client about ADs, and about the challenges of caring for a dying patient with an AD and of executing ADs.

Confidentiality and consent

For each interview, after taking a few moments to settle down and when they seemed ready, participants were asked to sign a consent form. They were fully reassured of their total freedom to participate or not and to answer some or all of the questions, and the confidentiality of the content – from any other participants and in the written report – was explained to them. They were also reassured that apart from me, only my supervisors would have access to the interview material, and that this would be used with pseudonyms throughout.

Interviewing patients and relatives - exceptional interviews

The interviews were planned as one-to-one, but there were two exceptions to this. The first was a patient who was being mechanically ventilated through the trachea (main respiratory tract), below her vocal cords, which meant that she spoke without a voice. She could be understood by reading her lips. She was the first participant in the study, and the primary information about her, provided by her husband in the preliminary call, made me feel that this was an urgent interview. We agreed that the husband would repeat the patient-participant's words aloud. The participant seemed comfortable, and the interview was fluent and rich.

Another exception to the 'one-to-one interview' rule was not premeditated or planned. An interview with the husband of another patient-participant was planned as one-to-one. Yet, shortly after I started the interview the patient came in. When she asked permission to stay in the kitchen to prepare dinner, I was too embarrassed to ask that we move to another room to continue the interview, and the husband replied that he did not mind. However, I felt a change in his tone of voice and body language shortly after. As I left, the husband confirmed that he was embarrassed and restricted by the presence of his wife in the room during the interview. I proposed to speak with him on the phone if he wished, but he did not take up this invitation.

Access, rapport and safety

In the phone calls and in the interviews with patients, rapport was quickly established and both the interviewee and I felt comfortable. There was one exception to this positive experience. One patient viewed the interview as a platform for further intimate relationship. He called me repeatedly although I clearly stated that I was not interested in any relationship, and that the content of the conversations was extremely embarrassing for me. For my personal safety, it was decided that no further contact would be made with this participant, even though this meant giving up the case study. It was decided not to engage in any further interaction with him for the purpose of interviewing other people related to him, and a short polite card was sent to thank him for his contribution to the project.

3.4.2.5 Transcription

All the interviews were transcribed verbatim in Hebrew. The fact that I heard the participants repeatedly during the process enabled me to recall: the atmosphere of the interview; participants' changing tonality; their emotional expressions; and of course the content. I tried to clarify participants' accounts while I was interviewing them, and felt confident that they had conveyed their accounts authentically at the moment of the interview. I did not offer the possibility of showing transcripts to participants for their comments. Their accounts relate to a specific moment, and rigour and caution were used to analyse their accounts. No participant asked to see the transcript. A few patients shared the hope that they would live long enough to read my thesis.

Quotes were translated to English with an attempt to best resemble the spoken version in Hebrew which often did not adhere to grammatical rules or to the way in which people may express themselves in writing. For expressions that have equivalence in English, the equivalence was used. Yet, for expressions that could not be replaced, an explanation was added in footnotes. I used the help of English speakers to provide the most accurate version in English that would best reflect the original version that was used by the participants. In the quotes I sometimes filled in in brackets words that were not spoken but rather inferred, or mentioned in subsequent sentences, to enable readers to have a better understanding of what participants meant.

Some other times the meaning of words made sense in Hebrew but not in English, so I filled in brackets a clarification starting with 'i.e.'.

3.4.2.6 Being a researcher who is a palliative care nurse

Being a researcher and a health care professional is not rare in nursing; however, this duality needs to be addressed as part of the transparency expected in qualitative research, and for the critique of the reader (Cohen et al., 2000a). My project involved people nearing the end of their lives. For some, death was imminent. One patient died during the fieldwork, and others may well have died since the fieldwork phase. The subject matter of this study was related to the needs and expectations of people at the very end of life, when they are already facing an LTC in its last phase.

It was agreed that if I found it important to inform participants on anything arising from the interview, I would do it after the interview was exhausted. Interviewing patients about end-of-life issues was not a new task for me, as I do it often in my professional capacity. However, interviewing with no intention of caring for them was totally different. The information that I was about to receive from them was not meant to help them with their health or quality of care. I knew this theoretically, but it became a challenge when patients shared their relationships with the health system and HCPs; when they described suffering that I felt could be reduced but was not; or when they held mistaken information and misconceptions related to the law, medical procedures, and the health system. With my knowledge as a palliative care nurse, I could not leave them entrapped in errors and lack of knowledge. The question was not whether I should interfere, but how I could do it in a way that would respect the boundaries of research as well as professional ones. The interviews were a different experience from interviewing people in the professional setting. I came to patients' houses because they wanted to help me in my study. I met them in their disability, yet they were willing to devote their time and energy to me. It was a poignant experience.

Another disclosure is related to the fact that I have also created my own AD. I am approaching my project not as an objective figure, but with an interest in promoting society's openness toward people's wishes at their end of life. This interest comes from my professional background, in which I have

accompanied hundreds of patients on their trajectory towards death for over twenty years, and found that this trajectory often lacks certainty as to what is best for the dying patient. I have tried in the interview to be aware of my personal preferences, and not to interfere or influence the interviewees.

3.5 Data analysis

3.5.1 Analysing phase 1

Findings from the interviews were transcribed verbatim and analysed. The first interviews were translated[20] fully and shared with supervisors for feedback and critique. This provided some reassurance as to the quality of the interviews and their richness, as well as guidance as to who could provide an optimal choice in the next interviews, and this was in itself the first step of informal analysis. When data collection had finished, the formal phase of qualitative analysis began. The analysis took place on three levels: first, each interview was read several times and divided into themes that were labelled and grouped with other seemingly-relevant themes. The next level was that of the case study: the interviews of each case were looked at as a unit, in which themes were compared and contrasted. Using the technique of writing the CS-story helped to make sense of the data, to differentiate between stories and facts, between my interpretations and participants' interpretations, and to start identifying issues that were more prominent and others that were less. Each CS added information and understandings to the previous CSs. Each story was summarized and then cross-compared with the other stories. Findings were compared and contrasted between the different cases, to make the most of the findings. Stake (1995) defines this process as art and intuition, and he describes the cognitive process of understanding the findings rather than how to perform the analysis technically. However, he suggests direct interpretation of individual occurrences, as well as aggregating occurrences until they form a class. At the same time, he acknowledges that some important features may appear as single instances, and describes the qualitative researcher's role as sometimes needing to look for meaning that is emerging from a single

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[20] Translation was made by me, being the one who interviewed, knew the setting and context, heard the tone of voice, and therefore was the closest to the data. In cases of doubt I consulted an English-speaking friend.

occurrence (Stake, 1995). Indeed, each occurrence was first analysed individually, immediately after each interview and while transcribing it. The analysis of each case was aggregated by listening to previous interviews before holding the next interview relating to the same case. The third level occurred during the writing-up phase, when I compared and contrasted within groups (patients, relatives, and physicians).

Being a novice researcher, I was preoccupied with questioning the quality of the interpretation and analysis of the findings. I find Mason's (1996) relation to the findings as 'unfinished resources' illuminating. Stake (1995) also relates to the analysis, saying that he aims to make sense of the findings by thinking about them as deeply as he can. In the approach of both researchers I found a humility that I tried to maintain while collecting the data and during its analysis. Stake (1995) views analysis as a personal technique developed individually by every researcher. This view is supported in examples of qualitative analyses depicted in Kassan and Kromer-Nevo's book about data analysis in qualitative research, which shows an amazing variety (Kassan and Kromer Nevo, 2010). On the other hand, others engage in a more prescriptive format, giving practical tips for aggregating the findings for analysis (Cohen et al., 2000a; Denscombe, 1998; Mason, 1996). Stake used the term 'horses for courses', because each research design is unique and may need unique tools to analyse the data collected (Stake, 1995), as does my study.

3.5.1.1 Rigour

Rigour was promoted by multiple elements during the process of this research. Credibility was preserved by thick description of the findings (Seale, 1999); by analysing the negative or exceptional cases in different aspects (content-wise and method-wise) (Barbour, 2001; Cohen, Kahn and Steeves, 2000b; Seale, 1999); by triangulating information within cases, between groups (various stakeholders' perspectives), and between methods of data collection (qualitative versus quantitative findings) to add perspectives from different sources (Barbour, 2001; Seale and Silverman, 1997); and through the long and persistent engagement with the interview materials, from the interview itself, through transcription, translations of quotes, to writing up the findings. Each and every interview was re-visited many times (Mason, 1996; Spencer et al., 2003). The disadvantage of being a lone researcher, and thus

unable to use peer-triangulation, was compensated for by my supervisors' debriefing and by sending them very detailed descriptions of the findings, at interview level (discussing the first interviews), at CS level (discussing all the CSs), and in the writing up of each new chapter on the findings. This additional view was meant to test my analysis by comparing it with others, to ensure that I had not invented anything that was not 'in the data', and to inform me of any 'blind spots' that I might possess, and that might hinder me from making the most of the data. This process of expert debriefing is important in assuring the credibility of the analysis (Cohen, 2000; Galletta, 2013).

A reflective journal was maintained throughout the process, from the first year of designing the study until the end of writing up the thesis. During the field work, I wrote field notes as well. Both reflective tools helped me to find meaning, to raise questions, and to examine my interpretations as far as possible (Galletta, 2013; Hammersley, 2012; Kahn, 2000; Mays and Pope, 1995). Writing my personal stance toward ADs before starting to collect the data as well as field-notes also helped to 'bracket' my involvement and to increase neutrality in face of the participants' stories (Kelly and Howie, 2007). Transparency was maintained regarding the design and conduct of this study, as well as the restrictions which appeared and decisions that were made as part of it throughout the process (Spencer et al., 2003).

3.5.2 Analysing phase 2

Data from the survey was analysed using SPSS statistical software. The analysis is mainly descriptive, as it is aimed to highlight the knowledge, attitudes and behaviour of HCPs and to identify gaps in them that may inform further research, education and/or policies.

The next four chapters (4-7) will present and discuss the data that was collected during my field work. Chapters 4-6 will present various angles of the qualitative case-study phase, and Chapter 7 will present the findings from the survey that was conducted. Preceding Chapter 4 is a synopsis of the eight case studies, and of the two patients who did not eventually form case studies, but who contributed to the data that was gathered. They will help the reader to view the data in context of the participants' lives.

SYNOPSES OF THE CASE STUDIES (CSs)

Note: All the participants are named in **pseudonyms**

Case study 1:

Patient - Noa (female), in her 70s. A mother (of two) and a grandmother; a former teacher.

Relative - Ben (Noa's husband), in his 70s. Former administrator; a healthy man who retired at the age of 60 to take care of his wife.

Physician - Dr Yahalom (female), in her 50s, had been a practising family physicians (often called general practitioner (GP) in the UK) for nearly 20 years. She sometimes assumed responsibility for the care of dying patients in her community, in the area close to her home village and in her surgeries, in addition to her routine job.

Noa and Ben lived in a small village. One daughter lived with her family nearby. Another child lived far away.

Noa struggled with end-stage MS (multiple sclerosis – a neurological degenerative illness) that had been diagnosed over 30 years earlier. She gradually became paralysed over the years. When I met her, she was totally dependent on others. Ben (her husband) was her full-time carer. Noa had been resuscitated more than nine years earlier in hospital due to a respiratory crisis, and was mechanically ventilated. When she was discharged from hospital with a mechanical ventilator she weighed 35 kg, and her prognosis was extremely poor. For nearly a decade she was mechanically ventilated at home through a tracheostomy (hole below her throat), without having been hospitalised even once before I met her. Noa died after a very quick and dramatic decline a few months after I interviewed her.

Advance directive (AD): Noa and Ben had held LILACH[21]-ADs for over 15 years. Noa made the first document when she was already ill, and had renewed the document in recent months. They did not complete the legal document. Apparently Noa did not know about the option, and Ben said that it

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[21] LILACH – 'living and dying in dignity' and Israeli organization to promote ADs among other.

was too complicated to fill out, and he thought that it was not necessary. Noa viewed Ben as her decision maker if she lost capacity. Her children knew that she had an AD. Around two years after Noa was mechanically ventilated, after stabilisation of her condition, she told Dr Yahalom about her AD. Noa and Dr. Yahalom had few discussions regarding Noa's end-of-life (EoL) wishes and AD during her long years of home care.

Note: It so happened that I interviewed Ben a week before Noa died, and Dr Yahalom a few weeks after Noa's death.

Case study 2:

Patient - Meira (female), in her 80s, a mother of two, grandmother, and widowed in the last years, after over 50 years of marriage. She came from a traditional Jewish family and was a Second World War (WW-II) survivor. She was a retired engineer who lived in a small city.

Relative - Lea (female), Meira's daughter, in her 60s, was an academician and lived on her own in a nearby city, and she also had a long-term condition.

Physician - absent

Meira had one kidney removed in the past due to cancer, and later had renal insufficiency of the other kidney that was controlled for many years with diet. In recent years, her kidney had started deteriorating and she was put on dialysis treatment three times every week, which was increasingly becoming very tiring for her. During this period she also suffered a cerebro-vascular accident (CVA) that left her disabled with weakness of the left side of her body, needing a cane but also the help of a full-time carer to prevent her from falling. She was frail and unstable, yet could still participate in activities of daily living (ADLs), even if only partially.

Meira's husband died a few months after his diagnosis of cancer, and while he was being treated. Parallel to his diagnosis and rapid death, Meira's kidneys deteriorated rapidly as well and she started dialysis.

Advance directive: Meira had had an AD for around 10 years. She said that when she was diagnosed with renal cancer, she had thought about and prepared her first LILACH-AD. She renewed the document only recently in

response to a LILACH recommendation. She was not aware of the legality of ADs and of the legal form. Her husband did not want an AD for himself. After Meira's husband died, she viewed both her daughters as her representatives for decision making if she lost capacity. She had not discussed her AD with a physician.

Case study 3:

Patient - Naomi, was in her late 50s, had never married and had no children. She lived on her own, in a city-flat (in a building with an elevator). She had no siblings, her parents died many years ago and her next of kin was a cousin who was emotionally very close to her. Naomi was a heavy smoker until a year prior to the interview.

Relative - Carol (cousin), was in her 60s, married, a mother of two and a grandmother. Both her parents were alive. She was an artist who lived in the same city as Naomi and she was Naomi's closest relative, both officially and emotionally.

Physician - Dr Barda, in his 60s, was a specialist in respiratory conditions with over 30 years of practice, and was Naomi's main medical carer. He worked in an outpatient clinic in a major hospital.

When I met Naomi she was facing the final stage of COPD (chronic obstructive pulmonary disease), but had no additional illnesses. Around that period, she had a lung capacity of 20% of the 'healthy' average, yet she was still teaching (limitedly). She could handle most of the basic ADLs[22] and most of the instrumental ADLs[23] with the help of designated equipment (such as oxygen; a Segway[24]), but with minimal dependence on external human help (house cleaning for example). Due to her severe breathlessness she regularly slept with an oxygen concentrator, and sometimes used it during the day. She was under the care of a pulmonary clinic and had regular breathing physiotherapy twice weekly.

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[22] Basic ADLs (activities of daily living) - daily activities regarding the care of one's body (such as bathing, eating, etc.).

[23] Instrumental ADLs (activities of daily living) - daily activities regarding the care within one's residence and/or outdoors, that are related to others (such as banks, shopping etc.).

[24] Segway - a two-wheeled self-balancing vehicle.

Advance directive: Naomi had had an AD for around 20 years. She had recently renewed her document following LILACH recommendations. She knew about the legality of ADs but did not want to use the legal AD because it was too complicated. She asked Carol to be her decision maker for EoL decisions if she lost capacity, and had told Dr. Barda about her AD.

Naomi had experienced an acute respiratory crisis during which she was mechanically ventilated for a few days, and then she gradually returned to her chronic state prior to the crisis. In the subsequent year she experienced further but gradual respiratory deterioration.

Case study 4:

Patient - Yarden, in her early 60s, was married, the mother of three and a grandmother. Yarden was a therapist. She described herself as religious and lived with her husband in a small religious community in a village.

Relative 1 - Koby (husband), was in his mid-60s, and worked full time in an enterprise.

Relative 2 - Yagil (son) was in his early 40s, married and a parent. He was also a therapist in a different field from his mother's. He was not religious and lived in a large city.

Physician - Dr. Shalom, in her 50s, was a GP for over 20 years, and a cardiologist. She lived and worked in Yarden's village, but worked part time in a nearby hospital. She was religious.

Rabbi - Rabbi Nakdimon, in his 50s, was the Rabbi of Yarden's community and lived in the same village. He helped me by shedding light on the view of the Jewish HALACHA (religious law) regarding EoL, dying and death.

Yarden was diagnosed with colon cancer and had received chemotherapy nine years previous to the interview. She had also had lung metastases surgically removed, one and two years after the first diagnosis. Since 2004, she had had no signs of illness and she was not actually facing EoL. She was fully active, at work and in the family. However, because her cancer was metastatic she was not sure that she could be cured, and regarded her healthy state as a temporary condition that she tried to prolong as much as

she could. Cancer was present as regular 'companion', and she described how each planned follow-up CT (imagery of her chest and abdomen) caused increased tension and fear that started some time before the test and lasted until she received the written results.

Advance directive: Yarden considered making an AD for the first time when metastases were first found (a year after diagnosis). She renewed her AD recently according to LILACH recommendations. She did not know about the legal AD form. Her GP knew about her AD document.

Additional information:

- Out of the three applicants who described themselves as religious in the primary phone call for recruitment, Yarden seemed to best meet the inclusion criteria for this study.
- During the period of my interviews, there was a process of communication in her family around Yarden's ADs and a change in decisions regarding who would represent her if she lost capacity.
- The interview with Koby (Yarden's husband) occurred in Yarden's presence.

Case study 5:

Patient - Omri was 84 years old when I met him. He was born in Germany, but I have no data regarding the year of his immigration to Israel, or his experiences in the Second World War, although he once mentioned receiving an indemnity from the German government. Omri was married, the father of two daughters, a grandfather and great-grandfather. He was a retired administrator who had lived with his wife in a southern city in Israel for most of his adult life. They lived in a ground-floor flat, and, at the time of the interview, his wife's full-time helper was living with the couple. Omri's wife was diagnosed with dementia about three years ago.

Relative - Vicky (daughter) was 60 at the time of the interview. She was married, a mother and a grandmother. She worked in education in the city where her parents lived, and she lived in a town not far from there. Her interview took place in Omri's house.

Physician - absent. The GP refused to participate in the study.

Omri described himself as having end-stage heart failure as well as a multitude of long term conditions (LTCs) that handicapped him, including diabetes, hypertension, angina pectoris (chest pain due to cardiac pathology), renal insufficiency, lower limb deep vein thrombosis in the past, carotid vein restriction and surgery, and a previous cerebrovascular accident (CVA). Omri also underwent various surgical procedures.

<u>Advance directive</u>: Omri had had an AD for over a decade, which he had made at the same time as his wife (who was in health at the time). He had renewed the LILACH-AD in the previous year following LILACH recommendations. He was not aware of the legal AD form. LILACH representatives explained that his wife did not need to renew her document because she had lost capacity, but Omri did not fully understand their explanation and seemed worried that his wife's document would not be valid. His GP did not know about his AD document. Omri had asked both his daughters to be decision-makers on his behalf if he lost capacity.

Additional issues:

- Before we started the interview, Omri asked me to spend a few minutes in the living room, with him and his wife, to socialise with her and to make my presence easier for her, because although he had told her that I was coming to interview him, she did not remember it.
- Omri seemed very interested in his GP's participation in the study, but he told me that his GP had refused to participate because she was too busy.
- As a result of a CVA Omri had speech impairment. His diction was flattened and parts of words were sometimes omitted, which made it difficult to understand him, and I had to ask him to repeat some of his sentences. The interview took more than two hours, and included many stories about various health experiences he had had.

Case study 6:

Patient - Shelly was 79 years old when I met her. She was newly widowed, a mother of three and a grandmother. She was now a retired health care

professional working with oncology patients, and later with elderly residents in a nursing home.

Relative - Dekel, one of Shelly's sons, was in his 40s when I met him. He described himself as a coach and as a philosopher, and was working as a freelancer. He had Type 1 diabetes ('juvenile-diabetes').

Physician - absent (Shelly did not want to ask her oncologist to participate because of her perception that the oncologist was overloaded with work and could not cope with it).

Shelly now had a metastatic colon cancer that had been diagnosed nearly two years before, and she was still under chemotherapy treatments aimed at controlling her cancer. Her husband was diagnosed eight months after her, with advanced pancreatic cancer. He had apparently refused any treatment for his cancer (except pain relief) and died four months after he was diagnosed.

Advance directive: Shelly and her husband had made their first LILACH-AD documents over a decade ago, in good health, because they identified with the concept. Shelly did not know about the legal form. She viewed her son Dekel as the decision-maker on her behalf if she lost capacity.

Case study 7:

Patient - Dov was in his early 90s, married, a father, grand-father and great grandfather. He was a retired agriculturist, who continued working until he turned 80. He lived with his wife in a village. His wife was frail, apparently due to cardiac illness and increasing dementia. She was Dov's age, and in the last couple of years she had had a permanent carer living in the house as well. Dov had escaped from Europe during WW-II and immigrated to Israel. He returned to Europe as a soldier in the British Army's Jewish Brigade before the end of WW-II, found his nuclear family (parents and siblings) all alive at the end of the war, and brought them to Israel. One of Dov's children had died from cancer at a young age.

Relative - Yoni (son) was in his 60s and worked as an engineer.

Physician - Dr Paz, was Dov's former GP, who had practiced for over 20 years. He regularly undertook the home-care of dying patients, from his and other colleagues' surgeries.

Dov had prostate cancer, but his cancer was stable at that time, and he didn't feel ill or dying because of it. He said that his EoL was near, due to his advanced age and that he was very much aware of it.

Advance directive: Dov and his wife had made ADs around a decade earlier, in full health. Very recently, LILACH recommended renewing ADs that were older than five years, and Dov was preoccupied with renewing his and his wife's ADs when I met him. Dov had also filled in the legal AD document, with the help of his GP. He had it registered in the national registry. Dov appointed his son Yoni to represent him if he lost capacity.

I decided that old age could be included as another variety of a terminal stage of life, although it is not a long-term condition 'per se', and to create a case study around Dov's story.

Case study 8:

Patient - Debby, in her late 60s, was married, the mother of two, and a grandmother. Debby was a retired worker in a publishing house. She lived in a city. Her flat was situated on the first floor of a building with no elevator.

Relative - Alon (husband), also in his late 60s, was a retired clerk.

Physician - absent (Debby's oncologist was on extended leave)

Debby had an advanced stage renal tumour, metastatic to her lungs and other organs. She was under oral (non-curative) chemotherapy treatment. She had evident breathing difficulty while speaking (noticeable in the audio-recording of the interview as well). From her descriptions she also experienced fatigue, weakness, and pain. Debby had help in the house three times a week, provided by the national insurance due to her disability. She used this help mainly for cooking. Her husband did the rest of the housework.

Advance directive: Debby and Alon both had ADs. They first prepared them when Debby's cancer relapsed, around five years ago. They were not aware

of the legal AD form. Debby expected her husband to represent her if she lost capacity.

Case study 9 (patient):

Patient - Adam was over 60, married and the father of four adult children. He worked in agriculture and in art and lived in a small village.

Relative and **physician** were not appointed due to safety issues that were explained in the methodology chapter.

Adam had faced ALS for over a year at that point and was paralysed in both legs, with considerable weakness of both his arms. He could still pick up the phone and dial, but could not hold a full glass of drink. He had a severe speech impairment, which presented as monotony, severe deformation of words and difficulty in retaining enough air to finish long sentences. Adam was fully dependent on help for all ADLs and had a fulltime helper who lived with Adam and his wife (who was still working). All his children were living elsewhere.

Advance directive: Adam first heard about ADs from his physician after he knew about his ALS. He decided to make an AD for himself. His AD was less than a year old. His GP knew about the document. Adam did not trust any of his family members to be able to make EoL decisions on his behalf. He hoped that his GP would be able to influence such decisions.

Case study 10 (patient):

Patient - Ehud was in his 80s, married, a father of three and a grandfather. He was a retired health care professional, and had lived in a village in recent years.

Relative and **physician** were not appointed due to Ehud's reluctance to disturb his family or physician to take part in the study.

Ehud had two malignancies: a chronic haematological illness that was latent and had been followed up for many years, and cancer of the urinary bladder which had been discovered two years ago, and for which he refused any

treatment. The tumour caused mild bleeding but no pain, and Ehud preferred to avoid the pain and discomfort of treating it.

Advance directive: Ehud had a self-made AD statement that he had written when he had a heart problem, 20 years earlier. Later, when he discovered LILACH, he and his wife decided to make LILACH-ADs. When he first heard that ADs had become legal he decided to fill in the legal form as well. He had it registered in the national AD registry.

CHAPTER 4: PATIENTS' PERSPECTIVES ON LIFE, END-OF-LIFE AND ADVANCE DIRECTIVES

4.1 Introduction

This thesis suggests (and will demonstrate in subsequent chapters), that the making of an advance directive (AD) is only a first step in a sequence that is meant to lead eventually to AD execution, in due time. In order to be put into action if the person loses capacity, an AD needs to be communicated and transmitted to others, such as relatives and health carers. To symbolise this sequential process, one can think of a 'relay race' in which not one participant but several are involved, who are running successively and who each may have some influence on the outcome of the race. The quality of the race depends on each and every participant's quality as a runner, but also on the skill with which the baton is transferred from each runner to the succeeding one. The process of creating ADs and sharing them with others will gradually be unveiled in the findings chapters 4, 5, 6 and 7. It will be initially looked at from the dimension and perspective of the AD-maker (in this study the 'patient-participant'). Following the above analogy, Chapter 4 looks at the first runner in the relay of preparing advance directives for future use.

As a first chapter of qualitative findings this chapter will answer some of this study's major aims, and show:

- What could be learned from the patient-participants' perspectives about the experiences, beliefs, values, and needs that led them to make and hold ADs.
- What influenced changes in the content of their ADs over time.
- The expectations patients had regarding their AD document.

The rich data that was collected lent considerable support to the view that the making of an AD document was indeed related to life experiences, beliefs and values as well as to personal needs and coping behaviours. Therefore, the first part of this chapter will attempt to demonstrate these in detail, to set the context and meaning of making an AD. The second part will look at patients' expectations toward their end-of-life and at how ADs meet these expectations.

Throughout this chapter, the term 'patients' will be used to refer to 'patient-participants'.

4.2 The findings which set the context

The first part of this chapter will present the findings related to:

1. Patients' experiences with their own long term condition (LTC).
2. The way patients cope with their illnesses.
3. Patients' expressed needs when facing a terminal illness.
4. Patients' views, values and attitudes regarding life and end-of-life.

4.2.1 Patients' experiences with their own LTCs

Patients' own experiences with a long term illness and decline seemed to have influenced their decisions, even if they did not perceive those changes in decisions as meaningful, but rather as subtle. Therefore, these experiences seem highly relevant when an attempt is made to understand the meaning of ADs in patients' lives. Experiences of illness always involved symptoms and worries. Patients' reports gave the impression of wide-ranging physical and emotional burdens, and these will be mapped out separately for description's sake. Not all the patients used the term *suffering* explicitly, when they described their symptoms or burdens. Sometimes it was the implicit tone of voice, facial expressions or the words during the interview that reflected suffering. In these cases, suffering could have been my own interpretation.

4.2.1.1 Physical symptoms

The physical symptoms described by patients were often related to their specific illness (such as itching in renal failure and shortness of breath in COPD[25]) or to the treatment of an illness (such as hypoglycaemia in diabetes). Pain however, was more commonly shared and did not seem to relate to any specific illness. Weakness was another predominant symptom that was unrelated to any specific illness. There was quite extensive data to draw upon

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[25] COPD – chronic obstructive pulmonary (lung) disease.

in patients' accounts of these two main symptoms; due to space, further exploration will draw on accounts that are illustrative of the overall set of accounts. Yet, it should be noted that there was an impression that the burden of symptoms was more often related to the patients' overall feeling of decline and reduced independence, which could be related to one symptom or a multitude of symptoms.

Pain

Pain was shared by most of the patients, who reported experiencing pain related to their illness or its treatments. Some feared pain without yet having experienced it. It looked as if the anticipation of an unpleasant symptom – in this case pain – could have a significant impact. Possibly anticipation could provoke as much or even greater distress and emotional suffering than the actual experience of the symptom (Dov, for example, expressed such an anticipated fear of pain). Patients had different views about how to cope with pain. Some of them feared pain so much that they were willing to take any medication to avoid or take away the pain, while others objected to the possibility of depending on medications because of their side-effects.

Ehud said he suffered a lot from pain and that he feared experiencing severe pain that would become unmanageable with ordinary pain-killers (such as paracetamol). He experienced the pain caused by the treatment of his cancer of the bladder, and knew that this pain was part of the treatment 'package'. He refused further treatments for his cancer because he did not want to experience such pain anymore. Like Meira, he objected to using opioids for severe pain because opioids affected lucidity, and caused other undesirable side-effects. He preferred not to be treated at all, even if this meant he would live less, saying:

> 'People think that [if] they take opium [it will help]. It's
> not true. They lose conscience [awareness] but the pain
> remains in many cases. Apart from this there are many
> medications that themselves cause severe side effects.../
> ...I don't want to start with opioids. If you [one] take pain
> killing substances in large quantities then your head

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[brain] doesn't work. I want to control my life. I may be
out of the ordinary' [Ehud, patient10]

Debby told me that she had constant pain but dreaded that it would worsen with the progression of her illness. Unlike Meira and Ehud, she was willing to use opioids and anything else that could prevent her from suffering pain:

'It [my general condition] is a bit worse each time. In the
last month I have a bit pain. Doesn't… matter. I know
that the maximum [length of time] I can do something
[=effort] is an hour and half. After that my legs hurt. I
don't work beyond [that length of time]. Today [at
present] I don't make effort also because I know that
when I am very tired, it brings [causes] head ache and
vertigo…/ …I made peace with my condition. I know that's
it [the end] [crying] I am afraid only from pain, [or]
difficult end, [or] to be left alone…/ …For myself I am
afraid of a situation of [being in] pain…/ …[I want that] if
he [Alon] sees [will see] me suffering [laughs
embarrassed] [he will give me] morphine tablets, [or] I
don't know what, just not [to experience] physical
suffering, I can't stand it, I am so weak as it is and… it's
very difficult for me. Now it's [already] difficult for me'
[Debby, patient8]

Weakness, fatigue or breathlessness
Meira had faced a kidney problem for over a decade when the interview took place, yet she described most of those years as good years. She had maintained a specific diet and for many years pursued her regular life quite fully. Her deterioration started to increase with the onset of dialysis that weakened her tremendously, and the biggest change happened after her first CVA (cerebro-vascular accident) 2 years later. Since then, she had lost her ability to walk on her own, and needed to be accompanied everywhere due to her instability. Her description reflects the difficulties experienced by Omri and Debby:

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'But the situation changed… very intensely… I, before the CVA, could walk from the house to the centre of [town's name]… and back… Alone. With the help of a cane. Without any problem. Today I can hardly walk [describes about 200 meters distance]. On my own I cannot walk at all. I have a helper because I am completely unstable. When I walk with a walker I tend to roll over. I must have someone with me [Meira, patient2].

Patients made efforts to carry on despite the additional effort and energy this required, using expressions such as 'grinding one's teeth' to indicate the significant extent of their efforts. Yet they seemed considerably disappointed about the gap between their previous and current abilities, and reported experiencing their reduced abilities as significantly reduced even while they described managing to do quite a lot on their own. Naomi described, the change and the difficulty in handling it, very clearly, saying:

'The situation is gradually deteriorating…, …more distress, less ability to walk, getting tired much quicker… to get breathless… much quicker… Talking sometimes causes breathlessness…/ …Every physical effort is tiring… even the slightest…, …Every walking after a while is [coughing heavily] it's tiring…, … on hazy days for example, I nearly climb the walls[26], with the house closed, it doesn't change anything of course, you know. In winter it's relatively easier for me' [Naomi, patient3].

4.2.1.2 Emotional and existential burden

Patients expressed a considerable emotional load that reflected both the decline of the body and their emotional reaction to the implications of the progression of their illness on their (shortening) future. They shared a variety of burdens such as:

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[26] To climb the walls - slang for 'being desperate'

- Loneliness
- Sense of worthlessness
- Sense of inhumanity
- Loss of cognitive ability
- Growing dependency on others
- Being a burden to themselves
- Being a burden to their loved ones

Due to the abundance of information regarding the emotional aspects of living with illness, only a few examples will be provided in the present section. These examples of the burden of non-physical symptoms were chosen because they are relevant to understanding other patients' descriptions. As mentioned in the previous section, some patients suffered from actual symptoms, while others suffered from the anticipation of symptoms and negative emotional experiences.

Loneliness

Omri for example felt lonely, because his wife, who had been his partner and supporter for decades, had now deteriorated mentally and not only could she not support him, but she demanded things from him that he could not always provide. He also felt that his daughters were not really attentive to him, and that there was a built-in generational gap between him and them:

> 'If I lie down, suddenly, I lose my senses, but you don't have anyone to do 'KRECHTSEN'[27] to. I am alone, with myself…/ …when my wife was healthier I could indulge myself [and complain to her:] ""this" hurts me, "that" hurts me" [she would say:] "Lie down, take this". Today I cannot tell her anything. I am alone and nobody knows…/ …you… are alone in the battle. The kids [adult daughters] don't really understand. I didn't understand my mother until…[she died either]…, …I don't even have any point [to

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[27] 'KRECHTSEN' - Yiddish: complaints

try to tell my daughters], and my wife is in a [poor] condition. So, that's it. So, that's it' [Omri, patient5].

Worthlessness, losing humanity

Some of the participants already felt worthless, while others feared that the moment would come when they would become worthless. Adam, who was the youngest of all the patients, related to himself as a *'useless old man'*. He felt that his children were angry at him for his condition:

'They are angry at me for being in this condition, I think, because they know a father that would solve any problem, whether technical, whether bureaucratic or at school' [Adam, patient9]

Adam said a few times during the interview that he could not discuss his condition with his family members because they had difficulty in coping with such conversations. His daughter, for example, challenged him by asking him if he had given up on the potential experience of being a grandfather. He told me that he wanted to be a grandfather although he disliked the thought that he would not be able to take his grand-children in his arms or read books to them. Yet, he felt that his life was running out fast, and that he was being forced (by his condition) to let his daughter down because he could not live up to her expectations from him as a father and grandfather.

Helplessness

Omri, Adam, Noa, Debby and Meira felt helpless due to the loss of their physical ability, and Meira exemplified experiences that were commonly expressed. Extreme weakness and loneliness after the death of her husband and another close friend affected her mood adversely, as she reported:

'I am helpless. It **kills me** you have, have no idea how much... that... I, all of a sudden, got to the situation... in which I'm unable. Unable [to do] this, and unable [to do] that... I just don't have the strength. This is also one of the components of my [low] mood.../ ...All sorts of things

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that… it was nothing for me to do…, …and today […3…] I simply can't… it is depressing my inability…/ …You understand? It's… all **accumulating** […6…] the husband that is gone, and the [fact that] the… friend is gone…. all [this] and also my disability, my helplessness […12…]' [Meira, patient2]

Dependency

The patients in this study sample had different levels of independence, and many expressed their distress at being or becoming dependent on others. Their accounts indicated that they strongly valued independence, all had been extremely independent prior to becoming ill, and they hated losing this independence. Adam and Noa, who were paralysed by the time of the interview, seemed to reluctantly accept being physically cared for by others, yet, most of the others expressed anguish at the anticipation of losing independence, as we can learn from Debby:

'If I am in pain…, and I won't be able, I mean, incontinence, and others will have to transfer me to the toilet and change my diapers, I don't call it life. It is existence' [Debby, patient8].

Some shared their active efforts to remain as fit as possible in an attempt to postpone the loss of independence for as long as they could. Some (Omri, Naomi, Shelly) seemed to prefer to use supportive equipment (such as walking canes, oxygen, a Segway, folding chairs) rather than having to depend on human help.

Being a burden

In addition to the emotional burden of losing independence, patients felt that their condition added a burden to their family members, and this feeling disturbed them greatly. Five patients (Meira, Omri, Shelly, Debby and Adam) had already experienced being a burden in different ways, as we can learn from Omri's description:

'But if I need to ask service from someone else [it is difficult]... People work. My children [work] from morning till night, therefore I don't [ask]..., I try not to depend [on my daughters].../ ...my elder daughter..., ...they say that it is..., ..."the sandwich generation". She is "cheeseburger". Why? Because she has grandchildren, children, and parents... and she has work as well, so how can she divide herself [between all these roles]? She is trying to be a model of a grandmother' [Omri, patient5].

Fear

Patients reported fears of symptoms that they had already experienced, and of the unknown future symptoms as they declined further. They explicitly or implicitly feared the suffering, whether due to loneliness, itching, air deprivation, weakness, or anything else. Noa's example will reflect the others' tendency to seek to limit what they perceived as potential causes of suffering. Noa apparently became very sensitive to changes in her body temperature and the oxygen saturation in her blood (as her physician reported to me). Her husband Ben told me that when she noticed such changes she did not want to go out of the house because she feared a sudden deterioration, knowing that it could be quick and dangerous. As soon as she could, she took measures to try and control the situation, such as starting antibiotics with the first signs of an infection, and/or using a higher oxygen concentration:

'In the past week I had probably some kind of flu and had difficulty breathing. [I used] an oxygen concentrator and an oxygen cylinder, that's all right [i.e. I agree to use], and I came out of this' [Noa, patient1].

4.2.1.3 Overall existential distress

Some of the patients (such as Noa, Meira, Shelly and Debby) expressed diminished cognitive ability that they attributed to treatments or to their illness. For one it was decreased memory, for another it was a decline in concentration, but they all expressed distress and disappointment at these

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mental changes, which added to an overall existential distress. Yet, it was not just the cognitive decline but other elements as well that seem to have influenced the overall distress of patients. Naomi expressed an existential distress that seemed to accompany her all the time, mainly because deterioration was unpredictable and could happen at any given time. She clearly described how, regardless of the good moments, her whole being was distressed, and how tired and weak she became:

> 'What do you [they] know about what I am going through [from] the moment I open my eyes in the morning and till I am going to sleep?... I may have had a good day with... a visit of [name] is wonderful... OK so, 1, 2, 3 hours, what about the rest of the time?... What do I know? This is something I cannot predict, [or] say OK if I do "this and that" it will be "this and that", and you know what? I don't want to live thinking all the time what, what to do in order not to feel so and so [bad]. Because you know what? This doesn't seem to me like life either. It seems to me that the meaning of life is not concealed in how to avoid obstacles, but how to create things.../ ...Living in suffering worries me. I know that in this way it's impossible to live. [It's] as simple as that. And this is related to me, to my head [mind] and my life concepts' [Naomi, patient3].

Following this portrayal of patients' physical and emotional experiences with their own illness, the next subsection elucidates some of the ways these patients survive with their illness.

4.2.2 Patients' coping with illness

An analysis of the interviews with the ten patients elucidated three main themes that appeared to help patients cope with their illness and decline, namely: being realistic, fighting actively to maintain independence, and on the other hand adjusting themselves to irreversible changes. These three themes will be explored below, using patients' own statements and descriptions.

4.2.2.1 Being realistic and aware of decline

Some patients (Noa, Omri and Shelly) related to their old age as being a fact that, in itself, was a reason to expect life to end relatively soon, pointing out the irrelevance of wishing to live much longer. All three used the same sentence: '*I will not die young anymore*'. Most patients thought that they had already lived a full life, as Meira put it:

> 'Everything that … was written about me in some kind of a book [i.e. destiny], (and I don't believe there is such a book), let's say… I completed it all: The travels **abroad**, the… plays, the concerts… the travel, aaaall of it. Everything which I had… I don't have anymore. My "budget" ran out […3…]. And … [emotional tone] this is sad' [Meira, patient2].

Patients, aware of the impending end of their lives, still attempted to live every day to its full potential. They did not want to look back with regrets about things they had not done while they could, at a point in time when they become too ill to do them. At the same time they reported actions that were meant to prepare them for dying and death (such as making an AD). They tried to avoid complications caused by their illnesses and maintain the best possible health condition, as described earlier, yet they were not keen on accepting just any medical intervention in order to carry on living. Omri, for example, explained the difference in his attitude toward medical procedures in the past and at present:

> 'It is simple. When I am in a [reasonable, normal] condition and there is a treatment that is reasonable, or even invasive, I go for it with courage…/ …What I had last week in my heart, in normal times I would go to the A&E[28] four times already [to take care of myself]. But I know that there is nothing to do, then, what [for] shall I lie in the A&E?' [Omri, patient5].

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[28] A&E – Accident and emergency department in hospital

Patients had hopes of living longer in order to experience future important life events, while mourning their awareness of the low probability they had of achieving these hopes, such as Debby who shared her wish to live four more years to witness her granddaughter's 'Bat Mitzvah'[29]:

> 'There is no time. This sense of time. Every day I sort of mark an X, a day less [on the diary], till the end which I don't know when it will be…/ ……I have what I have, and I know, and I am very realistic. I don't expect miracles. And that's what [Debby gets emotional] makes me sad: that I know exactly what will happen…/ …Sometimes I say… [that] I am not afraid of death [of] not existing anymore. I am not young. Maybe I will reach 70. I don't believe it but maybe…/ …I think I have 2-3 years more. I wish I am wrong and it is longer…/ …'She [granddaughter] has already asked me (They don't have problems children [with sensitive topics]): "Grandma, in my 'Bat-Mitzvah' will you be still alive or dead already?". I said: "I hope to be still alive"' [Debby, patient8].

4.2.2.2 Being 'fighters' – awareness, responsibility and internal locus of control

The term 'fighters' seems appropriate to describe all the patients who participated in the study, and it seemed to be based on: awareness of reality, being as active as possible in their own care, trusting themselves more than others, and having a high need of control. Although I did not perform personality tests on any of the patients who participated in the study, their accounts gave the overarching impression that they had a high 'internal locus of control'[30]. This section will exemplify these aspects of those patients' 'fighting' spirit.

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[29] Bat Mitsvah - Jewish girl's coming-of-age ceremony at the age of 12 years old.
[30] Internal locus of control – The belief that the individual can control and act upon life events in order to change their outcomes, rather than being dependent on destiny or others' actions.

Noa told me how 30 years ago, she had forced herself to climb Mount Moses[31] on a trip with her pupils. It was with great difficulty because she was already experiencing weakness, but she did not know at the time that it was due to MS (multiple sclerosis) because she had not yet been diagnosed. Then, 9.5 years ago, she had had a respiratory collapse and was mechanically ventilated. She said that she made a decision to fight for life, although she weighed 35 kilograms (77 pounds), and had a large and deep pressure sore. This is how she described herself:

> 'I am quite a realistic person and instead of lying in bed and crying, I decided that I live. I have children and grand-children and for them… this gives me strength and will to keep on' [Noa, patient1].

Most patients told me about their own particular 'climbs of Mount Moses', each fighting to maintain active and independent lives, working, shopping, driving and walking until the last possible moment, with a determination similar to that depicted by Noa on the trip to Sinai. Apart from Noa and Adam, who were paralysed at the time of the interview, and Ehud who avoided walking, other patients talked about their active efforts to walk as much as they could, whether with someone (Meira, Debby), a cane (Meira), oxygen (Naomi), a folding chair (Omri) or alone (Dov, Yarden and Shelly). Their self-reliance rather than dependency on others became clearer to me and most relevant when they discussed their end-of-life (EoL) wishes and needs, as will be revealed later.

4.2.2.3 Adjusting to change

It was noticeable that although patients were actively fighting to maintain their independence as far as they could, they also showed an ability to adjust to the change in their condition. This appeared as their strength. Most patients had to incorporate changes in their lives such as changes in diet, starting medications, using accessories and adapting their activities, in order to slow (or accommodate to) the deterioration that was expected due to their LTC.

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[31] Mount Moses – around 2,300 meters high mountain, believed by Christians to be the biblical Mount Sinai where the Jewish people received the Stone Tablets with the Ten Commandments carved on them.

They gradually became more sensitive to subtle changes in their physical or surrounding conditions (such as dust in the air, a higher fever, or reduced blood oxygenation). Some adaptations were extremely difficult (such as Meira's decision to have an A-V shunt[32] made although she refused dialysis). Some patients used psychological support when they felt the need to get stronger emotionally in order to better cope with their condition, as Yarden shared:

> 'I did change in the sense of giving to myself. I took more time to myself, for leisure activities, learning, enjoyable things, things I didn't do enough along the years. I was always in some crazy race to achieve… work more… and… and… and… [=etc., etc., etc…] I took less care of myself. This is indeed a change that I made, with psychological help. Along with the [cancer] treatments I had psychological support, and with it I changed, allowed myself to enjoy life… ,… it [life] may be limited therefore to enjoy what I can, yes. But in my daily life there is no change in time [length], work, or daily routine. No change' [Yarden, patient4].

Adaptation was a process that often began with frustration and hopelessness, and was gradually incorporated in the patients' lives, as Noa depicted very well:

> 'In the beginning I said [that] without my hands and feet I won't be able to live. One gets used to it slowly slowly…, [back] then I did not imagine all the processes…, when I woke up and understood that I won't be able to speak and breathe anymore I accepted it. I didn't cry…, it [the change] came slowly slowly, so each time [that something changed] I accepted it' [Noa, patient1].

Some patients shared 'ups and downs' in their condition, saying that there were good days and bad days, and this irregularity was more difficult to

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[32] A-V shunt (or fistula) is a passageway between an artery and a vein which is created for haemodialysis treatments.

handle than an on-going one-way deterioration. Using oxygen, resting, eating healthy and balanced food according to recommendations, and socialising as much as they could were examples of strategies that those patients used in order to adjust to their deterioration and in order to survive. One exception was Adam who quite quickly (within a few months) became paralysed and totally dependent. He sounded as though he had lost the battle:

> 'There is a quota, I ended my quota apparently…/ …I am not sad. It is kind of acceptance…/ …On the one hand I want to live. On the other hand I feel that I exhausted [my life]…, I am not interested in improving my condition. There is no such thing; the age takes its course as well, so I prefer not to live' [Adam, patient9].

4.2.2.4 'La joie de vivre' (the joy of living)

It is important to emphasise that all the patients told stories that showed their ability to enjoy life, their appreciation of life and the importance that they attributed to making the best of it. Against all odds, they appreciated witnessing the growth of their family; they travelled as much as they could. They pursued activities that were meaningful to them as far as they could, whether community volunteering, teaching, involvement in family life, or cultural activities. A few even reported improvement after the illness was diagnosed or as they became older, even with disability, as Dov shared:

> 'I can help her [Dov's wife] [with] whatever she needs. She lives a happy life. She isn't suffering…, We get everything [that she needs]…, I guess that there are many couples like us that in an old age […10…] get closer again and live their youth again […] I can say in one word, fall in love again. Close, getting closer to each other. Supporting each other…/ …it depends on the people and the relationship […] that they had […15…] but she tells me the same: "we are happy"' [Dov, patient7].

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4.2.3 Patients' expressed needs

During their interviews, patients mentioned various needs that were fundamental to their quality of life. When they became unable to fulfil these needs, it appeared that this had a negative influence on those patients' drive to live longer. Needs repeated as being important were: being significant to others, controlling one's life, and being independent. This sub-section will illuminate these needs by using examples shared by patients.

4.2.3.1 Being significant

Some of the patients referred, in various ways, to the strength that being significant to their loved ones gave them. For Noa and Debbie it was their significant role as pillars of the family (their husbands, their children and grand-children); for Omri and Dov it was their role as their wives' carers; for Shelly it seemed that it was her late husband, and it appeared as though after his death her role changed completely and needed re-defining. She felt that her youngest son made efforts to support her fight for life, and it seemed that she tried to satisfy him. Naomi had no family and felt free from obligations. She knew that her cousin was attached to her and would be sad when she died, and this was significant, yet she did not perceive herself as being crucial to her cousin's life. Meira indirectly implied that being significant to the community and the family gave meaning to life, and said in different ways that she did not feel that she could contribute anything to anyone any more, apart from worry. Speaking theoretically, Ehud said that when one is needed this justifies carrying on living. Adam spoke about the joy from his former volunteering activities, in which he could no longer participate.

4.2.3.2 Being in control

Being in control appeared to be a central need for most if not all of the patients, and this was indicated in many ways. Patient accounts placed a very strong emphasis on the need to have control over their lives. There also appeared to be a strong indication in patients' accounts that this was related to self-trust. All the patients seemed to trust themselves more than anyone

else, especially in relation to their own care. They showed knowledge regarding their illnesses, their treatments, normal and abnormal values of blood tests and the like.

Meira, for example, described how she knew every detail about the treatments and medications that were given to her; she was actively involved in her treatments because she was not confident in her health care professionals' ability. Thus she described how observant she was at every dialysis treatment (three times per week), to make sure that the Heparin (anticoagulant) was given to her at the exact time, so as not to re-experience a haemorrhage as had once happened to her. She also said that she always looked at her blood test results, to make sure that physicians did not ignore important information and omit necessary actions. This degree of vigilance undoubtedly appears to be out of the ordinary.

Omri's need for control was shown by the way he prepared himself to undergo one of his surgeries. His daughter told me how he got prepared before surgery for the possibility of not surviving it, and asked his notary to come to the hospital before the surgery, in order to transfer his 'timeshare'[33] to the name of his daughter, so as not to lose it if he died during the surgery. Shelly told me that she objected to having a helper for her husband when both her husband and she were ill. She wanted to take care of him on her own although at some point she nearly collapsed, being too weak and frail from her own cancer treatments to be able to care for her husband. In her testimony, Shelly admitted that the price that both she and her husband paid in terms of quality of life by refusing a helper was high. Debby's need to control presented itself in her insistence on being consulted by her husband regarding the care of the house. She said that she wanted to maintain her title of house keeper although she could not perform house-keeping chores anymore.

The elevated need for control also appeared in issues related to health decisions. Naomi's example was related to her respiratory condition. Because she objected to being mechanically ventilated, she reported that recently when

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[33] Timeshare - a form of ownership or right to use a property, which is typically a resort condominium unit. Multiple parties hold rights to use the property, and each sharer is allotted a period of time (typically one week, and almost always at the same time every year) in which they may use the property (Wikipedia).

she had experienced respiratory distress she had feared being tempted to call for help and added:

> 'Around 6 months [ago], I also had a day, [one] evening that I felt really bad. I remember [that] I left all my phones here [living room] in order not to call anyone. I said [to myself that] it will take a while longer perhaps, but at least I… it was simply… NOOOO [ventilation]! Out of the question!' [Naomi, patient3].

Ehud refused to lose control by using opioids. Yarden's need to control her ADs meant that she made unilateral decisions regarding who would be the decision maker on her behalf, leading to a family disagreement (as will be reported in details in Chapter 5). Debby and Shelly both reported their need to get prepared for dying. Adam reported a conversation he had had with his wife regarding his funeral ceremony, asking for specific music for example. Yet, the need to control the EoL went beyond requests for a specific ceremony, as will be shown later in this chapter (in section 4.3).

In order to cope with their illness some patients reported a need for accurate and honest feedback from physicians, as Noa shared:

> 'In [hospital name] I went to the best physicians. They say [i.e. said] [that] there is no remedy for this [MS]. Professor [Name] told me that he was very sorry, but to his regret there is nothing that can be done. He said that he speaks with me straightforwardly and doesn't give me all sorts of illusions. Before that, the neurologist I addressed did not want to tell me what I had and it made me lose the confidence in him and to transfer my care to others. If I need to cope with something, then I want to know' [Noa, patient1].

Patients seemed to try to take control over their illness, as Yarden put it:

> 'Look from the minute that the illness was discovered I made the decision to myself that…, the illness will not

guide me in what to do or not. I live with it [cancer], it is present all the time, it "breathes down my neck" [chasing me], present somewhere, but I don't live **according** to it, I live **with** it, that's how I define it…/ …I didn't make changes in my way of life in the sense of work or community activity…, as soon as I could…, It is good for me. I feel it is healthy for me…, [Yarden, patient4].

4.2.3.3 Independence and determinism

Yarden, Dov and Ehud were still independent at the time they were interviewed. Some of the patients were frail by then (see Table 4, page 103), yet they tended to describe themselves (when they had been healthy) as very independent. Such was the case of Noa who had lost her independence over 20 years previously and had been totally dependent for more than 15 years, and Adam who became totally dependent within one year. This also included Meira who became dependent and frail within two years of undergoing dialysis. Naomi, Omri, Shelly and Debby were also frail, but could still take care of themselves with various aids but without needing help from others. All of these frail people described themselves as having been very independent in their healthy lives. Possibly these accounts could have been somewhat exaggerated, in order to make up in some way for the patients' current state of being less than fully independent, yet their accounts were considerably supported by their relatives as well. Patients seemed also to be determined to live as they chose in many aspects, not only when they were healthy and independent, but also when their independence decreased due to their illnesses. Naturally, with their gradual deterioration they could live less according to their wishes and this seemed to affect them negatively, but they were determined to preserve their freedom to choose their way to live with their illness and to die as a result of it, as Yarden expressed:

'I have the privilege as a human being to decide what I want with my life. Not on lives of others…, On my life I will decide! Yes I am very determined about it…, I always

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keep to myself [allow myself] the last word' [Yarden, patient4].

Patients' determination regarding their rights seemed closely related to their values and views, which we will now look at more closely.

4.2.4 Patients views, values and attitudes to end-of-life

Although most patients expressed the joy of living, as shown earlier, all of them said that not every life was worth living. This could perhaps be related to patients' expressed needs to be significant, in control and independent, as seen above.

Ehud and others said that when one is not needed, life becomes unworthy. Ehud said that this could happen even while still having capacity. Adam said that if he could not maintain his activities he did not want to live, and Noa said that if she could not communicate anymore and be involved in her family's life she did not want just to lie in bed '*like a corpse*' (her words). Yarden and Dov feared also the inability to communicate with relatives, and said that communication was vital and without it, life became worthless, as Yarden stated:

> 'I made a [living] will that asks not to prolong life in case
> I will not be able to control my situation, or I will
> experience only continuous suffering and I will not want
> to continue to live this way' [Yarden, PT4].

Naomi said that she did not have a death wish but that she had always thought that life is not sacred, and should not be maintained at any cost, adding:

> 'This [being mechanically ventilated] is not life for me. I
> am not willing to live like this. It is horrible suffering. I
> saw my father with this [ventilator], what do I need it
> for?' [Naomi, patient3].

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Omri, Shelly and Dov, spoke about futile suffering from a life-limiting illness, as a reason not to prolong life. Debby said that inability to control the body is 'not life' for her.

4.2.4.1 Patients' philosophies of life and EoL

Most of the patients reported experiences with ill relatives, friends or celebrities as factors influencing their own views regarding living and dying with illness that had encouraged them to make ADs for themselves at some point. The difference between an internal philosophy of life and external experiences that had influenced it, was, of course, not always distinguishable because they were often entwined in patients' descriptions. They are therefore also linked together in this subsection. Due to the abundance of patients' EoL experiences with relatives and others, only a few examples were chosen to illustrate how external experiences may have influenced patients' philosophies and their own EoL plans and decisions.

Most patients had experienced the deterioration and EoL of one or both of their parents. Meira, for example, told me that she took care of her mother toward the end of her mother's life. After a series of cerebrovascular accidents, her mother became paralysed and totally dependent on help with the activities of daily living for eight years. She said that she had visited her mother in the nursing home three times a week, all those years, and added gloomily that she did not want her daughters to go through a similar experience:

> 'This is one of the things that… is troubling me… (A) [back then] my helplessness that I couldn't do anything […4…] I didn't have anything to do, but I had guilt that I cannot do anything to help… and… (B) the fear that it passes onto you as a… heritage… and I don't want for my daughters what I went through with my mother… that sometimes I drove away from her [nursing home] in red

light… I simply went out from there and wouldn't see where I am[34]' [Meira, patient2].

Naomi, in another case, described how death and dying had philosophically and theoretically preoccupied her throughout her personal and professional life, long before her illness began. She told me at the very start of the interview that she had always viewed death as preferable to being handicapped. She also shared her multiple experiences with death: good experiences as well as bad ones, expected deaths in old age as well as unexpected childhood deaths. She said:

> 'Already in the nursery school. We had then [at that time] meningitis; there was an epidemic in the country. And then [=later] I had a sister who died small [young], who I didn't even know, who was born a premature baby, and was already better, and then one of the nurses inserted the feeding tube to the lungs instead of to the oesophagus. I remember that I came home and there was no sister…/ …My father was also with emphysema [COPD]. He died when he was 60. I was 30 then. It [his illness] started 3 years earlier. It was an unbearable suffering. And I didn't understand, what for? What? Well, one could say "that's it" and that's it! By the way he wanted [to die] and my mother didn't let him, and she was a registered nurse. He wanted to die already, she didn't allow him, it was very hard. As we say: 'she wouldn't let go' [said in English]' [Naomi, patient3].

Omri's philosophy seemed also to be related to the fear of disability. He said that he would not want to be dependent on others, and did not see this situation as worth living:

> 'I saw in different situations, how people suffer…, …And I don't think that there is a need to prolong life when… there is no… benefit. If you are not useful in anything

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[34] Meira meant that her mind drifted away and she didn't pay attention to the traffic lights

and you are just a burden to your family and... your condition... there is no chance to improve [it]..., ...and things deteriorate..., ...I don't want to be in such a situation.../ ......I [am from] another philosophy..., ...To the grave you have to walk on your 2 feet. I think that way' [Omri, patient5].

Dov said that there were many members of his family with cancer and that these examples had made him aware of the risks of dying in suffering. He wanted to die with dignity, which again seemed to mean death without becoming dependent on others:

'And I, from the moment I became aware of this [cancer] and of the dangers of it [...5...] after I have seen my mother suffering before her death and... other patients outside the family, I decided that [...10...] a person must know when to end his life for his good and for the good of the family [...5...]. Because I knew that I am a candidate to be ill as well... I wanted to guarantee that I will be able to end my life respectfully' [Dov, patient7].

Debby shared her experience with a friend who seemed to have suffered a great deal in his last months of life. She seemed to dread the possibility of lengthy suffering:

'And we saw the [=his] end and it was in front of my eyes all the time. The last difficult 3 months. And I said: "this I don't want". I don't know if LILACH... it answers the criteria [i.e. responding to my needs]... but I said **this I don't want**' [Debby, patient8].

This section relating to patients' philosophies of life ends the first part of this chapter, which has sought to set the context in which the patients in my sample made their ADs. The next part will go into the details of the making and meaning of ADs.

4.3 The findings regarding the making and meaning of ADs

After setting out the context of the lives of patients with advanced illnesses participating in the study, the next section of this chapter will shed light on the meaning of making an AD document. It starts by considering the preparation of the documents. Next, it looks at patients' knowledge and understanding of the legal status of ADs. Lastly, it presents patients' expectations from the document as well as from other sources (such as family and physicians) in order to manage the progression of their illness and the increasing threat over their quality of life.

4.3.1 Making AD documents

This subsection will deal with the process of making AD documents. We will be looking at: the timing and triggers for preparing them at a particular moment, their contents, and changes that were introduced in them over time and as a result of life events.

4.3.1.1 Triggers, timing and the onset of making an AD

The details in Table 4 (next page), show that only three out of ten patients said that they made ADs in health, while the others said that they did it when they already had an LTC. There were various triggers for making ADs, and timing was different for the ten patients. They were mostly, yet not exclusively, related to illness. Most of the patients said they had made their first AD a long time ago, '*when it* [ADs/LILACH] *was in diapers*' said Omri, meaning that he made his ADs when the option had just become available. Most patients had apparently had ADs for over 10 years, but this was an estimate because most of them did not have the document at hand during the interview and did not remember the exact date of its making. Most patients reported having renewed their documents in recent months and years.

Table 4: Patients' illness, ability and timing of making ADs

Patient	Age	Illness/ affected system	Time from onset (years)	frailty	Need help in basic ADL*	Need help in instrumental ADL**	AD in health or illness	Years with AD	Know about the DPA***
Noa	>70	MS / neural	>30	+	total	total	illness	>15	-
Meira	>80	Renal Failure / urinary	15-20	+	moderate	major	Illness	10	-
Naomi	<60	COPD / respiratory	5-10	+	Minor	minor	health	>15	+
Yarden	>60	Cancer / GI	5-10		-	-	Illness	<10	-
Omri	>80	Multiple LTCs	10-40	+	minor	moderate	illness	>10	-
Shelly	>70	Cancer / GI	<5	+	Minor	Minor	health	>10	-
Dov	>90	Cancer / hormonal	5-10		-	-	health	>10	+ and filled legal AD
Debby	>60	Cancer / urinary	5-10	+	Minor	major	illness	<5	-
Adam	>60	ALS / neural	1	+	Total	Total	Illness	<1	-
Ehud	>80	Cancer X2 (blood / urinary)	15-20		-	minor	Illness	20 yrs	+ and filled legal AD

* Basic activities of daily living (ADL) – such as: eating, bathing, dressing, toileting, walking, continence
** Instrumental ADL – such as: house work, shopping, taking medications, using technology, money and transportation
*** DPA - 'The Dying Patient Act – 2005' which regulated ADs for the first time in Israel.

Three patients (Naomi, Shelly and Dov) said that they had made ADs in health because they thought it was right thing to do, and that they were still healthy when they came across this option. Apparently, having an AD was part of taking control over life which, as mentioned earlier, seemed a major predisposition of the patient sample in this study. Shelly and Dov reported that when they heard of LILACH they approved of the option and therefore made an AD. Naomi, in contrast with them, said that she had always thought about the idea. It sounded as though she had already had the idea, and when she discovered that her idea had become an option she made her AD.

Making ADs in illness

Seven patients out of ten made their ADs when they were already ill, yet the triggers for making ADs were different:

- Making ADs with the onset of a life-limiting illness (Meira and Ehud)
- Making ADs when the illness became worse (Yarden, Adam and Debby)
- Making ADs by coincidence, while being ill, because they became ill before ADs existed in Israel (Noa and Omri)

Meira and Ehud made the document in reaction to their first life-threatening illness (Cancer and Heart Failure respectively). Yarden and Debby felt at greater risk of needing medical care sooner rather than later when their cancer became metastatic, and they wanted to control which medical care would be (or not be) provided to them if they kept deteriorating to the point of losing capacity. Yarden said:

> 'When I understood the risk of the metastatic illness I turned to LILACH' [Yarden, patient4].

Yet, for both Yarden and Debby the idea of having an AD appeared to be part of their general philosophy of life, as Yarden described it:

> 'LILACH fits my way of thinking since always' [Yarden, patient4].

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Adam did not think of this option on his own but reported that his physician and his psychologist had talked to him about the possibility of making an AD, and it was only then that he started discovering and considering this option. While he was searching for information, he learned that his sister was already a LILACH member, and she helped him contact LILACH in order to receive an AD form. He was the only patient out of the ten who became aware of ADs through his physician.

Noa and Omri made an AD because the option became available, coincidently, while they were already ill. Both of them became ill many years before LILACH was established. Noa remembered having made an AD in the late 80s, but her document was actually dated mid-90s. She remembered that she and her husband were pioneers in making ADs and made theirs when they became aware of the option, adding:

> 'In the beginning, when Rita Gur founded it [LILACH organisation] we registered immediately…, … when it first came out [became available] we wrote the [living] wills…, …as soon as it was published by LILACH…, …the 80s' [Noa, PT1].

Seven patients had made their ADs in illness. In addition to them, Naomi (who made her first AD in health), told me that she had somewhat neglected her documents for many years until she became ill, saying:

> 'When the situation with the emphysema started to deteriorate a bit, then I made sure to renew it. The truth is that before[hand] I didn't really renew the living will, you know' [Naomi, patient3].

It may be that some patients had thought of the idea of having ADs but had not executed it, and that being diagnosed with a life-limiting illness had encouraged them to take action and actually prepare the document.

Which AD form was used

Ehud was apparently the only one of the group of patients who first made a free-texted document when he became ill years earlier. Only later he adopted

the LILACH form, and subsequently the legal form as well. No one else told me this.

They all (including Naomi, who said she had always thought about the option of controlling EoL) seemed to have begun making ADs once the possibility was presented through LILACH. Only two patients (Dov and Ehud) out of ten had both the legal AD document and LILACH's AD (see Table 4 page 103). Naomi knew about the availability of the legal document, but thought that it was unnecessary paperwork, and had apparently suggested to her cousin not to use it:

> 'Who takes [uses the form] from the ministry of health? Take LILACH. [It is] much more accessible' [Naomi, patient3].

4.3.1.2 The reported content of the document

Most of the AD documents were unavailable during the interview with patients because not all participants had managed to find them to show me at the time of the interview; therefore most references to the content of the documents are based on patients' reports, with little validation from the actual documents. I looked at the documents of Noa, Yarden and Ehud (the former two with LILACH AD and the latter with the legal AD). Most of the patients in this study did not remember the details of their documents but had an idea about their requests[35], although many of them could well need the documents in the near future. As Shelly clearly said, after spending many minutes looking unsuccessfully for the document:

> 'It's a pity that I don't have the document. I filled it out and that's it. I forgot about it. [I] don't remember what is written in it' [Shelly, PT6].

In at least one case, I witnessed a difference between what a patient thought the content was and what was actually written in the document. Table 5

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[35] LILACH's initial document was quite general, and people signed that they refused all life-prolonging treatments, but requested the alleviation of pain and suffering. Specific treatments that were mentioned were: Cardio-Pulmonary Resuscitation; mechanical ventilation; Dialysis; Chemotherapy/Radiation; Blood and its products; artificial feeding.

(below) lists all patients' reported preferences in their ADs regarding treatments that they refused or desired to receive. Because there was a variation of patients' wishes, the numbers in parentheses in the table refer to the number of respondents who mentioned the same preference.

Table 5: Patients' recollection of their treatment preferences in their ADs

Refused treatments (n)	Desired treatments mentioned
Mechanical ventilation (4)	Palliative care
Artificial nutrition (2)	Morphine
Nutrition in general (2)	Fluids
Hospitalisation	Reversible care
Chemotherapy (2)	
Arterial catheterisation	
Any life-prolonging treatment (3)	

Meira said that she refused mechanical ventilation, artificial nutrition and arterial catheterisation. Regarding nutrition, Yarden said that she did not refuse nutrition at EoL in her document, although this was what she had actually wanted to write. Yarden explained that omitting her wish to stop nutrition was the result of a few discussions she had had with the Rabbi in her community, who told her that this was a wish that he could not support. She expressed discontentment with the compromise she had made:

> 'I am still divided about it [nutrition at EoL], very much
> divided about it' [Yarden, patient4].

Naomi maintained that ADs in general are meant to let a person die in peace without suffering, and more explicitly she said that she would accept palliative care and fluids as the only medical measures at her EoL.

> 'Any palliative care I don't mind/ If it doesn't succeed,
> [then] at least there is no need for a court order to
> disconnect me from anything…, …The only thing maybe,
> that I am willing for them to give me is an infusion of
> fluids, so that I won't get dehydrated/ That's all. Beyond

> this nothing. Nothing that if the moment comes, they will
> need [will necessitate] to run to court [in order] to
> disconnect me' [Naomi, PT3].

This statement may sound very restrictive and unequivocal, but then Naomi added that the criterion for any other treatment should be the potential of its withdrawal without a court order, thus theoretically keeping the list of medical measures open to discussion and additions.

At first, Yarden said that she had written that in case of total paralysis, or inability to communicate verbally, or continuous unbearable pain, she wished not to prolong her life artificially with chemotherapy and similar treatments. Later she read me the content from her actual AD document (note the difference between her remembered version and the written one):

> '[In case of:] Unconsciousness, vegetable [state], severe
> brain damage without ability to identify [relatives],
> absence of ability to communicate [then she reads the
> treatment she refused:] artificial resuscitation [i.e.
> cardio-pulmonary resuscitation], mechanical ventilation,
> dialysis' [Yarden, PT4].

Noa and Shelly did not remember the content of the document, and both said that they (and their husbands) wrote what they thought was appropriate back then.

When Ben (Noa's husband, who was present in Noa's interview) brought the document, I read it out loud: '…In case I will not be able to make decisions related to my medical care, I request that my life will not be prolonged by artificial measures… either by withholding their use…, or by withdrawing them if they have already been used…'[36]. Noa said that she refused hospitalisation, and later she added:

> 'If I cannot function and the head [brain] will not work,
> then I prefer to end my life' [Noa, patient1].

Omri refused treatments altogether, saying:

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[36] My translation to English (T.M.).

> 'I don't wish to prolong life. I don't want to be fed, nor
> cared for, nor [mechanically] ventilated, nor nothing, and
> it's all written here and that's it' [Omri, patient 5].

Shelly did not remember the exact words in the document and summarised that she and her husband wrote that they did not want any interference. She asked for her life not to be prolonged in various cases (which she did not specify). She seemed to have an overall objection to life-sustaining intervention:

> 'I didn't look… I wrote what I thought then, and I
> assume that this is what I think today as well. What
> shall I… say? That I do want them to give me 'this'
> treatment and don't want them to give me 'that'
> treatment? I don't want treatments [at all]. 'IM KVAR
> AZ KVAR'[37]. That's it' [Shelly, patient 6].

Dov said that at the end of his life he would like to shorten the time as much as possible, because suffering in an irreversible situation seemed pointless in his view:

> 'I would like to shorten as much as possible [my life]. If
> I arrive to this [EoL] I would like to cut it short…/
> …Suffering is part of life… there is no life without
> suffering… one is suffering… without choice, in order to
> get out from a situation that endangers his life…[9
> seconds silence] [But] to suffer… without having the
> possibility… to cure and keep living, it's unnecessary'
> [Dov, patient7].

Debby hoped that if she became incapacitated her husband would do whatever possible to prevent or alleviate her pain:

> 'If he [Alon, husband] sees me suffering [laughs
> embarrassed] morphine tablets, [or] I don't know what,

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[37] 'IM KVAR AZ KVAR' - an expression that means: If I refuse/take/accept part, then better refuse/take/accept the whole

> just not [to experience] physical suffering, I can't stand
> it, I am so weak even now and… it's very difficult for me.
> Now it's [already too] difficult for me' [Debby, patient8].

Adam seemed to select his choices according to his illness and his speculations on the causes for his final and critical deterioration. He thought that his respiratory and digestive systems would be the ones to collapse, but did not have concerns about his latent Hepatitis, therefore he said that his explicit orders were:

> 'That they won't insert tubes to my stomach and that
> they won't resuscitate me… Although I am carrier of
> Hepatitis C and my liver functions are 80-90% I don't
> think that I will die from this. [It] seems more actual to
> me [to restrict medical measures regarding] stomach and
> respiration' [Adam, patient9].

Ehud said that he wrote a very brief request not to prolong his life and not to suffer. This wish was common to all the participating patients, even if they expressed it in different words.

For those participants who were unable to locate the actual AD document, it was not possible to know if what was actually written in the document matched their recollection of what they had written. I suggest there might be some mismatch between what was written and what people said, given that participants who did locate their AD found things written there that they did not remember. However, the examples above show that these patients knew clearly what they wanted, even if they did not remember the exact content of their AD documents, or where the documents were placed. A point worth thinking about is that the documents were pre-made forms, which contained few medical conditions and medical treatments[38]. Perhaps it is not surprising that some patients recalled the parts in the document that were the most relevant to their illness. So for example Yarden, who has cancer, did not remember refusing dialysis in her AD but remembered her refusal of

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[38] The specific treatment options that are mentioned in LILACH-ADs are: Cardio-Pulmonary Resuscitation; mechanical ventilation; Dialysis; Chemotherapy/Radiation; Blood and its products; artificial feeding.

chemotherapy. Beyond the exact content of ADs let us now look at patients' overall expectations for medical care in the event of their potential loss of capacity.

4.3.2 ADs - expectations from the document

According to the Israeli Dying Patient Act (DPA), ADs can contain requests to limit treatment or to ask for full treatment. In my sample, all the patients had expectations for treatment limitation if they lost capacity and no one expected to be treated fully should this occur. Some patients related to specific treatments and others to a more general expectation. Noa and Adam refused the insertion of substances and tubes into their body. Meira wanted her document to be respected should she become unconscious, without her daughters feeling in any way pressured to prolong her life. In a severe tone, she said that she refused a renewal of any arterial access if her shunt became inactive if she had lost capacity:

> 'I have a shunt for dialysis. So in case the shunt doesn't operate, I [would probably] enter a comatose state. [shouting:] **I don't allow** that they connect [dialysis machine] to my artery here [shows:] under the collarbone or the groin. I wrote … I mean [if] **there isn't** [the shunt] then **there isn't.** I will be gone [dead] if the shunt is closed [i.e. occluded]' [Meira, patient2].

Naomi said that she hoped to die at home, but if it came to needing health care, she hoped that with the help of the document no active measures would be taken apart from palliative care.

> 'If they could stabilise me without all the artificial means and to ease my condition without all this, it's fine… fine, I don't have any problem [with that]. I don't have a death wish anyway… Perhaps they could stabilise me somehow without a mechanical ventilator and it's fine…/ …Any palliative care I don't mind' [Naomi, patient3].

In the next chapter, Naomi's experience of needing her AD will be described in greater detail (see Vignette 2, page 147). She reported that when she felt a potential respiratory crisis coming on, she prepared to have her document near her, hoping to get relief from her distress without using active life support:

> 'I even put the AD on the pillow next to me. I explicitly wrote there 'not to ventilate'… no intubation, nothing, only relief. Sedation. Just to relieve [me]' [Naomi, patient3].

Yarden hoped that if she could not control her life and body, and if she was in continuous suffering, her nutrition would be stopped:

> 'I said that if I enter unconsciousness, I request that my nutrition will be stopped. Because as long as someone is conscious, [it] could be that not providing nutrition is also [a] kind of suffering…, I requested not to do things to prolong my life' [Yarden, patient4].

Shelly said that if she became incapacitated or if she deteriorated physically, she did not want further chemotherapy:

> 'I don't want treatments…, If I get to the condition that… I lose control…., not knowing what is becoming of me at all [Shelly, patient6].

Adam said that he was not sure how the AD document could help him at all, and referred to his specific request not to intubate and ventilate him, as mentioned before. Ehud Omri and Dov said that if they lost capacity, they did not want to receive any treatment at all.

4.3.3 Changes in the documents over time

When I asked patients about changes in their views and wishes over time, they usually said that they had not changed their mind. Yet, some of them shared new understandings as they experienced physical decline and their

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illness progressed, which led them to add various clarifications. Noa, for example, reported adding refusal of hospitalisation because she viewed her home as the best place of care, whereas she viewed hospitals as potentially dangerous. Meira added refusal of arterial catheterisation if for any reason her 'A-V shunt'[39] became inactive. She also said that in her primary AD document she refused dialysis, and she subsequently removed this statement because she was already on dialysis[40] and she realised that stopping dialysis would bring back her intolerable suffering from the itching caused by the accumulation of toxins in her body. Naomi said that she added the word 'emphysema' (i.e. COPD, her illness) on the top of her AD document to make clear that she was aware of her medical condition, thus validating her request not to prolong her life. Yarden added inability to communicate as another reason not to prolong her life, explaining that such inability was worse than death to her. Ehud (whose cancer was being followed up by a religious physician) said that he added to his document the request that physicians who opposed his opinions regarding dying and death should not be his carers when he approached death.

The above examples suggest that patients' experiences of life, illness and communication with their health care teams led them to refine their requests in their AD documents. The variety of their experiences may explain why there were accounts of many distinct and different changes to their AD documents.

4.3.4 Legality of ADs: missing knowledge and misconceptions

Seven out of ten patients (see Table 4 on page 103) did not know about the Israeli 'Dying Patient Act' (DPA) or the legal AD form. They were aware of LILACH's form, and three of the seven (Meira, Yarden, Omri) told me that recently (months to a few years earlier) the form had changed and that they were asked by LILACH to renew their documents, and to add witnesses. Not all of them were aware that having ADs was now legal in Israel, although, as

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[39] A-V shunt or fistula is a passageway between an artery and a vein which is created for haemodialysis treatments.

[40] Meira said that she was put on dialysis, when she was in critical condition, in pre-comatose stage, without giving consent (against what she had written in the AD). Her daughter presented the situation differently.

a matter of fact, the LILACH organisation is continuously informing its members about changes and developments regarding ADs through its twice-yearly bulletin and other means. When I asked Yarden whether she had the legal AD, she said that she did not know about ADs being legal, or about the legal form. She expressed interest in this option and wrote down the details of the internet source for further information. Yarden as well as others (Meira, Debby, Shelly, Adam) did not know that ADs must be renewed once every 5 years to be legally valid.

Three out of ten patients (Naomi, Dov and Ehud) knew something about the DPA, the legality of ADs and the AD legal form. Naomi, in her interview, referred to having the legal AD form as unnecessary. She said that both forms (LILACH's and the DPA's) were based on the same principle, yet the LILACH form was more accessible (i.e. user-friendly). Dov and Ehud, on the other hand, had filled in the legal AD form in recent years:

(1) **Ehud** had some medical background and managed to fill in the form on his own. He told me that his form was returned to him by the Ministry of Health, to clarify and correct some inaccuracies, before it could be approved and a copy could be kept in the national database for ADs.

(2) **Dov,** on the other hand, asked his former GP (Dr. Paz) to assist him with filling in the form. He said that the GP not only explained to him all the medical treatments that were listed in the AD form, but helped him to find his way through the form as a whole. Dov described the legal form as both 'heavy' and 'slim'. By 'heavy', Dov meant that it was difficult to fill out, clumsy and that it used difficult terms. 'Slim' because it did not provide answers to all Dov's expectations, as will become clearer in a later section regarding patients' dissatisfaction from AD documents. Dov was not the only one to think that the legal document was problematic. Ben (Noa's husband) was of a similar opinion.

Another legal aspect was that patients reported some confusion between being: a 'witness', a 'surrogate/proxy decision maker', and simply holding a copy of someone's AD. Most of them related to all the terms as meaning 'potential surrogate decision makers'. This was also seen in the case of Yarden, which is described in greater detail below (Vignette 1, next page).

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Vignette 1: The example of Yarden regarding the misconception about 'a witness'

Yarden said that she discussed with her Rabbi the various requests and wishes that she wanted to include in her AD. As mentioned earlier, she said that they had some disagreement that led her eventually to compromise (her words) and exclude her request from her AD 'not to be nourished' if she became incapacitated. Yet Yarden did not seem to fully accept her own compromise, saying: 'I am still divided. I am still very much divided'. She reported that this incomplete agreement led to her decision that the Rabbi should not be asked to sign her AD document. She was worried that he might make decisions which she did not approve, knowing that he could not support the idea of stopping nutrition on religious grounds:

> 'He [=the Rabbi] told me: "if I will have to make decisions, then
> I will have to decide according to the religious guidelines", so I
> didn't make him sign [the AD document]' [Yarden, PT4].

Yet this was a misconception of the role of the witness, which legally means an acknowledgment that the patient has made the AD without pressure from others, rather than becoming a decision maker for the patient in case of incapacity.

Moreover, Yarden was unfamiliar with the fact that according to the DPA it is illegal to ask for nutrition to be stopped until death becomes imminent (i.e. expected within less than fortnight). Her unfamiliarity is not surprising, because in the LILACH form such a limitation does not exist.

Naomi, Dov and Ehud, who knew about the DPA, presented different criticisms relating to the fact that its application is limited to the last 6 months of the patient's life expectancy[41]:

A. Naomi rejected the 6-month criterion because according to her it did not serve all LTCs the same, namely her own COPD. Naomi was aware that her lungs had already been functioning at less than 20% of their normal capacity during the last year, and that her illness was already medically considered an 'end-stage-illness'. She thought that it was wrong to measure her distance from death by time, but that it should be done rather by pathology and by the fact that she was in the last stage of her incurable illness:

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[41] Six months life expectancy is the criterion of being 'a dying patient', and one basic condition for applying ADs.

'What is the DPA? I [have] read it…/ …excuse me… according to this category I am not a dying patient. Nice [being cynical]. This law is worthless. What is this law, to say when I am dying or not? If I arrive tomorrow to [hospital's name] as I did, I am not [considered as] a dying patient… see this arrogance. How can you [=they: physicians] say if it is 6 months, the [expected] death time? Maybe he [i.e. a patient] will beat the statistics?' [Naomi, patient3].

B. Dov thought that some people were in stages of dying for longer periods than 6 months, and therefore the definition of the law might cause them to suffer for a long time before their ADs could be applied and treatments withheld:

'This document is… very thin. All it gives is 6 months [to be called 'a dying patient']. And why should someone suffer [let's say] a year till he gets to the 6 months?' [Dov, patient7].

C. Ehud viewed it from the perspective of the physicians' inability and unwillingness to predict the life expectancy of patients accurately enough:

'There are so many doubts inside [the DPA]. Among other things, they [physicians] need to decide… [that] a person has not [more than]… I think 6 or 3 months to live. [I] don't remember exactly. Which physician can say that you have [=one has] 6 months? They always have excuses [to avoid such predictions]…/ …nowadays most physicians will not agree to take chances with this [6 month prediction] definition' [Ehud, patient10].

Apart from the issue of prediction, the findings show that not all the patients knew exactly what the boundaries of ADs were. Debby for example did not distinguish between withholding and withdrawing life supportive treatment. Yarden did not know that it was illegal to ask to stop nutrition at any moment prior to when death became imminent.

A misunderstanding regarding the status of the document once its owner becomes incapacitated drew my attention to a serious ethical and legal concern regarding incapacity. In this study, this issue emerged because the wives of two patients (Omri and Dov) were incapacitated at the time when interviews were held. When those patients told me about the renewal of their AD documents, each of them said something about their problem with renewing the ADs of their spouses who were without mental capacity. Omri said that he had asked for help from LILACH and that they had advised him to renew only his own AD document, apparently telling him that his spouse's old document would continue to serve her as an AD till her death. When he told me this, I had the impression that he had followed the advice but did not understand why they had advised him in this way. During my visit to interview his daughter a few weeks after his interview, he asked me to try and ask his wife some questions because he wanted to know whether she remembered having made an AD in the past and what she understood it to be.

In the case of Dov, I understood that he brought his wife's new AD document to the GP to sign[42]. In this case two problems appeared: (i) the patient did not understand that once incapacitated, his wife did not need to (and legally and ethically could not) renew her document; (ii) apparently the GP did not know the regulations and the role regarding ADs, and breached the ethics of care by signing a document of an incapacitated person (Dov's wife).

4.3.5 Patients' mistrust in their loved ones, the medical system and the political establishment

Some patients were not sure how their AD document would help them. They hoped that the document would represent their wishes but not all of them trusted either the medical system or their relatives to act on their behalf. Noa and Ehud referred to an event that was published in the media (while the data was being collected), in which the family of a football player who sustained an injury resulting in brain death refused to donate his organs although he had an organ-donor card. They both used this example to tell me that they were not confident that their ADs would be carried out. Yarden made a concession

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[42] The signature means that the GP gave all the necessary information about medical treatments available in the AD document.

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in her AD when she omitted her wish not to be fed if she lost capacity, yet she did not seem to really agree with her concession. Naomi said that she expected ADs to be unequivocally respected in Israel, as are DNR[43] orders in the USA. Naomi experienced a respiratory crisis, and expressed great disappointment about how the medical staff had taken care of her during the crisis. In the first part of this chapter, I gave the example of her new strategy to cope with a respiratory crisis (after her negative experience) by putting away all her phones so as not to be tempted to ask for help. This seemed to be a hard and sad (perhaps even extreme) illustration of a deep mistrust in the ability of the medical system to answer her needs.

Dov said that he did not trust physicians to be able to withhold treatments, and hoped that ADs would force them to respect this wish. Yet he referred to ADs as backup for what he described as a 'worst case scenario', when he would be unable to speak for himself. Meira also showed little trust in her health carers, and said before I left:

> 'Wish me not to get [to need] a living will' [Meira, patient2].

But apart from mistrust in the medical staff, some patients found it hard to trust their loved ones to be able to handle their dying in the way they wished. This worry could perhaps have been linked to issues of maintaining self-control, yet patients also seemed to understand that it was a very difficult task, and two of them (Yarden and Ehud) honestly said that if they had to make decisions for their loved ones, they were not sure how they would do it either.

Yarden and Debby, who were aware of how difficult it was for their husbands, tried to find sources of support for them, feeling that they would find it difficult to make EoL decisions for them in due time. Debby asked her siblings to support her husband, while Yarden built a support group made of family members, a close friend and the GP.

Ehud and Dov related to the policy makers with disbelief, thinking that a minister of health who is an orthodox Jew has no interest in encouraging ADs

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[43] DNR – Do Not Resuscitate orders.

but rather the opposite. Ehud expressed a fear that if attempts were made to improve ADs, the Jewish orthodoxy would strongly object, and this might lead to a worsening in the status of ADs.

With little trust in the medical system and policy makers, and with their empathy for the difficult task they were expecting from their relatives, all the patients in this sample looked for alternatives, as will be unveiled shortly.

Ehud said clearly that he would not allow his family to hospitalise him if he became incapacitated, yet he added that he did not trust them to be able to execute this wish although they agreed with his request:

> 'I don't allow my family to bring me to a hospital…, they [family] agree with that. They know it is so…, The problem is not that they won't understand. What they will understand with the mind is fine. [but] what will happen when they will be faced with [a situation]… and the physician will say: "we can save him and he will be fine" and… "no worries" and such… It's awful, these people who put pressure on others' [Ehud, patient10.

4.3.6 ADs being 'not good enough' and the search for alternatives

One finding was surprising because it appeared in the findings of all ten patients: They all viewed ADs as a desperately unsatisfactory solution to their need. I found it surprising, and unexpected, that all patients viewed ADs as so partial that they all spoke about their need to have another solution. They referred to their AD as a default option, as Dov expressed it:

> 'Not to prolong life. This is what the law enables' [Dov, patient7].

As mentioned before, the patients who participated in the study appeared to have a high need for control and some level of distrust in the ability of health carers and their loved ones to cope with the end of their life as they would really like. Whether it is related to this or not, all ten patients spoke about

alternatives and many had actively searched for a solution that would rely on themselves as much as possible. This is such a highly significant finding in my study that rather than providing one or two examples, I wish to present as many patients' voices as possible, in their own words (in Table 6 below). My aim is to allow these voices to 'stand alone', for the reader to consider this data fully with as little screening and interpretation as possible, before proceeding to analysing and discussing it. In order to protect the participants' confidence, and because they exposed sensitive material, I will not identify them by name, nor use their study serial number. I will identify them with the letters A-J, changing the order from that used in the sample.

Table 6: patients' alternative solutions for the end of their lives

Patient identifier	Patient's quote
A	'Look, if it was possible in this country, I would even say, that same as I could [go to the vet to] give my cat an injection to put her to sleep [i.e. kill her], and **I did**, I would rather have the same. But this is possible only in the Netherland or in few places in the world…, I even consider this option…, that if I felt that it went only in the direction of continuous suffering without any [prospect], maybe I would go to Holland [Netherland] if it was possible'.
B	'If I cannot identify [relatives] and be involved, then I don't want to live… Let them end me [kill me]… with I don't know… an injection by the physician… If I will see that it is possible I will ask Dr [name] and if not I will kill myself'
C	'First of all I searched for something I could take so that I will not be saved [resuscitated]. It is not simple. Today one cannot buy arsenic and all sorts of things. Finally I bought something and I had to sign etc. OK. I got the medication. They asked me to sign [my request] and asked me why I needed it. Besides this I took not a [big] quantity, [in] three times, I made a 'SLICK' [i.e. secret stockpile]'. 'Here [Israel] a physician cannot give… a [lethal] prescription and nothing at all. I am very much in favour of this [giving lethal prescriptions]. Going to kill one self by hanging is better? They can

Patient identifier	Patient's quote
	even remove you from there (the rope)'.
	'I hope that I won't have a brain haemorrhage [and] that I will be able to end life with the medications that I prepared in advance'.
D	'I don't want to wait for such a situation that I… won't be able to do anything. I want to do something while I still can. Before I lose everything. To be remembered. To be remembered as a human being and not as kind of horrible thing. [I wish to] either die from a heart attack or something similarly sudden, or that someone will do it for me [kill me]. I think it is much more dignified. When you see documentaries now [of people who] either drink something and go to [eternal] sleep, or are injected [with] something and go to sleep. That's it, doesn't hurt'.
	'If you have a dog that is very ill and suffering, then you put it to sleep. So why not here? What? Are humans worse than dogs?…, He who is in bad condition and don't want to live, don't find reason, then he needs to be allowed to die in dignity. **This** is dignity'.
	'If it [illness] will keep progressing and if it [my condition] will become very bad I won't wait…, inject KCl [potassium chloride] to the vain…, I don't know if I can do this to myself but this is an excellent method'.
E	'I don't want to live and I was told that my body will betray me fast [enough] not to need to commit suicide'
	'I am a person of action. If I cannot do [be active, then] I don't want to prolong it [life] more than needed.
F	'If something happens, that… or that I am a vegetable God forbid

Patient identifier	Patient's quote
	or… to end, to end, to end, to end, Don't keep me [alive]. Adi Talmor[44] did totally sensibly…, in a controlled way without pain… I think [continues laughingly] that it is ideal if one can say so'
	'I thought to end life by myself if I will be in situation where my brain will still work. To take pills. That's it. It doesn't hurt'
	'Pain is no life, and waiting until it [death] will occur naturally, this is my fear for the last months [of life]'.
G	'There are situations that definitely are worth ending life and not dragging it at all cost, very simply…, There are situations that better to end them…, When the moment comes when you see that that's it, and you know where it is going to, what for [add] another day, another two days, another year? What for? What for?'
	'I may need to find other measures, as simple as that…, it has happened before and it will happen here…, If I don't have some wonder-pill that I can take and say 'bye bye' it means that I need to accumulate pills…, and then also to decide: "OK, then today I will take it" although it is not the condition [to need it], and that's a pity, just pity'.
	'It is a pity that someone like…, Motta Gur[45], went [and] stuck to himself a bullet in the head. It is very sad that they force someone to end life in such a way, instead of a much more…, elegant way. Yes? Getting to bed, sleeping and not waking up, rather than sticking a bullet in your head…, You know?…, the pressure from the illness is reduced because all of a sudden you feel in control'.
	'I heard of someone who went to Holland [to die]. Well, now I don't have the money to go to Holland, but it may be a good idea to start saving…, Look it is just unbelievable this thing… that they don't help

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[44] Adi Talmor – A renowned Israeli radio-announcer, who hastened his death with the help of the Swiss Dignitas organization in 2011.

[45] Motta Gur – A former Israeli politician and Chief of Staff of the IDF (Israeli Defence Force) who committed suicide by gunshot when his brain cancer became an advanced and incurable illness

Patient identifier	Patient's quote
	people to end life with dignity'.
H	'A dignified way [to end life] is to put an end to life when you get to this situation [suffering]. Not to prolong [life] is [...10...] the little that the law enables. Actually, what I want is much more..., I [...8...] would like that someone who suffers... from a terminal illness in a terminal state, an incurable illness, will get medical help to end his life, and not be forced to face a situation where he needs to find alternative ways.../ ...what exists in Switzerland is excellent.../ ...I would like to shorten as much as possible [my life]. If I arrive to this I would like to cut it short [...8...] for what [to prolong it]? I can only tell you that I have prepared myself in case that I get to this situation..., I prefer that we won't speak about it. It is a legal offense..., Do you have to know the means? What I will do? [...10...] someone that [...10...] someone determined will find a way. There are ways that are easier and ways that are more difficult and... with the help of medicine it can be done much more easily... and this is what I wish to be [available]'
I	'Can I tell you something? [points to the audiotape embarrassed] I will finish myself' 'The hesitation is very difficult [in quiet voice:] I want to tell a secret. I went to the A&E and I took with me, in one of the times that it looked to me that... I feared to have a stroke, and I took with me, I took pills that I have here around 20 years. Little stock, I have a little stock. I took care of it'.
J	'If it depended on me only, I would go to some hotel... and... hang a note on the door: 'please don't disturb' [said in English] [...9...] that's it..., I wouldn't... like... to do this to them [children]... because it is not nice to live with this' 'If I could write whatever I want I would have asked an injection... that would finish me on the spot..., No one needs to know about this..., it is a secret [...3...] [between] physician [and] patient..., the

Patient identifier	Patient's quote
	person falls asleep and that's it…, Don't you understand? I don't want, ah, to pull the trigger by myself. I want everything to look natural!'.

As can be perceived from the findings above, all ten patients wished to be able to terminate their life actively, in certain conditions. They all wished to have a pill or an injection to use not only if they lost capacity, but also if they felt that their life was not worth living anymore due to extreme suffering as they perceived it to be. Most of them spoke about ending life while they still had the capacity to do so, knowing that it was illegal and that no one else would do it for them once they lost capacity, or once they were unable to kill themselves (such as if they became paralysed). Knowing that such a 'wonder pill' was not available, they shared their solutions with me, some more overtly, while others only insinuated them to me.

Note: Patients were aware of the illegality of their solutions and shared them as secrets. Some were more cautious than others, yet I find it highly important to safeguard all of them, to allow the evidence to be presented without breaching the confidence and safety of the participants.

4.4 Discussion

From the findings presented in this chapter, there are many issues which could be discussed and compared with previous evidence, such as the illness experience. Yet, due to limitations of space and considering other data that will be presented in subsequent chapters, I have chosen to focus on the most prominent issues that emerged from the analysis, which I find substantially related to autonomy. Other issues will be discussed elsewhere in the thesis, or in additional publications.

4.4.1 Discussing autonomy, ADs, and their meaning for the patients

The data presented in this chapter is strongly related to autonomy: patients' awareness of and involvedness regarding their illness and care, their individual wishes regarding life and its quality, their determination to express their wishes in writing, and their considerable need to control their lives and their impending death. Autonomy relies on an individual's ability to make decisions based on knowledge and understanding, and based on free will. Both the findings and previous literature show that in reality there are a number of problems regarding 'informed consent' and 'free will'.

4.4.1.1 Autonomy and 'informed consent'

One of the basic assumptions regarding autonomy is that people make decisions with full awareness and understanding of the choices, and of their respective risks and benefits (hence the term 'informed consent'). However, as shown earlier, this postulation has been proven inaccurate by the findings of this study. Some patients were not aware of important issues such as: the legality of ADs, the meaning of being a witness in the AD document, and what treatments could be refused and under which conditions. In relevant examples (such as Dov's and Omri's cases) patients did not understand how ADs should be handled in case of incapacity. Recently-published evidence has also noted the lack of knowledge of some people making ADs, such as: confusion over terminology, legal issues, boundaries and possible outcomes or applicability of ADs (Andrews, Patel, Sanchez-Reilly et al., 2010; Jackson, Rolnick, Asche et al., 2009). These findings regarding the partial understanding of ADs suggest that patients' expectations from ADs may eventually be unmet, either because the document was illegal, or because patients tried to use the document in ways which were inappropriate or legally invalid.

4.4.1.2 Autonomy and free will

An additional critical view of autonomy relates to another of its basic assumptions, which maintains that decisions are made in 'free will'. In practice, in the examples of some of the patients in this study, many of the patients' decisions regarding their present life were apparently affected by their relationships with loved ones. Meira, for example, reported feeling obligated to continue her treatments. She thought that if she stopped treatment, health care staff would pressurise her daughters, and this seemed even more unbearable to her than her own suffering. Although it was not her only motivation to carry on with dialysis treatments, it seemed significant to her:

> 'If I stop dialysis they will immediately call my daughters and start troubling them… this is something I don't want. They [physicians] won't leave me alone…/ …as long as I am competent I don't want… I try… to trouble my daughters as little as I can' [Meira, patient].

A similar ambiguity appeared in Noa's and Debby's accounts: while they said that they were already too tired to keep on living and wished their life to end, they were also clearly saying that their dear ones needed them and that this commitment was important for them. They were talking simultaneously about death wishes and about the wish to remain alive as long as possible. Omri shared his preparedness to end his life, yet also his many efforts to remain alive because his wife was extremely dependent on him and he thought that in her current state of mild dementia, her condition would deteriorate considerably if he died. These and other examples in the findings support the claim that autonomy is seldom detached from the individual's relationships, and the individual is rarely completely free to make decisions regarding their own life, health and death. The theoretical view of autonomy looks at individuals very narrowly as if they are 'atomistic individuals', unrelated to other individuals (Dodds, 2000; Kendrick and Robinson, 2002). This concept of individualistic autonomy is criticised as 'narrow', perhaps due to its assumption that health care decisions are made in free will. Feminists argue that because the individual is part of a social network, decisions are rarely purely based on free will (Dodds, 2000; Kendrick and Robinson, 2002). The

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term 'relational autonomy' seems a much more appropriate lens through which to look at autonomy, because most individuals are part of meaningful relationships that not only affect their will, but also shape who they are (Mackenzie and Stoljar, 2000). This aspect of relational autonomy will be explored in greater detail in the next chapter, which looks at the interaction between patients and their relatives regarding ADs.

The most noticeable and troubling evidence stemming from the findings presented in this chapter is the clash between individuals' autonomy and the principle of social justice, which will be at the centre of this discussion.

4.4.1.3 Autonomy and the principle of social justice

This chapter highlights a discrepancy between the law and patients' wishes or plans for their dying. This discrepancy appeared to be related not only to ignorance of the 'Dying Patient Act' (DPA) but also to a deep desire to have control over a lingering death, and this issue has additional moral implications. As shown in the findings, this was not related to 'death wishes' but rather to: anticipatory fear from suffering in all its forms, considerable need to be in control, and a determined emphasis on the quality of life rather than its length. Patients did not know all the details and boundaries of ADs, but perhaps this did not trouble them because they had their own mind set on something that went beyond ADs and beyond the law. Importantly, most of the participants identified with wanting to control their EoL, not only if they lost capacity but also if they lost their independence. Not only does the Israeli law not support this, but it totally denies the option to hasten death. Before going any further with a discussion of this issue therefore, it should be emphasised that the findings do not claim to represent the general population, nor even the older population in Israel. They may to some extent represent people who have made ADs, but this may be suggested as the subject of further research. The tentative claim that the findings may represent some AD holders lies in the fact that, without any reference being made (within inclusion criterion for this study or within the preliminary phone conversations with participants), all ten patients shared in their interviews either a wish to hasten death or, in some cases, real plans and tools for such a death. While my sample was quite small, this finding is clearly significant.

Previous research evidence regarding the wishes of patients who have made ADs rarely refers to participants' explicit wishes to hasten death, unless this was the clear focus of the study (example: Schroepfer, 2006). Most studies examining patients' preferences (which tend to be quantitative), tend to make a comparison between given options, either regarding forms, statements or scenarios (Abbo, Sobotka and Meltzer, 2008; Moody, Small and Jones, 2002; Pekmezaris, Breuer, Zaballero et al., 2004; Pruchno, Lemay, Feild et al., 2006; Sahm, Will and Hommel, 2005a). In those studies the option of hastening death was not available to participants, and indeed some studies concluded that patients' preferences are not always expressed in full due to the structure of the forms, which allow only limited choices (Abbo et al., 2008; Moody et al., 2002).

Pautex, Notaridis, Derame et al. (2010), in Switzerland, went a step further and tried to investigate patients' preferences and values less rigidly, without using a copy of a set AD form. After providing information about ADs, the researchers asked those patients who were interested in making them to write their preferences down on blank paper. No one asked for the option of hastening death, although three participants were described as members of the 'right to die' organisation. The researchers also reported following patients who remained in the same hospital until their death, to see if ADs were respected. One of the noted outcomes of this follow-up, as reported by the researchers, was that three patients who were members of the 'right to die' organisation died peacefully and naturally without needing to hasten death (Pautex et al., 2010). This was one of the few studies that referred to patients' wishes to hasten death in a study that did not focus deliberately on this issue. Another study attempted to identify if there were medical conditions that were perceived worse than death (Yung, Walling, Min et al., 2010). The majority of respondents stated that coma, mechanical ventilation or tube-feeding presented circumstances in which they would prefer to die rather than experience such conditions/treatments (Yung et al., 2010). In a systematic review conducted by McPherson, Wilson and Murray (2007) which investigated 'self-perceived burden', there is evidence of suffering caused by the anticipation of becoming a burden, which was regarded as worse than death and was linked to hastening death (McPherson et al., 2007). McPherson et al. (2007) related to the term 'self-perceived burden' as

'*empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self*' (McPherson et al., 2007: 115). In a recent systematic review of seven qualitative studies looking at reasons for patients' wishes to hasten death (see Monforte-Royo, Villavicencio-Chavez, Tomas-Sabado et al., 2012) it was found that the 'sense of self' was not only diminished but for some patients it was lost, and this caused existential suffering. The 'loss of self' reflected: loss of body function (and with it loss of independence), loss of control over life, and for some also the loss of meaning (Monforte-Royo et al., 2012). My findings support the findings of Monforte-Royo et al. (2012) and indicate that not only do patients' 'self-perceived burden' in regard to others and its anticipation make them suffer, but also the anticipation of losing independence in regard to themselves. In addition to the empathic concern regarding their relatives, their independence was so valuable that losing it appeared inhumane to them, and for some this was worse than death.

Previous evidence shows that suffering, which may present itself in various ways, may be a reason for some people to wish to hasten death, when there is no hope for reversal and when the process of deterioration is lengthy (McPherson et al., 2007; Monforte-Royo et al., 2012). Yet in referenced evidence regarding ADs, people did not ask to add 'hasten death' to their documents as a remedy for their suffering. In my study too, no one wrote in their document that they wanted to hasten death. In all ten interviews it was a secret that they revealed, perhaps while 'unburdening' themselves of their secrets to me. Most of the patients did not consider it an option to share this secret with their relatives, nor with their physicians. Most of them felt forced to keep it a secret in order not to involve their relatives in a criminal act. In such circumstances it is not surprising that they considered ending their lives while in full capacity. This was seen as the only way to assure that their ultimate wish not to live, if they became incapacitated, could be respected. From the moment they were incapacitated their lives might not be prolonged, but they knew very well that such a situation could last a very long time, and this was an unbearable thought for most of the participants.

These findings add to previous evidence by highlighting a need that seems so profound as to cause some people to consider breeching the law. The fact

that respectable individuals might feel a need to disregard the law suggests a conflict of values and not mere delinquency. The Israeli law, as well as laws in most countries of the world, absolutely forbids any form of hastened death. Laws are gate-keepers of the social order, and are intended to reflect its moral standards. When we look at the findings of the current study, moral '*justice*' seems to encompass aspects that are broader than both pure resource allocation and looking at 'the public good'. In view of the prevalence of the finding (i.e. the fact that all the patients who participated in my study wished to have the option to shorten life actively under severe circumstances), it may be necessary to find a better balance between the value of the individual's *autonomy* and the value of *justice (*by protecting the interests of society as whole). Reflection of such a new balance in legislation may improve the possibility of preserving social order while keeping the value of autonomy. This may in turn enable people with similar needs to those of the patients in this study to express their needs openly and share them with their significant others and their Health Care Providers.

4.5 Conclusion

This chapter presented the experiences, beliefs, values, and needs that led people with LTC who are approaching death to make advance directives (ADs). It also discovered how these patients' experiences, especially after becoming ill, influenced changes in the content of their ADs over time. Lastly it identified patients' knowledge and understanding of what ADs are, and their expectations and ideas as to how their ADs could potentially help them if they lost capacity, as well as the limitations of ADs to do that.

This first step in the 'relay' of making an AD now needs to be safely transmitted to other players, in order to make the AD a relevant resource for the dying patient. The descriptions of the other players (relatives and physicians) will be held respectively in the following chapters.

CHAPTER 5: PATIENTS AND RELATIVES - THE INFLUENCE OF RELATIONSHIPS

5.1 Introduction

The previous chapter centred on the perspective of individuals who have advance directives (ADs). Yet, although ADs are the creation of an individual (the *patient* in this study) they are put in place to be carried out by others and not by the AD holder. The metaphor of a relay race was used in the previous chapter to highlight the fact that making an AD is only the first step in a sequence. The next steps, i.e. transferring the AD message to relatives and

Figure 8: Potential relatives who may be involved in patients' ADs
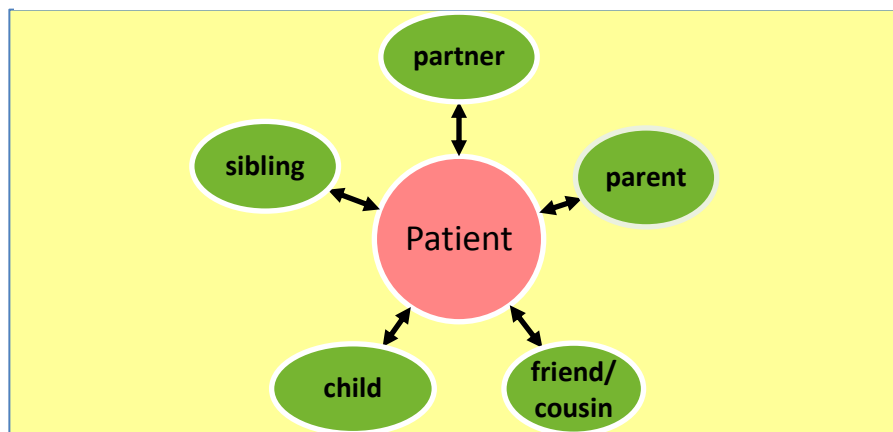
physicians, will be investigated further in this and succeeding chapters, to enable a broader view and a deeper understanding of the meaning of ADs in the lives of people who face end-of-life (EoL) due to a long term condition (LTC). This chapter will start by examining whether, to whom and how ADs are communicated to relatives; what patients expect relatives to do with such documents in relation to end-of-life decisions; and how relatives are affected by these expectations (the term '*relatives',* refers to a diverse range of relatives who may be involved in ADs, as indicated in Figure 8, above). It will then proceed to examine challenges and dilemmas connected to patients' attempts to ensure that their wishes regarding their own EoL will indeed be fulfilled. Lastly, this chapter will discuss the main issues, compared with

existing evidence. In short, this chapter looks at 'patient-relative' dyads which interact around ADs in complex ways.

5.1.1 A few explanatory notes

Before presenting the findings, it is important at this point to remind the reader of some contextual information. First, the distinction between the definitions of an *advance directive*, appointing *a proxy decision maker for end-of-life (EoL) decisions*, and *a witness*, as explained in Box 1, page 12 based on the Israeli 'Dying Patient Act - 2005' (DPA) (The Dying Patient Act, 2005). Second, the patient-participants in this study, who were all LILACH members, had used the pre-made AD forms provided by the LILACH[46] organisation. Many were completely unaware of the existence of a legal AD form (see English version of the legal AD form in Appendix A, page 256). Both patients and relatives tended unknowingly to confuse: *ADs*, *the appointment of a proxy decision maker for EoL,* and *witness,* and used them interchangeably, apparently unaware of either the legal relationship between the three or their legal restrictions. The moment when patients handed their AD documents to their relatives was understood, by patients and relatives alike, as marking the appointment of these relatives as future decision-makers who would advocate according to the patient's wishes (which were expressed in the AD) towards the EoL. Interestingly, the legal document appointing a proxy decision maker was not prepared by any of the participants in my study, even by those who had completed the legal AD document after the DPA enactment, and on the whole this appears to be due to lack of knowledge. It is therefore important to bear in mind while reading this chapter that the findings presented below reflect the meaning and understanding of ADs in the lives of patients and others around them; this does not necessarily follow the law, its boundaries and definitions, or generally accepted norms. One extreme illustration of a misconception that emerged from the interviews was the idea that an AD was some sort of permission for LILACH's representatives to actively stop life-support measures (permission that is not granted to anyone in Israel):

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[46]LILACH- an Israeli organisation to promote living and dying with dignity. LILACH's AD pro-forma differs from the legal AD document, although in recent years it was amended to better fit the demands of the Israeli Dying Patient Act.

'what I actually understood from it [AD document] was that if something happened to him [father] from this list…, …I [can] call them, [i.e.] this organisation [LILACH], someone from this organisation and they come to help me actually… to disconnect him, let's say from a ventilator, such as [i.e. which] physicians are forbidden to do, or all sorts of things like that' [Vicky, daughter, case study 5 (CS5)].

Based on the perception of patients and relatives in my sample, and although the latter were not legally appointed, I would like to emphasise that:

- I refer to the relatives, whom patients viewed as their representatives in the event of loss of capacity, mostly as *decision makers,* even though they were not officially appointed as such.
- When *nomination* is discussed in this chapter, it means the **non-official** choice of *decision makers* by patients, rather than the legal appointment of a proxy decision maker through an official legal document.

I hope that these clarifications will assist in better understanding the complexity of the following findings. I invite the reader to view them as echoes of people's values, emotions and needs, rather than as a reflection of their misinterpretations of legal documents (an issue which will be addressed later in this thesis). The first issue to be looked at in the findings is how the idea of having an AD was shared with relatives.

5.2 Sharing the idea of ADs with relatives – a process or an event?

In the study sample a distinction emerged between spouses and other relatives in terms of how the process of sharing ideas unfolded concerning ADs, EoL wishes and views regarding illness and dying. With spouses, there seemed to be a process of sharing, while with others it appeared more as an event. In order to better follow the subtleties and variations of the findings below, Table 7 (below) describes for each of the interviewed patients: their

spouse's status and attitudes to ADs, as well as revisions regarding the *decision maker*.

Table 7: Spouse's status and attitudes to ADs, and altered decision-makers

Patient	Spouse's status		Decision maker for patient's AD*		Relative's attitude toward ADs			
	alive	with capacity	previous	current	Toward patient's AD		Does the relative hold an AD?	
					spouse	non-spouse	spouse	non-spouse
1	yes	yes	spouse		+	unknown	yes	unknown
2	no	N/A	spouse	children[47]	+	+	no	no
3	---	N/A	cousin		---	+	N/A	no
4	yes	yes	unclear	spouse	mixed feelings	+	no	no
5	yes	no	spouse	children	+	+	yes	no
6	no	N/A	spouse	children	+	+	yes	no
7	yes	no	spouse	child	+	+	yes	no
8	yes	yes	spouse		+	Mixed feelings	yes	no
9 [48]	yes	yes	unknown		-	-	no	no
10 [48]	yes	yes	spouse		+	+	yes	unknown

* Decision maker as perceived by the patients. They were not officially appointed as proxy decision makers.

5.2.1 Sharing ADs with spouses and non-spouses

Nine out of ten patients in my sample were married (of those, two had become widowed) and had children, while one patient (Naomi in CS3) had no nuclear family and her decision maker was a cousin (see Table 7, above). Eight out of nine married patients[48] (all but the patient in CS9) seemed to have had a long, on-going process of sharing ideas with their spouses over the years, during which patients and their spouses had exchanged views on many issues including EoL wishes and ADs (see Table 8, page 137). Such exchanges were often triggered when one of the spouses heard about the

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[47] The terms child/children are used throughout the chapter as a shorter form for adult-child/adult-children

[48] Due to the limited data from patients 9, 10 (explained in the methodology chapter) the findings in this chapter will focus mainly on patients 1-8, adding when relevant the limited data from patients 9, 10.

option of making ADs (in the media or from people around them); when they experienced others around them dying of long-term illness (eight out of ten patients had shared such experiences); or when they heard stories of known Israeli celebrities with LTCs (such as Ariel Sharon[49] and Motta Gur[50]). Hence, between spouses, the option of having ADs often stemmed from repeated and accumulated reactions and conversations about occurring events. In many accounts, discussion appeared to be one means of processing the idea and getting insights into wishes and needs, as Ben (Noa's husband) described it:

> 'It is not that we sat one day [and said:] "let's talk about that" [i.e. ADs]. It developed over the years, the definition "this I don't want", or, "that I don't want". It wasn't clear whether it [AD] had legal stance. It was more [a] declarative [act].../ ...it is something that crystallises [i.e. forms] continuously' [Ben, husband, CS1].

From what the patients and some spouses shared about it, discussing ADs or EoL between couples was easier when both spouses were in general agreement about them. In six of the case studies of married patients in this study (CSs 1,5,6,7,8,10) both the patient and the spouse had made ADs, whereas in the other three cases (CSs 2,4,9) the patient had an AD but their spouse did not. When the latter occurred, it was sometimes more difficult to discuss EoL issues. In CS4 for example, Yarden's husband Koby told me that he was unable to discuss his wife's AD at first, but when her AD document was ready and became a concrete fact he could not ignore her need any longer, and he then tried to cooperate with Yarden and became involved in the process, to the point of using the plural tense ('we') when he described the process to me:

> 'I tried to ignore [the AD] till it was finalised..., ...I chose to ignore till I saw the complete, the paper [i.e. AD document]. She was told that she needed two witnesses.

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[49] Ariel Sharon – A former Israeli prime minister who had a severe stroke, and who has been in a comatose state since 2006. He died 11th January 2014.

[50] Motta Gur – A former Israeli politician and Chief of Staff of the IDF (Israeli Defence Force) who committed suicide by gunshot when his brain cancer became an advanced and incurable illness.

> We decided to include the Rabbi. We told him and we
> signed him [Koby, husband, CS4].

In another example, Adam (CS9) reported that his wife's resistance to discussing his EoL preferences was so significant that he felt quite isolated and could not discuss such issues with her at all. Yet most of the accounts regarding spouses showed a tendency to communicate with them over many years and gradually build mutual understanding around EoL care needs and preferences.

With non-spousal relatives, the sharing and discussion of patients' ADs was often different from the manner in which it occurred between most of the couples in my sample. Patients often approached their non-spousal relatives about their ADs when their mind was already set about their wishes and after completing their AD document, rather than '*developing insights together over the years'* [Ben, husband, CS1] (i.e. often having had a process of conversing about their wishes with their spouse in the past). In addition, as reported by patients and relatives alike, the way in which patients approached their non-spousal relatives with their ADs seemed quite technical and quick; it was more a 'one-time event' of factually telling relatives that they had an AD and handing a copy of the AD document to them, as will be demonstrated later (see also Table 8, page 137).

After looking at the way in which the patients' idea of an AD was shared, the next section will look at how patients engaged relatives to become their future substitute decision makers. The data in the following sections will highlight the fact that such an engagement was not as simple as patients tended to see it, especially with non-spousal relatives.

5.3 Choosing and nominating the decision maker among relatives

In order to demonstrate the first layer of complexity in engaging relatives to be decision makers for EoL issues, this section will focus on who was chosen to represent patient-participants (see Table 8, next page).

Table 8: Patients' attitudes toward relatives in regard to ADs

	Sharing the idea of AD	Nominating a decision maker
Spouses	Long process throughout common life trajectory	Mostly the default nomination; Mostly unspoken and taken for granted by patient and spouse alike
Non-spouses	Mostly a one-time event of handing in the AD document +/- additional comments	Usually a second-line nomination when the spouse is absent, deceased or without capacity

5.3.1 Choosing the spouse

In eight out of nine CSs in which patients were married, whether at the time of data collection or in the past (and now widowed), it appeared that the first choice for decision maker tended to be their spouses. Interestingly, the nomination of the spouse was not directly spoken about in the interviews with patients and relatives alike, and was not explicitly written in the AD documents that I was able to read (Noa's [CS1] and Yarden's [CS4]). The impression that it was 'obvious' to most couples is supported by the example of Debby and her husband Alon (in CS8), which clearly shows that both see the husband as the executor of the patient's wishes:

> 'I speak with my husband [Alon] openly and clearly. I tell
> him exactly what I want, what I feel, what I want him to
> do for me now or later' [Debby, patient, CS8].

> 'I will do what she [Debby] wants' [Alon, husband, CS8].

In this CS, Debby also told me that she had informed her siblings of her AD in case for some reason her husband was not there when something happened to her, again, indirectly relating to her husband as the 'obvious' decision maker. Nominating the spouse seemed obvious to most of the patients as well as to their spouses, but I could only have the voices of two spouses (Ben in CS1 and Alon in CS8) because at the time of the interview with patients[51], only these two were the nominated decision makers[52]. Apart from these two

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[51] The nomination of Koby, the husband in CS4, occurred after the interview with the patient and this is discussed in Chapter 3.

[52] In CSs 2,5,6,7, I could not interview the spouses because two were deceased and two others lost capacity before the data collection; in CS10 I was not granted permission to interview the spouse.

cases (CSs 1,8), accounts from patients and other relatives whom I interviewed in the other cases indicated that it was taken for granted that before they lost capacity or died, spouses were the expected decision makers and vice versa (i.e. most spouses apparently expected the patients to be their substitute decision makers if they lost capacity before the patient). Further evidence that the role of the spouse as decision maker was an obvious choice was provided from two other examples in the sample: The wives of Omri (CS5) and of Dov (CS7) lost capacity and the husbands were their official decision makers (i.e. legal guardians) for all health decisions (including future EoL decisions).

Two husbands, Ben (CS1) and Alon (CS8) suggested that a key reason for being nominated in the role as decision maker (should their wives lose capacity) was that they shared similar views with their wives about life, dying and death:

> 'From the beginning we were in complete agreement [with each other] about this, unrelated to her [Noa's] illness. The idea looked positive to us…, …[for] 52.5 years there is some kind of, ahh, let's call it joined walk. We have many common areas of interest, not only on this issue' [Ben, husband, CS1].

> 'First of all it was a shared idea of both of us. We thought about it together, we spoke about it; [then] went [on] and **performed** it'. [Alon, husband, CS8]

But this view (that in order to become a decision maker the person needs to hold similar views) was not unanimous within the data. In two examples, husbands who did not share the same views as their wives about the need for an AD, and who did not make an AD, regarded themselves as their wives' nominees: In CS2, Meira's husband was immediately believed (according to one of the daughters' reports) to be Meira's decision maker, and kept the role as long as he was alive; whereas in CS4 it took Koby a while until he viewed himself as an optional decision maker for his wife (this will be explained in greater detail in Vignette 2, page 147). CS9 is the only example in the sample where the patient (Adam) felt unable to nominate his wife as his future

decision maker, because she was not ready to speak about Adam's EoL at all, let alone take the role upon her.

5.3.2 Choosing non-spousal relatives

Choosing non-spousal relatives as decision makers occurred in five CSs. In four of those cases (CSs 2,5,6,7) it was reported that (adult) children were nominated secondary to the nomination of spouses, and this had happened only after the patient's spouse died or lost capacity. In a fifth case (CS3) the patient did not have a nuclear family, and when she became ill she chose two decision makers: her closest relative (a cousin) to whom she was emotionally attached, and another friend.

5.3.2.1 Nominating children

Regarding the nomination of children, in three cases patients related to all their children as being equally responsible[53] for making decisions on the patient's behalf if they lost capacity:

> 'The [three] children know. I have a stand and they listen…, …And they [adult children] discuss among themselves. Facing my children won't be a problem for me because whether they like it or not they will [all] accept what I say' [Shelly, patient, CS6].

In two other cases there seemed to be reasons for nominating one child over others, as the example of a patient (Meira, CS2), and another example of a relative (Yoni, CS7) can show:

> 'I decided that the one who will be responsible is my youngest daughter…, …she can be tough when it's needed' [Meira, patient, CS2].

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[53] According to the DPA it is possible to appoint two proxy-decision-makers (but not more) so that the second may substitute for the first, in case of absence or refusal (The Dying Patient Act, 2005: 80).

'He [father] thinks that I will… be more balanced, less emotional, and that I will spare him unnecessary suffering' [Yoni, son, CS7].

Vicky (daughter in CS5) viewed herself as the most suitable nominee because she perceived herself to be more practical than her sister. Her father Omri, however, did not differentiate between his daughters and expected both of them to act as his representatives in due time. Noticeably, the accounts of patients and children who explained the nomination of one child over the others usually involved attributing specific qualities to the nominees such as toughness, assertiveness, being practical and being less sentimental.

To summarise the findings from all the CSs regarding choosing a decision maker, it appeared that patients had a hierarchy of priorities in their nomination: The preferred option for a future decision maker was for the spouse, who was usually perceived as the 'natural' or obvious nominee; when this was not possible, the next choice was one or more of the children, and when neither were possible, the patient chose people who were emotionally close to them.

After describing the choices of whom to nominate (see Table 8, page 137), the next section will relate to the communication patterns between patient-participants and their relatives regarding ADs.

5.4 Communication about ADs between patients and non-spousal relatives

As mentioned earlier, the data indicates that the process regarding ADs was different when it involved spouses and when it involved non-spousal relatives. This section will concentrate on the communication with non-spousal relatives because on the whole it appeared more complex and problematic. Children did not seem surprised by the fact that ADs were made, because it had emerged from statements disclosed by the patients from time to time, as some children shared:

'Before that [i.e. before making the AD] it was always [spoken], yes, ever since I remember…, [father said:] "If something happens to me [and] that I won't be able [like when] I couldn't talk, I couldn't [do] this, I couldn't [do] that, this is the most scary, that's the most scary thing". Dying never scared him. Dying is the easiest' [Vicky, daughter, CS5].

'It was clear that she has a view on this matter and she doesn't want to prolong life in [just] any condition…, …I am sure that there will be something general that will be known to all [of us], if you speak to other members of the family. The fundamental existence of such a request [Yagil, son, CS4].

However, although children were not surprised by the fact that their parents had made an AD, they faced difficulties which were related at least partially to communication barriers.

5.4.1 Communication barriers regarding ADs

'Passing the baton' from the patient to the non-spousal relatives was often reported to happen by simply handing the AD document to them, and with little (if any) conversation regarding its content. However, some specific problems and communication barriers are important to underline.

5.4.1.1 Not sharing the making of ADs with relatives

One possible issue of communication between patients and relatives was that most of the patients did not think it was important to include their non-spousal relatives in the process of making ADs, while some of the relatives expected such sharing. Meira (patient in CS2), like other patients, did not want to include her daughters in the making of the document:

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'I didn't include them [daughters] in the writing process because I didn't see a need for this' [Meira, patient, CS2].

Yoni (son in CS7), like some other children, seemed to expect to be included in the process:

'It isn't that he came to discuss with me first whether to do it or not, and if I could take part.' [Yoni, son, CS7].

5.4.1.2 Patients overlook their relatives' need to communicate

Most patients tended to describe the communication with their non-spousal relatives regarding their ADs as a straightforward act of handing the document to them. Some, but not all patients reported adding a short explanation or statement of their wishes. Some patients took it for granted that their relatives knew them well enough to know what they meant or wished, thus they did not see a need to discuss their wishes with their non-spousal relatives. The next examples from some patients illustrate this claim:

'We went over the [AD] form and I explained to him [Yoni] what I hand over to him. I didn't expand the words [i.e. explain further]' [Dov, patient, CS7].

'They each have a copy... and it is written there what I want..., ...When I joined LILACH I told them: "For your knowledge"..., ...They know me [Meira, patient, CS2].

'I explained to them what a living will is. I said: "you should do one as well" ..., ...I told them that I don't wish to prolong life. I don't want to be fed, nor cared for, nor ventilated, nor nothing, and it's all written here and that's it' [Omri, patient, CS5].

5.4.1.3 Relatives' feelings of being unprepared

Most of the children reported that their first sight or knowledge of the document was quite abrupt:

> 'Then one evening my father announced to me that he filled in such a form [i.e. AD] and [that] I was appointed to be responsible..., a year, 2, 3 [years ago]' [Yoni, son, CS7].

> 'I didn't know that he [Omri, father] had contacted this association [i.e. LILACH]. He came one day with this form [i.e. AD].../ ...I think a few years [ago], 3, 4 I don't remember exactly [Vicky, daughter, CS5].

> 'I remember that she [Meira, mother] said that she wrote [an AD]..., ...and that's it, she gave us [a copy]. She said that she went to a lawyer, or to whoever she needed to go to, and that she prepared copies for us' [Lea, daughter, CS2].

The (adult) children's reports seemed to reflect that this encounter caught them unprepared (though they were not surprised) and that in most cases there was no further dialogue about it. In contrast to the one-dimensional accounts of the patients, the descriptions given by most of the children about the way in which ADs were communicated to them highlighted how much more complex the whole process of being given this responsibility is. Some complexity is reflected in Yoni's words below, and will unfold further later in the chapter:

> 'He didn't even ask me if I was willing.../ ...I guess I would have taken the time to think before I would have told him "yes". But he didn't ask me, or [rather], on the spot, he told me that he nominated me and if I was OK with that, and if I was willing to look at it [AD document].' [Yoni, son, CS7].

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Most non-spousal relatives thought that they did not know exactly what the patient wanted or meant. Yagil (CS4), for example, said that his mother talked about EoL wishes from time to time, yet such vague conversations did not reassure him enough, because he had not seen anything in writing and did not know what an AD form looked like or what it contained:

'She said once or twice, and didn't specify, that if it came to a certain, unclear, situation she doesn't want [to prolong her life].../ ...[she said that] there are situations in which she wouldn't want to keep on living, but [it was] not in a written form. [it was] orally in an undetailed manner.../ ...Till this day I haven't seen the [AD] document, I don't know what it looks like, what's written in it, what she chose to define as a situation in which she doesn't want resuscitation'[Yagil, son, CS4].

5.4.1.4 Having different perspectives on communication

Parents and children seemed to view communication in different ways. Yagil, for example, did not recall any real conversations regarding his mother's (Yarden) AD, but meagre sporadic statements:

'She mentioned it from time to time but there weren't conversations on this' [Yagil, son, CS4].

Surprisingly, Yagil's experience was quite different from the impression that Yarden (the patient and Yagil's mother) reported having gained from conversations with him and other family members:

'I spoke with them [family] and didn't find any objection. No objection. Absolutely. With my husband and with my children.../ ...The children asked more questions.../ ...My children asked very much, about what it [AD] includes, what does it mean, what is the meaning of this to me, especially my elders [i.e. elder children]'. [Yarden, patient, CS4].

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Communication with non-spousal relatives about EoL wishes and/or ADs was most often reported by relatives as overly concise and was experienced by many relatives as too simplistic; it was sometimes so vague and informal as to pass unnoticed. Apparently, not many questions were asked at the occasion of handing over the copy of an AD:

> 'She explained what is [an] AD; that she doesn't want to be 'messed with' [i.e. annoyed with medical interventions] too much..., ...I don't remember if we had questions. Could be that we didn't... It [mom's view] was quite clear. [I] simply don't remember to be honest' [Lea, daughter, CS2].

One reason for not asking too much seemed to be related to the difficulty relatives have in talking about sensitive issues with patients, as will now be illustrated.

5.4.1.5 Having difficulty discussing death and dying

Discussing their parents' AD was difficult for children in the sample, although some were more explicit than others about it. Yagil for example said that one reason for such difficulty may be that discussing EoL wishes with patients evokes emotional distress for relatives:

> 'I am not that happy to talk about it. I don't believe in the evil eye or something, but it is nevertheless giving a name to something that frightens you. It is always deterring. It's the kind of thing that most people would rather not talk about unless there's no choice' [Yagil, son, CS4].

Children's strategies for coping with this difficulty varied. Lea (CS2) for example told me that whenever her mother said things that seemed relevant to EoL decisions, she took notes and kept them where she kept the AD copy, hoping that these statements would help her in the future to make decisions

on her mother's behalf, but apparently she did not ask her mother for clarifications:

> 'I also write there, in her famous file, the secret one [a file Lea named "mother's documents" and where ADs are kept], I write all sorts of things that she says. I hope that we will know what to do'. [Lea, daughter, CS2]

Yagil and Vicky described another strategy for coping with discomfort by avoiding it as much as possible:

> 'And now, not long ago he [Omri] told me: "it [AD form] was renewed. He gave me this [the copy]..., ...he told me that there are new criteria, new things. I didn't even read it. I put it in the drawer to keep it.' [Vicky, daughter, CS5]

> 'It is a kind of 'middle arrangement' to know [that] it [ADs] exists and deal with it only when we will have to' [Yagil, son, CS4].

5.4.1.6 'An illusion of consensus'

Another potential difficulty of communication around ADs was that patients probably spent a lot of time thinking about their EoL wishes while alone because it was an important issue for them, so much so that they ended up feeling as if they had talked about it with others much more than they actually had:

> 'They [AD makers] have an illusion of consensus..., ...good chances that here as well it will be like this..., ...She [Yarden] didn't get into details, and neither did we because we hoped very much that it won't come to this [the moment to need the AD]..., ...she is dealing with this much more [than us]..., ...check with my mother, she thinks that I know more than what I really know.../ ...she

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is much more preoccupied with this than us, and yes, she is in a constant anxiety, I know this for sure..., ...My mother went through a process and it was probably intimidating to her as well [at first] to deal with this. But when you are ill there is this point when you understand that you have to deal with that, or you make a choice [to ignore], that will have very high costs, so rather you face it and not "leave it in a drawer" [=try to avoid it]' [Yagil, son].

5.4.2 Possible consequences of these communication barriers

Gaps between the needs of relatives (especially non-spouses) and those of patients with ADs appeared to affect not only the communication between them but also possibly the outcomes and experiences of both patients and relatives. The specific example of Naomi (patient) and Carol (cousin) in CS3 (see synopsis on page 71), is outlined in greater detail (Vignette 2, below) to illustrate this claim usefully. Here, circumstances arose where Carol might potentially have had to act on the AD, yet Naomi lived to 'tell the tale' and comment on Carol's actions at that time.

Vignette 2: The example of the communication between Naomi and Carol [CS3]

Both Naomi and her cousin Carol shared a family story about their grandmother who repeatedly declared that she refused any active medical treatments to prolong her life. When the grandmother became critically ill, her daughters (i.e. Carol's and Naomi's mothers) kept her at home and stayed with her until she died, days later. Their decision was supported by the grandmother's GP. From the separate sharing of Naomi and Carol I could detect that this was viewed by both (Naomi and Carol) as a dignified death, and as a positive example of how life with a long term illness should optimally end.

Possibly based on their shared family history, stories and views, Naomi assumed that her wishes and ADs were clear to Carol. Both Naomi and Carol reported little if any discussion around Naomi's wishes when she nominated Carol as her decision maker and handed her a copy of the AD. Yet, in the 'moment of truth' when a respiratory crisis occurred (see synopsis), Naomi was brought to hospital urgently and was mechanically ventilated, apparently after much pressure from the medical staff on both Naomi and Carol. Naomi survived this intervention but ultimately this gave rise to

a conflict between the two (Naomi and Carol) that left Carol confused about her role as decision maker. Naomi on the other hand reported being left frustrated at being mechanically ventilated against her wish. Looking back in retrospect, Carol said that she had in her mind the idea that ADs are for a gradual decline, as in cancer and renal failure, and that she was not at all prepared for an acute respiratory crisis:

> 'I never thought this would be the situation I will be in.../ ...I... when I signed it [AD document] I saw [in my mind] my friend [who had cancer].../ ...'If you know that there is no way back... I go to the physicians and say: "Let her [i.e. allow her to die in peace]...". There is no question at all! I have no doubts! But when my cousin is suffocating and we need to ventilate her and then we will see, sorry this is not the same situation.../ ...I didn't think that this will be the situation [that] I will encounter... although I saw her father... [lying] in the [hospital's] corridor and he had this desperate look in his eyes'. [Carol, cousin, CS2].

Naomi alternatively reflected on her misconception that her thoughts were clear and obvious to Carol, and shared her insight that she should have been more explicit about her wishes:

> 'We cannot assume what's in the other's mind... Thoughts, feelings, emotions, wishes. If we don't talk about it no one can know what [we mean]. If you want something, say it. How can you expect?.../ ...and this is what happened here. I mean... I made her sign, and another good friend of mine, on the AD [document]. Now, it was clear to me, especially in light of my [health] condition that this is a matter of life or death. I had no doubt. She [Carol] wasn't aware, or didn't want to know. Doesn't matter.../ ... My cousin wasn't... wasn't ready. I know. Look, it is one thing when you know theoretically that there is something like this [AD]... and different [thing] to say OK now you end all this [i.e. life]'. [Naomi, patient, CS2].

Apparently in this CS, Carol had regarded the respiratory crisis as an isolated, acute and reversible event, or perhaps she was not fully aware of the severe stage of Naomi's illness. Naomi, in contrast, seemed totally aware of her gradual deterioration, of the growing odds of having the next crisis, and of the growing likelihood she would not be able to overcome the next crisis or would not be released from the next mechanical ventilation. Naomi was aware that her illness was in its last stage, and described her condition as 'end-stage COPD'.

I chose the above example to emphasise that although in some cases participants felt comfortable with someone who shared the same or similar views (as presented earlier), shared views about EoL are clearly not enough and communication is critical. Barriers to communication can (and did in the above example) severely affect the ability to make decisions at critical junctures, and therefore effective communication is pivotal to nominating a proxy decision maker for EoL care.

5.5 The decision maker role

The previous sections portrayed who was nominated by patients with ADs, how patients conveyed their ADs to their relatives, and the barriers to communication and their possible outcomes. This section describes how the transmission of responsibility for EoL decisions (which was typically symbolized by handing the AD forms to relatives) was perceived by both patients and non-spousal relatives, with greater emphasis on the relatives.

5.5.1 Adult children's reactions to being in the decision-making role

The following examples of 'patient-child' dyads (from CSs 2,5) illuminate an aspect of the gap between patients' descriptions and those of their nominated relatives. Two pairs of accounts are presented in order to stress the contrast between patients' reports of the seemingly straightforward reaction of their relatives, and their children's reports.

The first example is Meira's account compared with her daughter Lea's perspective (CS2), which shows that behind the apparent respect and acceptance there is a child's worry over taking responsibility and making the 'wrong' decisions:

'They [daughters] accept, eh, all my decisions. They know that [i.e what I want]... that's it [...2...] and they respect... my wish. And because I... still am... not entirely senile... they... accept what I say' [Meira, patient, CS2].

'And it's a bit frightening, between you and me, a bit frightening. Of course it's frightening. To decide for mother? Of course it's frightening..., ...The frightening [the fear]... the difficult, [is] that maybe I will decide something wrong [yes]?... That I will make a mistake. Well, I presume that eventually we will do it together, my sister and I. Yes, I sure hope so..., ...Maybe what scares me is that suddenly I will have to initiate... to make a decision. Look, it is frightening for me, I can't help it. It's frightening.../ ...[sighing:] I hope we won't get to it' [Lea, daughter, CS2].

Next is a similar comparison between the accounts of Omri and his daughter Vicky (CS5), which shows that a passive reaction and neutral facial expression may hide difficulties in coping with the patient's requests:

'They [daughters] are obedient they don't argue. Really! Now that you ask a question, I am thinking [about] what their facial expression was. [it was like:] "Father wants it so [i.e. this way], then so be it"' [Omri, patient, CS5].

'There were already situations when we thought that it's the end, operations, hospitals. It [AD form] wakes the memories of those times... yes [it's hard], that's why I put the [AD] document in the drawer. But this is my personality. I am the opposite of him [father]. I cannot worry for the long term about such difficult matters..., ...I neutralise any worry... put away, repress. Maybe it is an outward appearance, maybe it is half [partial].../ ...

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> Look, if let's say, if it is a cerebral event [i.e. CVA], you
> [i.e. one] always have the hope that it will be absorbed,
> pass, recovered, these sorts of things, this is the
> difficulty..., ...perhaps [it is] not yet the end..., ...I will
> have more difficulty to decide when is the [right]
> moment..., ...I hope we won't get to this moment, what can
> I tell you [laughed, embarrassed]' [Vicky, daughter, CS5].

It can be noticed that the patients in the above dyads emphasised obedience or compliance with their requests, while children in the dyads were preoccupied with their own fears of making 'wrong' judgements and/or 'wrong' decisions regarding their parents.

Different types of reactions of children to their nomination as decision makers were noticeable, and I identified these as: distress, reassured acceptance, and refusal (see Table 9, below). We will now look at the three types of response in turn.

Table 9: Adult children's degree of obligation to their nomination as future decision makers

Acceptance		Refusal
Distress	Calm	
Lea (CS2)	Dekel (CS6)	Yagil (CS4)
Vicky (CS5)		
Yoni (CS7)		

5.5.1.1 Adult children's distress at their nomination as decision makers:

Most children who were interviewed (CSs 2,4,5,7) expressed distress at their nomination. One description is particularly illustrative of the emotional burden that children experienced:

> 'At first I didn't think. I told him [father] "OK"..., ...then
> you start to think about the meaning.../ ...Ever since it
> has penetrated [to me] I am walking around with a stone
> on my heart, because it worries me very much.../ ...one of

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the things that are heavy on me, is the realistic possibility that I will have to decide, whether they [parents] will be connected to [medical] devices or not. [It] is very bothering…/ …I am bothered from pressure of the family…/ …I am mostly frightened if I am [will be] doing the right thing…/ …to be honest, I am afraid, a mortal fear from the moment that I will have to decide [for the parents]…/ This will be, I think, the most difficult decision that I will have to make in my entire life' [Yoni, son].

5.5.1.2 Accepting the role

Contrary to the last three examples above (of Lea, Vicky and Yoni's reactions), Dekel (Shelly's son in CS6) seemed to accept the decision-maker role without fear or question. He viewed it as quite a trivial nomination (taking the place of his father who was now dead). He reported feeling quite confident with his mother's wishes regarding EoL; he wanted mainly to ensure the best outcomes for his mother and he was preoccupied with the best ways of fulfilling these outcomes:

'[For] anything [i.e. any medical procedure], before [it] will be connected [to her] I will ask if it can be disconnected. It's a frightening critical junction, that if you miss the right second, afterward you need high court just to allow your mother to die…/ …I sit, now I know where I am watching. I sit there and watch like a faithful dog and nobody passes without me knowing what it is. And it's a rule that is general enough so I can remember [i.e. internalise] it easily. I don't have to remember any specific tube. I just need to remember to check everything before it gets in [i.e. inserted to Shelly's body]' [Dekel, son].

5.5.1.3 Refusing the role

Unlike four children in this sample (CS 2,5,6,7) who felt obligated to their nomination as decision makers (whether they were comfortable with it or not), in CS4 things appeared differently. Yagil (son of Yarden, CS4) did not want to become the decision maker and indeed refused to take on the role. I will use this example (see Vignette 3 below) as an exception that may be useful through comparison to clarify the dynamics in the other CSs.

Vignette 3: The exceptional example of role-refusal

In CS4, the patient (Yarden) perceived that her husband was uncomfortable with discussing her EoL preferences and AD, and therefore she did not want to force him to take on the role of decision maker:

> 'My husband, it frightened him a bit, all this issue. At first, he
> sort of [asked:] "what do you need it [AD] for?"'. [Yarden,
> patient, CS4]

Yarden said that she wanted to nominate a decision maker who would feel comfortable with making decisions on her behalf if she lost capacity. She thought that if the nominee had similar views, this would make it easier to take decisions on her behalf when the need arose. Yarden trusted her son to be suitable because both she and her son shared similar views regarding not prolonging life when capacity is lost during long term illness. She described how she decided to nominate her son without discussing it with him at all, and apparently just took his agreement for granted:

> 'I haven't discussed with him [son] about this, but I told him
> that I will choose him as the person who will execute my
> wishes. It will be easier for him than for my husband…, …I
> don't know if my husband will collaborate that much [with my
> wishes] but definitely my son [Yagil], my daughter [name] and
> my friend [name] [will collaborate]' [Yarden, patient].

Yagil (Yarden's son) confirmed that Yarden's wishes to nominate him as her future decision maker were not discussed with him previously, and he expressed disagreement with her decision to nominate him over his father:

> 'The first time it [i.e. the nomination as decision maker] was
> discussed with me was actually after you [i.e. the researcher
> TM] addressed my mother. She did not share this with me
> previously. I am not sure whether she decided previously
> exactly who she wanted [to be the decision maker]…/ …I am
> not sure that she thought about this enough. Her choice of me

> was not based on enough thought, definitely not on consultation, with me, or with my father I think, and this, I think, was quite an unreasonable decision of hers' [Yagil, son].

Koby (Yarden's husband) viewed himself as the 'natural' decision maker for Yarden in the future, despite their differing views on the matter. After Yarden changed her choice, and nominated her husband Koby instead of her son Yagil, Koby said:

> 'He [Yagil] was very frightened, to be honest, and rightly so! It was completely impractical to go to him. Then she [Yarden] asked me. Naturally, she had to turn to me and not to him'. [Koby, husband]

Yagil viewed it improper to put him in a potential situation where he would have authority to impose something on his father, probably because it reversed their hierarchical father-son relationship:

> 'Will I have the power to force my father to do something [that] he doesn't want to do? This doesn't seem right to me. It seems better that it [AD] will be something that we will all share the knowledge about, and if there is no extreme reason why not, then it's more proper that the husband, my father, will do it [make decisions] rather than I'. [Yagil, son]

In the above example, it is noticeable that despite Yarden's report of choosing a decision maker based on selecting someone who shared her views, the accounts of both her son (Yagil) and her husband (Koby) did not connect the nomination with the decision maker's views at all. Both of them strongly maintained that a spouse is the first priority as a decision maker and that this priority must be respected regardless of views, unless there are good enough reasons not to allocate one's spouse to this role. I suggest that the issue of role refusal was raised particularly in this CS because this was the only case in which an attempt was made to nominate a child while the patient's spouse was alive and competent, and this created a different scenario from the ones I presented earlier.

As one can notice from this section, the children added their criticism of the process, and indicated that the experience was mostly difficult and their needs were sometimes overlooked. Most children expressed a burden that was put on them when their parent nominated them as future decision makers

and deposited the AD document in their hands for them to keep as a reminder of their role. A similar burden was expressed by Naomi's cousin Carol (CS3, Vignette 2, on p. 147).

5.6 Dilemmas

Along the lines of the multiple interviews two dilemmas emerged in which the interests of patients and relatives seemed to collide: (1) whether becoming a decision maker was a "real" choice; and (2) whether having shared values on dying and death was a guarantee that they would make good EoL decisions and be likely to follow a patient's wishes. The first dilemma will be further elaborated on in the discussion, and now let us look at possible contradictions between patients and relatives.

5.6.1 Are shared values sufficient to make EoL decisions?

There were indications in the findings that the existence of shared values between the AD holder and his/her nominated decision-makers does not necessarily lead to the right choice of decision-maker, because other elements could influence the potential decision-makers.

5.6.1.1 Different interpretations of reality

Perspectives and evaluations provided by some relatives as to when the patient's suffering is too substantial to carry on living were quite different to those of patients in the same CSs. In CS3 for example, after experiencing Naomi's respiratory crisis, Carol and Naomi differed in their interpretations of the respiratory crisis. Carol viewed it as an acute event, while Naomi viewed the acute event as embedded in a trajectory of considerable deterioration and suffering. Naomi disclosed the difficulty of fearing the next crisis and the lack of any control over it, which apparently contributed to her existential suffering as could be seen in an earlier chapter from her words: '*What do you [i.e. others] know about what I am going through [from] the moment I open my eyes in the morning and till I am going to sleep?...*' [Naomi, patient, CS3, see complete quote in Chapter 4 page 88].

Another example of different interpretations of the patient's situation was noticeable in the case of Meira and her daughter Lea (CS2):

> 'I don't feel a human being at all…, …today I am only an addition to a dialysis machine […3…] that's all' [Meira, patient, CS2].

> 'I wish her to live as much as she deserves, as much as there is… that she remains a human being… but not to be 'SHEVER KLI'[54]… Look, in her view she is definitely 'SHEVER KLI', but in my opinion she hasn't reached that. 'SHEVER KLI' is… what grandma was…, …she was totally dependent…, …['SHEVER KLI' is] when she needs someone to get her on her feet, wash her, [and] wipe her behind' [Lea, daughter, CS2].

5.6.1.2 Contradictory interests towards EoL

Some examples exposed that even when participants shared common values throughout their life trajectories, they seemed to face opposing 'interests' (i.e. emotional needs) when the illness progressed and the patient was dying. In these CSs, relatives supported the idea that at the end of a long-term incurable illness there is no need to prolong life. Yet, when the patient started to talk about their worries about the future and about being tired of their disability, partners reported difficulty in coping. Such was the example of Noa (CS1), who reported existential suffering (see the details in Vignette 4, page 172), and Ben who reported avoiding and not allowing these issues to be discussed because he could not face the thought that Noa would die:

> 'She [Noa] raises all sorts of questions from time to time. I repress…, …[She is preoccupied with] deterioration, that there will be deterioration. The situation today, we can't say it is good, but is

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[54] SHEVER KLI - literally: broken vessel. Used in the sense of being weak, frail, exhausted, the shadow of oneself.

controllable…, …Thoughts about "ending the career"

[jargon for 'dying'] I don't accept [long silence]' [Ben,

husband, CS1 when Noa was alive].

The potential for an earlier separation as a result of the patient dying (than might be achievable with maximum medical intervention) seemed quite difficult for some of the relatives (Ben, CS1; Koby, CS4; Alon, CS8). The findings suggest that nominating relatives in order not to prolong the life of their dear ones (the patients) presented a conflict of values for relatives: They wanted their patient-relative to live longer, yet they also wanted to respect these patients' wishes not to prolong life and not to keep on suffering. This evoked anguish from both the forthcoming death (and permanent separation) and from having to make difficult decisions. This may clarify the different perspectives and evaluations given by relatives from those given by patients as to when life becomes unworthy of living, which recurred in some of the CSs, (such as in the example of Meira and her daughter Lea's contradictory interpretations, on the previous page).

The findings presented in this chapter looked at processes, problems and dilemmas related to the 'patient-relative' dyads. Table 10 below highlights the main issues that emerged from the findings related to this dyad.

Table 10: The main issues emerging in this chapter's findings

Processes	Problems	Dilemmas regarding AD

• Sharing the idea of ADs with spouses and non-spouses
• Hierarchy of nomination among relatives
   – spouses
   – non-spouses (children → other)
	• Communication barriers with non-spousal relatives regarding ADs
	• Poor outcomes due to limited communication (Vignette 2, page 147)
		• The decision-maker role - choice or obligation?
		• Clash of interests when the patient is dying.

The current findings on the 'patient-relative' dyad regarding ADs will now be compared and contrasted with previous evidence. Special weight will be given to those studies that looked at patients who actually experienced life in the last stages of dying from a long term condition, and at their relatives.

5.7 Discussion

The issues related to this chapter which will now be discussed are: The nomination of a decision-maker for EoL care; communication barriers regarding ADs and EoL care; the relevance of similar views regarding EoL care shared by the patient and the nominated relative; and the dilemmas regarding the decision-maker role. Some issues will be addressed in greater detail than others.

5.7.1 Which relatives are included as decision makers?

In this chapter, evidence suggested that there is a hierarchy in nominating relatives as EoL decision-makers. It appeared that patients preferred spouses to be their future decision-makers in case of incompetence. When this was not possible, the next best choice was children, and when both were impossible, the patient chose someone who was emotionally close. In some cases of nominating children there seemed sometimes to be reasons for preferring one child over others. There was only one case in which a more distant relative (a cousin) was chosen although, emotionally, it was a very close relationship. In all the discovered studies looking at patients and relatives, the affiliation was listed: spouses and children; siblings; parents (of ill children); secondary family relationships (nephews, grandchildren, etc.); 'in-laws' (affiliations through marriage); friends and/or staff (in long term residences) (Barrio-Cantalejo et al., 2009; Bernal, Marco, Parkins et al., 2007; Caron, 2005; Engelberg, Patrick and Curtis, 2005; Hines, Glover, Babrow et al., 2001; Meeker, 2004). Yet I did not find any reference to priority or hierarchy in choosing one relative over another as is suggested in my analysis, but only reference to quantities. In the studies that provided quantitative data, the proportion of spouses that were nominated as decision-makers was always the greatest (Nishimura et al., 2007; Sloan, 1990; Sulmasy et al., 1998). I did not find any mention of reasons why patients chose a specific relative to be their decision maker. I have not found support in other studies for the finding (which appeared in several cases here) that parents tended to nominate children who were perceived by them as assertive and as emotionally tougher than their siblings. The fact that in three examples in the current study, after the spouse became incapable of being a

decision maker, the nominees were children (rather than siblings, or friends) raises questions about whether it is incidental or whether perhaps children are viewed as the preferred second-line nominees after spouses. The study by Nishimura et al. (2007) suggests that children are indeed viewed as the next priority after spouses: When spouses were an option they counted for 41% of the surrogate decision makers and children for only 16.6%, whereas in cases that spouses could not take the role (if they were deceased or incapacitated) children were the predominant choice of 41% of the screened AD documents (Nishimura et al., 2007). The numbers of each occurrence in my study are too small to draw any conclusion. In view of the hints that exist in other data, perhaps 'hierarchy of nomination of decision makers' can be an issue for further exploration in future research.

5.7.2 Communication between patients and relatives over EoL issues

Patients' communication patterns regarding ADs appeared different with spousal and non-spousal relatives in the present study. In most of the CSs where non-spouses were the nominated future decision makers, there was an impression of a one-off handover of the AD copy, rather than patients sharing with their relative the views and preferences which appeared in the AD documents (as was most common with spouses).

The topic of the different communication styles with spouses from those with non-spouses has not been identified within other studies for comparison. However, the importance of open communication between patients and their surrogate decision-makers in general has been emphasised in different ways in many existing studies (Barrio-Cantalejo et al., 2009; Caron, 2005; Hines et al., 2001; Meeker and Jezewski, 2004). For example, in Meeker and Jezewski (2004), relatives stressed the need to generally know the person and patients' wishes, through open and repeated communication. Relatives suggested asking patients direct questions regarding their wishes and discussing with them: 'worst case scenarios' (such as the need to be mechanically ventilated); the patient's preferred place to die; and when the patient wanted treatment to be stopped (Hines et al., 2001; Meeker and Jezewski, 2004). A secondary analysis of the findings regarding relatives of cancer patients who

acted as surrogate decision makers shows that the first and most frequent recommendation of such relatives was to discuss EoL issues as early as possible, before anything happened (Meeker, 2004). Thorough discussions that could ensure that the patient and the relative perceived the patient's preferences in a similar way were viewed as promoting the ability of relatives to act as decision-makers on behalf of the patient (Engelberg et al., 2005) whereas lack of discussion seemed disadvantageous to relatives (Caron, 2005). In a study which looked at the experiences of relative-caregivers and decision-makers of patients with late stage Alzheimer's disease, relatives reported not knowing what the decision-making role entailed, and expected to be guided by health care teams. It was not mentioned whether or not patients had AD documents to help those relatives, yet some relatives reported feeling incapable of making decisions, to the point of delegating the role to medical staff altogether (Caron, 2005). I find it disturbing that in my study, which looked at patients with capacity who had expressed wishes in writing and in advance, non-spousal relatives expressed similar difficulties to those reported by relatives of people with Alzheimer's disease who lost capacity. It is worrying because the aim of preparing an AD is specifically to prevent this difficulty by expressing wishes in advance. In my findings, 'worst case scenarios' and specific issues regarding EoL were rarely discussed, and many relatives were not sure what they were expected to do, which suggests that perhaps an AD document in itself does not provide enough guidance for EoL decisions.

Apparently, the onset of a life-threatening illness, relapse and hospitalisation may and should serve as triggers for conversations between patients and surrogates about ADs and EoL wishes (Hines et al., 2001). Such repeated communication appeared more with spousal decision-makers and seemed to be generally missing between patients and non-spousal relatives in my study. The relatives' ambiguity that emerged in my findings, from their need to know their patient's preferences and at the same time protect themselves from the stress of such conversations, may have been a factor hindering deeper conversations. From the patients' angle, it seems erroneous that patients put their trust in their relatives to make decisions on their behalf but tend to speak overly laconically about their values and EoL wishes, taking it for granted that their relatives are familiar with them.

5.7.3 The decision-maker role

There is some previous evidence to support my findings that patients tend to arrive at decisions about who will take on the role of the decision-maker without considering relatives' perceived ability to make decisions, underestimating the information that relatives need in order to make decisions on behalf of these patients (Hines et al., 2001). In most of the examples of a non-spousal decision-maker, relatives expressed worries about being in the position to decide for the patient, and feared making the 'wrong' decisions. They also described feelings of concern and emotional distress related to talking and thinking about, and later witnessing, the future decline of their patient-relative. In most circumstances, when children were nominated as decision makers, they seemed to keep their worries and distress from their patient-relative. Similar to my findings, the decision-maker role appears in other studies as difficult but at the same time 'natural' for relatives (to take on this role) (Caron, 2005; Meeker, 2004). Studies found that relatives perceive their role as being gate-keepers to protect patients' quality of life until they die, and to respond to the needs expressed by patients. Relatives feel actively present at the side of the patient, and try to adapt to the patient's changing condition (Meeker, 2004). Sometimes relatives view themselves as information agents from the outside world to the patient and vice versa (Meeker, 2004). These aspects were supported only once in my data, in the case of Dekel (the son in CS6) who felt responsible for knowing the reversibility of treatments that were offered to his mother Shelly, and who was exceptional in my sample.

5.7.4 Accepting the decision-maker role

Regarding acceptance of the nomination as decision maker, a contrast existed in my study between patients' descriptions and those of their 'nominated' non-spousal relatives. While patients reported an upfront acceptance by their relatives of their wish to nominate them as decision makers, the relatives felt themselves mainly compelled to accept the nomination. Patients seemed to disregard the effects that discussing ADs as well as nominating a decision maker had on the nominated relatives. They placed significant emphasis on finding a potential decision maker, and that

need drove them to the point of actually imposing the role on some of their relatives, who had too little preparation for it.

The moral obligation to accept the decision-maker role was related by a few participants (directly and indirectly) to the fifth biblical commandment[55] (or to a similar respect to their non-parental loved ones). Even in cases where there was a sense of choice, it was influenced by commitment, a meaningful relationship, and understanding of the reality (for example, the fact that Naomi had no other family). There did not seem to be a purely 'free' choice to become (or not to become) a decision maker.

Previous research reflects the difficulty of being the decision-maker. It shows that some relatives want help from health care teams in order to make decisions (Caron, 2005; Hines et al., 2001); others would even give up the decision-maker role altogether (Caron, 2005), while others may prefer the support of medical staff but without interference in their decisions (Meeker and Jezewski, 2004). In the current study most relatives hoped they would not have to make decisions eventually, but remained in the role; some thought that they would need medical and other advice, but none wanted to totally leave decisions in the hands of medical staff. This option was generally perceived as undesirable, but this issue will be looked at in the next chapter in greater detail.

5.7.5 Being a decision maker while holding different views

Some participants (including relatives) were inclined to view similarity of opinions regarding EoL as guaranteeing the suitability of being a good decision maker at EoL. Yet it was not always the case. Holding different views, as Yarden and Koby in CS4, has been noticed in another study (Meeker and Jezewski, 2004). In both examples, relatives viewed themselves as capable of acting as future decision makers regardless of their disagreements, thinking that their role was to represent the patient rather than themselves: "*That's what I'm there for. I'm there to be him, not me*" (Meeker and Jezewski, 2004: 332). To go even further, I will suggest (as seen in Naomi and Carol's case, in CS3 earlier) that having similar views sometimes

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[55] Fifth commandment in the Decalogue: "Honour your father and your mother, that your days may be long in the land that the Lord your God is giving you" [Exodus, 20:12]

acted to obscure and hinder communication and furthermore, it increased the illusion that making decisions would be easier or more possible when people hold similar views regarding EoL.

5.7.6 Conflicting or multiple interests?

The explicit and implicit commitment to patients that surmounted relatives' own emotional or physical needs has also been found elsewhere (Meeker, 2004). Yet evidence supports that being a surrogate decision maker places the relative in an inherent and repeated conflict: on the one hand honouring the precious moment of the patient's deterioration and approaching death by acting in their interest, while simultaneously exposing relatives themselves to stress and to guilt related to the decisions they need to take for their patients (Caron, 2005; Hines et al., 2001; Meeker, 2004). However, in a similar way to the commitment of relatives to patients, many of the patients shared examples of decisions regarding their current life, which were apparently affected by their commitment to their relatives. Autonomy of both patients and relatives in this study did not seem to exist in the void but was embedded in meaningful social relationships. Many decisions that were made during illness and declining health reflected aspects beyond 'pure' free will and autonomy. Although patients and relatives seemed preoccupied with different issues, both parties seemed challenged by dual inner commitments: to themselves and to their 'significant others', as discussed in the previous chapter in regard to *relational autonomy*. The inner conflict between fulfilling one's own wishes or the wishes of others was obviously emotionally stressing and burdening to patients and relatives alike. It may have added complexity to the possibility of discussing ADs and EoL wishes, and issues related to the execution of patients' ADs.

5.7.7 Conflicting values

At a higher level, there is an inherent conflict between the pure form of autonomy (which is all about the individual), and relationships (which is about the interaction of the individual with others around him). Between two individuals in a relationship (such as a patient and a relative), who each have

autonomy, there must be a boundary to each one's freedom, so that one's autonomy does not breach the other's, as illustrated by the saying, '*The right to swing my fist ends where the other man's nose begins[56]*'. This does not mean to say that others have rights to decide for the patient, but that autonomy needs to be re-considered when it hurts someone else's autonomy.

Some of the relatives who took part in this study, as well as in previous studies, expressed difficult emotions and various degrees of distress, which were evoked by exposing them to possible patients' wishes: to end life; not to prolong it; or to nominate those relatives as decision makers on behalf of those patients. It was noticeable that some relatives did not see any way to refuse taking on this role, although morally they had autonomy as well. In such examples, again, one could sense what 'relational autonomy' (see previous chapter) is about, and how difficult it was for relatives to freely choose what they did or did not want to do for their patient-relative. The patient's autonomy is not more elevated than that of the relative simply because the patient is apparently very ill or dying. Yet, real-life of relationships showed that people chose to breach their own autonomy in order to protect their patient's autonomy toward EoL. It seemed however that a multitude of interests were simultaneously driving the actions of patients as well as of relatives. Concurrently there seemed to be a conflict of values within each of them: when patients give priority to their value of autonomy, they hurt the value beneficence toward their relatives; when they prefer to do good for their relatives this contradicts their own need. The same applies to relatives (see schema in Figure 9, next page).

It therefore seems important that in the process of nominating decision makers for EoL decisions, attention and thought is given to weighing the overall 'good' of the patient as well as their relatives. It may be that, as with any dilemma, for each individual case there would be a need to weigh all the aspects, including the protection of patients' and relatives' autonomy and other values, in order to make a moral decision. Evidence suggests that in many cases patients and relatives need help from health care teams to be

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[56] Current evidence indicates that the saying under investigation began with Prohibitionist orators who expressed it using a variety of formulations during their speeches. John B. Finch communicated the earliest known instance in 1882. Ascriptions to other famous individuals such as Abraham Lincoln and Oliver Wendell Holmes (Junior or Senior) do not have any support at this time http://quoteinvestigator.com/2011/10/15/liberty-fist-nose/

better able to have significant communication between them (Caron, 2005; Hines et al., 2001; Meeker, 2004; Meeker and Jezewski, 2004). I suggest that external help may enable such communication to safeguard all parties involved, i.e. patients and relatives alike, and enable them to reach optimal outcomes, together with providing support in handling the emotional burden of concessions that each party will need to make at the actual EoL.

Figure 9: 'within-between' - conflicting values between the individual and 'others'
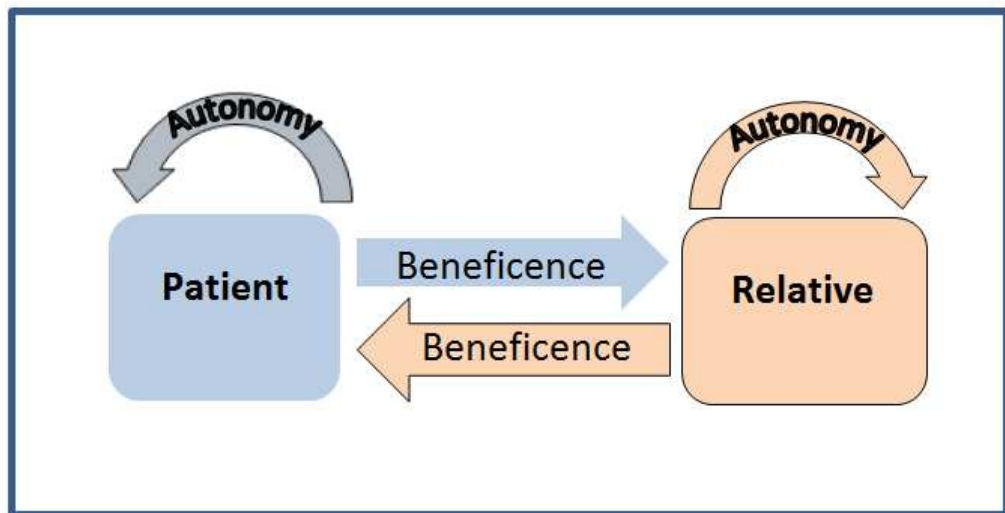
One of the challenges that have been illuminated in this chapter is that the needs of the patient and those of the relative grew apart as the patient's EoL approached. It looked as though patients were more preoccupied with escaping the emotional and physical suffering, while the relatives were more concerned with delaying the moment of absolute separation by the death of the patient. This overarching challenge seems extremely difficult to handle and requires the best possible setting, including communication and emotional support for the patient and for the relatives.

5.8 Conclusion

The preliminary aim of this chapter was to look at relatives' perspectives of the role of ADs in the care of people close to them toward the EoL, but it did more than that by looking at the 'patient-relative' dyad and allowing a better

understanding of its complexity. Findings were related to the sharing of the idea of making an AD; the nomination of decision makers; the communication around this, and the perception of the role by both parties. This chapter has highlighted challenges and dilemmas that arise when patients attempt to include others as their future decision makers for EoL decisions. In all these aspects, the findings illuminated the complexity that seems to hinder 'passing the baton' from AD holders to their relatives in the AD 'relay'. The next chapter will look at the additional complexity when physicians are included in the procedures related to ADs.

CHAPTER 6: INTRODUCING THE FINAL ACTOR IN THE 'ADVANCE DIRECTIVE-RELAY' - THE PHYSICIAN

6.1 Introduction

This chapter is the final chapter to present qualitative findings from this study, and adds the perspective of the third partner in the 'advance-directive relay' (i.e. the joint undertaking of preparing and communicating advance directives (ADs) in a way that will enable their use at the proper time). The chapter will look at the role of the physician regarding ADs and end-of-life (EoL) decisions, drawing on physicians' various experiences and views expressed in interviews with them. The role of the physician will be demonstrated by presenting one detailed example, before comparing this with the experiences and views of the other physicians who participated in the study. In this chapter I chose a unique, perhaps unrepresentative example, because it was as close as possible to end-of-life (EoL) communication guidelines (see discussion), as will be demonstrated shortly. Overall, the physician's role will be looked at from multiple perspectives, chiefly using the voices of physicians gathered in interviews, but also adding those of patients and their relatives.

This chapter starts with a description of the physicians who were related to this study (either by participating in it or by declining to participate). It then proceeds to provide some contextual information regarding physicians' knowledge and role perception of EoL and ADs, before later describing the findings from two perspectives: (1) Physicians' experiences with ADs, EoL communication and decision-making, and (2) the same or equivalent experience as viewed by the participating patients and their relatives. A discussion of some of the issues elucidated will conclude the chapter.

6.1.1 Describing the physicians among participants

In order to provide a wider picture of the findings related to the role of the physician in making and communicating ADs, it is important to look first at the study's sample, and at potential participants who did not take part. Seven physicians in total participated in the study but only four of them had any connection with the participating patients (patients 1,3,4,7). In the case of six

other patients (patients 2,5,6,8,9,10), physicians did not take part in the study; this was perceived as a highly significant finding in itself (as discussed later in this chapter), but it was also methodologically problematic (as discussed in the methodology chapter).

The physicians may be compared in a few possible ways (see Table 11 below): (1) GPs versus hospital physicians; (2) rural versus urban GPs; (3) inpatient versus outpatient hospital physicians; (4) case study (CS)-related physicians versus physicians 'outside' of the CSs; (5) participating versus non-participating physicians (the importance of the non-participation of physicians in this study will be described shortly and will be further explained later in the chapter). The relationship between these sub-groups may be clarified when presented as a matrix:

Table 11: Possible ways of comparing physicians in relation to the CSs

		Community GPs		Hospital physicians	
		rural	urban	Outpatient	Inpatient
Participating	CS*-related	CS1*, CS4, CS7	CS4	CS3	CS4
	Non CS-related			RS** Neurologist	GIM***
Non-participating			CS5	CS2, CS6, CS8, CS9, CS10	

* CS – case study *** GIM – specialist in general medicine

** RS – specialist in renal diseases

The above table shows that the larger group of participating physicians, those related to the participating patients, consisted of GPs, whereas hospital physicians comprised the majority of non-participating physicians. Table 12 on page 170, describes the physicians and provides further information about their clinical specialty, their relation to case studies (CSs), their workplace setting, and whether the non-participation of a physician was initiated by the patient or by the physician.

6.1.1.1 Reasons for non-participation

There were different reasons for physicians' non-participation. One of the six (the GP in CS5) was reported by the patient (Omri) to have refused his request to participate in the study because she was overloaded with work. In three other cases (CS 2,6,10) it was the patient who refused to approach the physician (with a request to take part in the study). Patients gave various reasons for this: not feeling able to consider any particular physician from the group of physicians as being the primary carer; discomfort in asking a physician to dedicate time to the study, due a perception that their physician was over-worked; the thought that if a physician was religious then asking questions about ADs might embarrass them. In addition to refusals, Debby's oncologist (CS8) was on long-term leave and could not be reached until the end of the data-collection period. I had hoped to interview her later over the phone, but in the end this was not possible[57]. With Adam (CS9), a decision was made not to recruit a physician and a relative, due to safety issues explained in the methodology chapter.

6.1.1.2 Remedies for the missing voices

Having only four physicians as my body of evidence regarding the point of view of health-carers potentially limits the contribution of the third partner to the findings, and having six voices missing was perceived as problematic, and was a limitation in relating to the case studies. After discussing the options with my supervisors, we agreed that although I could not fill the absence, I should try to add the voices of some other physicians, outside of the case studies, by interviewing them. As previously mentioned, most of the missing voices were those of hospital physicians who were key to the care of the participating patients (such as specialists in renal medicine or oncology). It was agreed that interviewing hospital physicians from similar specialties might add value, and represent some of the perspectives of missing participants. I therefore interviewed three specialists in different long-term conditions (LTCs): A neurologist, a specialist in general medicine (GIM) and a specialist in renal medicine.

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[57] In the very last weeks of the data-collection period and over a few more months I faced personal ill-health issues that prevented me from taking on further commitments such as another interview.

Table 12: Information regarding the physicians

Patient number	Patient name	Physician's name	Physician's speciality	Reason for non-participation	Setting
1	Noa	Yahalom	GP		Rural community
2	Meira	--	(renal specialist)*	Patient reluctance	
3	Naomi	Barda	pneumologist		Hospital
4	Yarden	Shalom	GP (and cardiologist)		Rural religious community
5	Omri	--	(GP)	Physician refused	
6	Shelly	--	(oncologist)	Patient reluctance	
7	Dov	Paz	GP		Rural and urban community
8	Debby	--	(oncologist)	Long leave	
9	Adam	--	(gerontologist)	Safety issues	
10	Ehud	--	(haematologist)	Patient reluctance	
Out of case interviewees		Agmon	neurologist		Hospital
		Azriel	GIM specialist		Hospital
		Ash	renal specialist		Hospital

* (renal specialist) – the parentheses indicate that the physician did not take part in the study

When I arrived to interview the renal specialist she refused to be recorded on audio-tape (although I had explained this to her in writing in my introductory request). Unfortunately, personal events that followed this interview (see footnote 57 on page 169) prevented me from writing field notes immediately. The notes that were made during the interview provided only limited information that could be used as evidence. Therefore, most of the data that will be highlighted in this chapter relies on interviews with three GPs and three hospital specialists. The interviewees provide the variety that was desired in the design of this study: the hospital physicians represent different specialties; among the participating GPs, one worked in a city community as well as in rural communities, another worked in a religious rural community and in a hospital, and the third worked in a secular rural community.

Having described the group of physicians in the study, the next section discusses findings related to their overall views and experiences with dying patients, to set the context for findings that are specific to ADs, which are the focus of this study.

6.2 The context: Physicians' experiences with dying patients

Before discussing the findings that were directly related to ADs, it is important to contextualise the sample of physicians involved in the study because there is an expectation that ADs will be executed by them. The findings were related to the role perception of physicians in the care of patients nearing EoL, and their experiences around communication with dying patients are part of, and a crucial foundation to, a better understanding of the findings that were more closely related to ADs.

6.2.1 Physicians' world views and role perceptions regarding EoL

As outlined above, this chapter will develop a discussion starting with the following key example (see Vignette 4, next page, regarding CS1[58]). The example of CS1 is singular because: (a) it was an extremely long EoL home-care experience that lasted for a decade, while the average length of EoL home-care in Israel, as stated by the participating GPs, is around a fortnight; (b) it was the only example in this study that could be reviewed with the physician retrospectively as one whole process of care, because the patient died before I interviewed the GP; (c) it appeared to work relatively well for all three participants in the CS: the patient (Noa), her husband (Ben) and the physician (Dr. Yahalom). It is one of two actual experiences in this study in which EoL decisions were needed and ADs could be used. Yet because the patient retained capacity up until two days before she died, it is perhaps limitedly representative of patients who lose capacity a longer time before death. Even though it may not be perfect, I suggest that this CS is a useful

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[58] CS1 – Noa, a patient with MS, was mechanically ventilated at home for many years. Her personal carer was her husband Ben, and her main professional health carer was Dr. Yahalom. See synopsis of case study 1, page 71

example when we try to understand the meaning of ADs, of people facing death due to a long term condition (LTC). The vignette (below) is a detailed illumination of Dr. Yahalom's experience with Noa, her perception of her role, and the world views she communicated during the interview.

Vignette 4: Dr Yahalom - the central example of a palliative-care physician

Dr. Yahalom (in CS1), was in her early 50s and had been a GP for around 20 years, practising in rural communities, one of which was the village in which she lived. Around nine years before I met her she was approached by 'the unit of continuing care'[59], and was asked to take care of Noa. This involved weekly home visits and being on-call for emergencies. Dr Yahalom agreed and became a participant in a multi-disciplinary team who took care of Noa at home. It was not the first and not the only time that Dr. Yahalom had taken on the care of a critically ill /dying patient. Initially, she thought that this would be a short-term case. Noa had a poor prognosis, as Dr. Yahalom described:

> 'Indeed when she [Noa] arrived [from hospital] weighing thirty
> something kilos with such [showing 'big size' with her hands] a
> pressure wound [bed sore] in her buttock… no one believed
> that she would survive. **Contrary** to the living will we did the
> maximum…, …The truth is that when she arrived everyone
> thought that there was no potential [for survival] here' [Dr.
> Yahalom].

Dr. Yahalom believed that the intensive and dedicated care that was given during many months by all parties involved helped Noa's recovery, yet she thought that Ben (Noa's husband) was the principal carer. She said:

> 'The first 2 years we had many struggles really…, …He [Ben]
> invested **hours** [loud] and hours to look after this pressure
> wound. And [gave her] 'these' massages and 'other' massages.
> Many things that indeed… that if we gave up [on, she wouldn't
> have survived]…' [Dr. Yahalom].

From interviews with the three participants in CS1 it seemed that after persistent care lasting around two years, the situation stabilised and Noa and Ben built some sort of routine. Yet, Dr Yahalom described how every now and then a respiratory infection started in Noa's body. It was expressed as a mild fever, with subjective respiratory

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[59] The unit of continuing care is in charge of providing complex home-care after discharge from hospital of patients who are mechanically ventilated, with central venous catheters, complex pressure wounds, feeding tubes, and/or similar complications.

difficulty (although Noa was breathing through mechanical ventilation), and decreased oxygen saturation[60], adding:

> 'Then she would tell me this… and… I would put her on antibiotics… and it [the infection] would pass…, …From time to time I would say: "If it is [only] one day, let's give it a chance, perhaps it's a virus. Let's give it a chance. You [Noa] will say when is the moment [to start antibiotics]". It was sort of clinical impression: OK, 'here' antibiotics will help, 'there' not, something like that' [Dr. Yahalom].

During many years Dr. Yahalom came regularly, every week (apart from additional visits in crises such as during infections) and spent time with Noa and Ben. She said:

> 'I would go there [Noa's house] once a week whether necessary or not. Medicine had nothing to do with this… especially in the last years when it was really stable. OK, increase [dose], decrease [dose], this cream, another cream, I would just come… once a week for 45 minutes, an hour if I had the time, [we would] sit and chat [on] literature, films, [they] tell me their stories, each time something new, another forgotten uncle or grandmother, sort of all the time like that' [Dr. Yahalom]'.

But from her other descriptions it appeared that Dr. Yahalom did more than listening to stories. She identified Noa's emotional distress and anxiety and told me how she suggested different resources to help, and how all the options were rejected by the couple:

> 'She [Noa] was full of anxieties… all the time, about the other family members. As if instead of worrying about herself she was/ it was a sort of preoccupation with the health of the others and what is happening to them. Once I gave her something anti-depressive, but at some point they [Noa and Ben] decided to stop it and that she'd better cope as is [without medications]. And I gave her all sorts of exercises…, …and I encouraged them to meet a social worker… they 'flattered her away'[61] after one visit. I tried all sorts of things [even] psychology. They told me: "you will be our

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[60] Oxygen saturation – the level of oxygen in the blood which indicates the effectiveness of breathing.

[61] 'Flattered her away' – jargon in Hebrew that means rejected her and sent her off.

psycholog/[word cut]" [they] sort of fluttered [i.e. dismissed]
all this' [Dr. Yahalom].

Dr. Yahalom thought that they needed help but she did not impose it, because she felt that this was part of the couple's coping strategies, which were helpful most of the time:

> 'Their defence mechanisms were like this. And they worked
> excellently..., ...I felt no need to breach them but it was very
> important for me that there will be room for these things...,
> ...There was no legitimacy for negative emotions. There wasn't!
> Ben didn't legitimise negative emotions, [as if they] didn't
> exist..., ...and then... sort of she [Noa] couldn't speak [express
> feelings]! On what bothered her the most! The fact that it is
> hard on her and [that] she wants to die. And that she has no
> more strength to keep with... being dragged back and forth...,
> ...She would tell me. Even when he [Ben] was present she would
> tell me this. He would dismiss her words and I would tell him:
> "Ben. We need to hear it"' [Dr. Yahalom].

Dr. Yahalom told me that she could hardly notice respiratory changes by auscultating (listening to) Noa's lungs due to the mechanical ventilator and Noa's overall poor respiratory condition. Yet, Noa could identify subtle changes in her condition very accurately and this was very helpful in reacting effectively and in providing quick and efficient treatment. Dr. Yahalom trusted Noa's identifications of small changes and reacted accordingly.

From Dr. Yahalom's sharing, around two months prior to Noa's death her cardiac condition changed. This was expressed by high and irregular heartbeats which fatigued Noa. Dr. Yahalom discussed the options with her, and eventually Noa agreed to the mildest treatment that could be offered. Yet, a few weeks later, Noa noticed that she was swelling and accumulating fluids. Because this mild treatment was the only recent change in medications, it was stopped. Four days later Dr. Yahalom received a call from Ben saying that Noa had a fever. When she came for a home visit she noticed a more complex situation, and she was not sure whether it was cardiac or cerebrovascular worsening, or an infection. She told me:

> 'And then indeed the question was "what shall we do with
> this?"..., ...and I raised the possibility of referral to hospital...
> and she [Noa] still said "No. Please, no" and I said **but** [let's see
> what happens]. I said OK I will wait' [Dr. Yahalom].

A day and half later Ben called Dr. Yahalom again in the middle of the night, crying for help because Noa's condition had further deteriorated. When Dr. Yahalom arrived at their house she told Ben that there was nothing more she could do in the home setting

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(she had started antibiotic treatment the day before). Ben wanted to take Noa to the hospital and Dr. Yahalom did not object. She said that she told Noa about the decision to hospitalise, adding:

> 'We [Dr. Yahalom and Ben] told her [Noa] that we take her [to the hospital] and she… she said… something, "just not to suffer" something like this' [Dr. Yahalom].

Dr. Yahalom said that the hospitalisation lasted another day and half and Noa died in the hospital in a department of general medicine, with intravenous antibiotics and surrounded by her family. She concluded the story of Noa's death by describing how in spite of repeated declarations by Noa and Ben over the years that she refused hospitalisation whatsoever, Ben could not bear the thought of giving up on his wife although Noa had repeatedly expressed her readiness to die. Dr Yahalom said:

> 'He [Ben] wanted to do everything [possible], in spite of the signature [ADs], in spite of it all, and in spite of the [Noa's] "don't do, and do not resuscitate me, and do not ventilate me and do not…" [laughs]. Ventilated for so many years. "Not to take me"/ and all through this time he [Ben] was with her with this thing: "not to the hospital. Everything at home. And if I have to die I will die at home. I cannot take it [hospitalisation]". In the moment of truth, sort of when it was real… that's it. He probably needed it, to feel that he did everything. Yes' [Dr. Yahalom].

Dr. Yahalom said that she was ready to support Noa's decision to die at home if she felt that it was her wish but she thought that in the end this was not totally clear. She said that she perceived Noa and Ben as ambivalent toward hospitalisation: they dreaded it yet a decade earlier Noa's life had been saved in hospital (her lungs collapsed while she was in hospital and she was resuscitated quickly and recovered). Dr. Yahalom thought that towards the very end of Noa's life, this ambivalence caused delaying hospitalisation till the final moment, when it became too late to save Noa. Dr. Yahalom suggested that perhaps an earlier hospitalisation would have saved Noa's life once again.

In the few examples that Dr. Yahalom shared with me (of other patients apart from Noa) she was consistent in perceiving her role as 'going with the patient' in making medical decisions, although sometimes this was difficult to do. She believed that she had to provide information to patients, in order to allow them the choices that were most suitable for them, and that eventually she had to adapt to the patient rather than the opposite. She added:

> 'As a physician you adapt yourself to the patient in front of you all the time, sort of you are a bit like a chameleon many

> times…/ …There is indeed a question here: when do you give up
> [on fighting for life]…, ..Sometimes there is this thing that
> with people who give up, you give up with them' [Dr. Yahalom].

In the above account of Dr. Yahalom, the key elements that I wished to emphasise were: the ability to discuss EoL issues with patients and commitment to exploring those issues with them; ability to listen to patients, to trust them and to respect their choices (patient-centred communication); interest in patients and an active attempt to distinguish their uniqueness (empathy); ability to put one's own world views aside and respect those of patients (emotional resilience); efforts to bridge between a respect for the patient and for relatives when these were not completely compatible. In the example above, for most of the time Noa retained capacity and made her own decisions. She lost her capacity shortly before she died (around two days before death), and only then did Ben and Dr. Yahalom make decisions on her behalf.

To the image provided by Dr. Yahalom regarding the role of the physician toward the dying patient, additional world views of the participating physicians will now be added. For analytical and comparative purposes, GPs are presented separately from hospital physicians.

6.2.1.1 The role perception of GPs

The three GPs viewed their role as their 'patients' safeguards' (term coined by Dr. Paz), because they felt closer to their patients than other specialist physicians, as Dr. Paz expressed it:

> 'The family physician has the real role in this issue
> [LTCs]. In the hospital in my opinion (and I worked there)
> they don't respect this wish [AD?]. Everything works
> fast. Everybody… doesn't want to think to these depths'
> [Dr. Paz].

Keeping the patient at home

Attempting to keep a patient at home, or in a nursing home, rather than sending patients to hospital appeared to be perceived by all three GPs as their central role regarding dying patients. Dr. Paz explained that at home, patients' wishes not to prolong life are more achievable than in hospitals:

> 'The family physician has a role to safeguard the patient.
> At home it is still possible. In the hospital in my opinion it
> isn't possible..., ... I am in the opinion that one who is
> sentenced [to die from his illness] and is not turning the
> world up-side-down [i.e. fighting against the illness and
> looking for medical interventions] there is no need to
> prolong his life artificially" [Dr. Paz].

All three physicians said that they knew their patients very well, and that in hospitals there is not enough time for the staff to get to know patients well enough to make decisions that will reflect those patients' wishes and views closely. Dr. Shalom, for example, was practising in the community as well as in an acute ward in a hospital. She said that her communication with her patients in the two settings was very different, and that she felt much more comfortable making or helping to make medical decisions for patients in the community, where she could have repeated conversations with them. She said:

> 'I have an advantage with the long-lasting acquaintance
> with the people here [in the community]. When I know it
> is the end, it is much easier than when I know a person
> [just] one or two hours' [Dr. Shalom].

In specific situations during the LTC trajectory, there may be acute exacerbations or additional health problems which may seem acute and reversible, and are considered to be better managed in hospital. All three GPs shared such examples explaining the circumstances in which these situations turned out to be more complex: when patients deteriorated suddenly, quickly and irreversibly, and died in hospitals despite their previously-expressed wish to die at home and the preliminary intention of the physician to respect their wish. One such example was shared by Dr. Paz:

'I had a patient, [a] very wise man that was my patient in the Kibbutz[62].../ ...and he was 83 and totally lucid.../ ...and we had an agreement that if something happened to him ...we keep him at home/ ...that if for example he has... the situation is irreversible.../...And [but] he was misfortunate to have a minor... cerebrovascular accident. I saw that he had a slightly 'heavy' talking... and [was] with a slight weakness of his hand. What do you do in this circumstance?..., ...[You] call an ambulance. And to my regret.../ ...in the hospital.../ ...he gradually deteriorated and deteriorated. [He] was [mechanically] ventilated. At the end, I came to visit him, he was in a unit for [chronically] ventilated patients in [name of a geriatric hospital]. I failed, [because] he asked me [not to hospitalise him]. But how can you [i.e. one] know what will happen?' [Dr. Paz].

Dr. Shalom and Dr. Yahalom also shared some detailed examples of what they perceived to be successful and non-successful experiences with dying patients and with their relatives, all of which highlighted that sometimes reality manifested itself in ways that neither the patient nor the physician could foresee. Sometimes an acute health event may develop to a terminal stage too quickly and irreversibly, so that patients' wishes may become non-realisable, as in the previous example.

Physicians' individual attitudes

The three GPs said that overall they felt comfortable with people who say what they want. They expressed respect for patients' views, as well as having their own conviction that their personal values and preferences were irrelevant in their encounter with a patient, and in the process of decision making regarding the patient. The three expressed more esteem towards patients who made the request to limit what they perceived as a futile treatment, rather than

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[62] Kibbutz – A small community that was historically based on communist principles or as Marx defined it: "From each according to his ability, to each according to his need". All benefits and expenses were equally shared among all members. Today, a Kibbutz is a privatized rural community except in a few rare cases.

the opposite demand for excessive medical procedures. Dr. Shalom's words represent this position:

> 'I respect a lot a man who is 82 years old who says: "I have lived my life. Now I decide with sound mind not to have the surgery, if tomorrow I have a heart attack"…, I admire such people. I am a coward I don't know what I will want [for myself]. There are people who don't want to be a burden on their family and I respect [that] and don't pressurize. It doesn't mean that I won't continue to suggest options, but yes [I respect their decisions]' [Dr. Shalom].

Dr. Yahalom addressed the opposite scenario: demanding maximum treatments when there is no more hope. On the one hand she liked this request less than a request to limit treatment, yet overall she reported she felt more comfortable when patients had requests of any kind rather than when they did not know what they wanted. She said:

> 'I am sure that I will less like it…, …People who fight hard for their lives obtain all sorts of things [i.e medical procedures]…, …[but] I will do it [go with the patient]. The question/point that is difficult to me is when… It is not 'real' [life] anymore… when it is more a burden on the surrounding relatives than some kind of quality of life. [Yet] Perhaps it is also something that makes it easier for me. [When] it is his [patient's] decision [and] my consideration isn't 'there' [i.e. my personal view isn't involved].' [Dr. Yahalom].

However, GPs were not comfortable with all patients' requests/scenarios. Although they perceived their role to be receptive to any choices made by patients, they did share some difficulties. First, events sometimes turned out differently from expectations, and such experiences were sometimes challenging for the GPs and remained in their memories for long time (as shared by Dr. Paz earlier). Second, it seemed that it was more difficult to let a patient go at some times than at others. Dr. Yahalom, for example, described

that when the chances of recovery were relatively high she found it hard to accept that a patient (especially, although not exclusively, a younger patient) might simply give up without even trying to fight back against the illness. A third difficulty was shared by Dr. Shalom, who said that even in the last moments of a patient's life it was harder to abstain from action than to be active because this contradicted her medical education:

> 'It is much simpler, when you see someone in his last moments, to do whatever you can [do]. It resolves your hesitation and questions like "why didn't you do?". If I don't do, it keeps poking: "Perhaps I should have [done something]? Perhaps I should have?" It's **difficult** [loud], it's very difficult because not for this purpose we do what we do [i.e. study medicine]' [Dr. Shalom].

Dying at home perceived as a quality parameter

Two GPs perceived that dying at home was a parameter of quality of home care at EoL, while another related to the place of death more neutrally. Dr. Paz for example estimated that when he worked in the Kibbutz, 80% of his patients with LTCs died at home. The same proportion happened in the nursing home under his charge. On the other hand, in the city setting he said that there were less than 50% deaths at home. He used this comparison to illustrate his belief that people in rural or nursing home settings felt more comfortable with dying at home than in the city. Dr. Yahalom shared the view that dying at home was usually the best outcome of home care at EoL. But all three GPs acknowledged that their view did not always match their patients' needs and that some patients needed to go to the hospital, if only to mark the fact that they are continuing to fight their illness and not succumbing to it.

Communication about end-of-life (EoL)

All three GPs said that it was easier for them to discuss EoL issues with patients who initiated such conversations. In their experience, when a GP initiated the communication it was more difficult and often communication was limited. They said that some patients got scared when the GP initiated talking about EoL preferences. Dr. Paz emphasized however that in his experience

there were differences between populations in his various surgeries (clinics). He found that it was less easy to bring up EoL issues with the urban population under his care, whereas in the rural communities where he worked, patients opened up to such conversations more easily. He also pointed out that he needed to have an impression of the patient before he could decide how to converse about EoL, and that being new in the current (urban) surgery hindered his competence. It was not clear whether this perceived hindrance was related to his unfamiliarity with the ethnicity of the local population, their traditions and/or languages (a large proportion of Ethiopian and Russian Jewish minorities), and/or to being new in the surgery and at the beginning of establishing trust and relationships with patients as individuals. Nevertheless, Dr. Paz appeared to feel cautious in addressing sensitive EoL issues. He said:

> 'With the patient it is very much depending on him. I check what he understands about his condition, what he was told, what are his expectations. [It] depends on him. If he tells me: "doctor, I know that I am about to die and just make [sure] that I won't be in pain [and] that I will not suffer" [that's one thing]. How many [people] like this are there? If he tells me "oh, horrible, I want so much to continue [to live] and why don't they find a cure for me?" then, what am I going to talk to him [about]? Then, I can say to him "listen I am here, by your side, I will help you with whatever I can. I will give you palliative care". I am not getting into it too much…, …I don't prevent the communication from the patient, [but] I don't force him either…, …The patient doesn't have to know all the fates [forecasts]' [Dr. Paz].

Dr. Yahalom also distinguished between the quality and depth of communication when it was initiated by the patient and when she initiated the conversation. She reported finding that the former option enabled a much more meaningful and open conversation. Dr. Shalom seemed the most hesitant of the three participating GPs about initiating EoL conversations. She felt that such communication about preferences must come from the patient. She held the view that if she initiated the conversation about preferences,

most patients would be scared because they might not be ready for it. She added:

> 'The physician and the nurses are part of the community. We know [the people] and we know how to direct [them]. There are [old] people that if I talk to them about it [ADs] they won't understand "where do I come from" [i.e. why do I talk about it now]…, …Most of them are aware that the time becomes counted, yet the majority, even if aware, won't understand where have I 'parachuted'[63] from, if I start investigating [their] plans [and this is] although they are not 18 [years old] anymore' [Dr. Shalom].

In addition to the barriers coming from the patient's side, there seemed to be some barriers coming from physicians. Dr. Paz said frankly that he found gaps between desirable and actual communication that physicians make with patients, generalising that:

> 'We [i.e. physicians] talk about ideology and we don't practise it. It's not simple…, …We are not asking all the patients [about their preferences]. We could ask as a routine… [but] we don't. The [work] day is loaded… you [the physician] enter corners [situations] that you don't know how you will get out of them…, …We [physicians] don't do this because of many reasons: time, awareness, [we] don't know where will it lead to, fear from causing pain to the patient: Why should he [patient] leave [the surgery] with bad feelings? [The patient may wonder] why the physician who is supposed to heal him all of a sudden asks him these questions? Maybe the physician knows something that he [patient] doesn't know?…, …in my belief I do have to ask more' [Dr. Paz].

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[63] Parachuted – 'to parachute on someone' is a jargon for 'coming by surprise' or 'appearing from nowhere'.

Overprotecting the patient from emotional pain often seemed to 'cover' physicians' own discomfort from communicating about sensitive emotional issues; perhaps they were protecting themselves from emotional pain as well. This issue will be further elaborated in the discussion section.

Communication with patients was undoubtedly the core interaction of GPs, but in many cases, especially in EoL care, physicians had to consider patients' relatives, introducing another element to be looked at. All three GPs regarded communication with relatives as mandatory in the proper care of the dying patient. One example could be drawn from the vignette showing the relationship between Dr. Yahalom and Ben (Noa's husband). Dr. Yahalom viewed Ben as part of Noa's life and care, and she usually met both Noa and Ben together in her home visit.

Families were not perceived by the GPs as one-dimensional, because not only would families sometimes disagree with the physician, and/or with the patient, they might also disagree with each other. For example, Dr. Yahalom shared the story of a young dying patient who asked her to explain to him what would happen to him. She understood that the patient wanted to know what to expect before dying and she gave him information, with a reassurance that she would be there to ease any suffering. She shared how the patient's sister and wife (who were present in the conversation) were angry with her because they thought that she had spoken too openly with the patient. She said that it took a long time and much explanation and support until they could calm down from their anger.

A second aspect of difficulty reported by GPs was when they had the impression that relatives wanted to 'get rid of' the patient, which GPs perceived as unethical:

> 'I had many families who said "well he is old let's leave him and not do anything". This [is] against the conscience, against the will. I don't have to agree. I am not here to kill people just because the family said [that] he [patient] is old and they don't have the strength to take care of him' [Dr. Paz].

The third aspect of involving relatives was related to hesitations sometimes coming from relatives, and their need to be reassured by physicians that indeed the patient had made the right decision in choosing to refuse lifesaving treatments:

> 'Sometimes it is more difficult to the family than to the patient. The patient goes through a process and comes to term [with his condition] and afterwards all is clear to him. The family, it is a different process that they need to go through. Sometimes I had to speak with the family because they asked themselves if they did the right thing' [Dr. Shalom].

After looking at the issues raised by the GPs regarding their relationships with patients and relatives, we will now proceed to the hospital physicians who participated in the study.

6.2.1.2 The role perception of the hospital physicians

The hospital physicians who participated in the study came from different clinical fields, as described in Table 12 (page 170). Two were working in specialized outpatient clinics within the hospital whereas two other physicians were heads of large inpatient wards; most of them had experienced both inpatient and outpatient settings. This subsection aims to cover the issues raised by these physicians regarding their role-perception toward patients at EoL.

Communication - forcing an open door?

Apparently, in the hospital setting (as seen also with GPs), communication was easier with patients who initiated it than when it had to come from the physician. It was almost as if communication is possible when the patient least needs it and has clear ideas about his needs (thus 'forcing an open door'):

> 'People who are very very aware of themselves and have thought about it [their wishes], really really don't need my <u>input</u> [English] I mean, they have thought about it,

and with them there is no problem to talk, [like] an open page, an open book [i.e. frankly] to talk about it at any level. It doesn't require a lot of time and if I see that they understand, sometimes without needing questions that come from me, then there is [=I have] no problem with that [i.e. with their decisions]' [Dr. Barda].

Yet, compared with the GPs, the hospital physicians were less prone to start a conversation about EoL issues. Also, even when the patient initiated such conversations, the hospital physicians seemed to feel less comfortable taking part.

Discussing sensitive issues

It seemed that overall, as illness progressed, the growing disequilibrium between remission and deterioration made communication more difficult for the hospital physicians. From the various interviews, it appeared that having something practical to talk about promoted conversations. Thus when the aim was to discuss treatment options rather than to address EoL care plans with patients, it was easier for physicians. In such occasions, sometimes EoL issues came up as an additional, somewhat incidental, outcome:

'I, personally, don't feel comfortable to talk on ah... on ah... "You have a month to live" or "Do what you need [i.e. prepare yourself]"... Not when it is told in such harsh [i.e. direct] way, and not in a non-harsh [i.e. softer] way. I don't, don't like. But ah... yes I initiate it... sometimes... especially when this has practical implications. For example when I must talk about [lung] transplantation and then... Let's say there is a possibility of transplantation... Then yes, then ah, it is possible to initiate a conversation. If you ask about me, yes I am doing it: "Have you thought about options?"; "Have you thought about extreme options?"; "What if?" Etcetera, etcetera. And then the person gives me the 'feel' how

> can I 'cross the bridge'[64] with him. I mean in what degree
> of directness can I talk to him about this, and it [i/e/
> the conversation] rolls on, yes' [Dr. Barda].

This kind of swing between discomfort and obligation repeated itself with a few physicians, yet communication seemed even less feasible in an acute inpatient setting.

Dr. Azriel worked in a busy acute medical ward, where staff usually had little chance to get to know patients very well before making critical medical decisions. Dr. Azriel said that when the patient was lucid the patient would decide for himself. Regarding a patient without capacity, he added that in an acute setting some incapacity might be temporary, and that he had felt responsible for ruling out and treating an acute element that could mask a patient's underlying degree of capacity. The culture of communication in Dr. Azriel's unit, as he described it to me, was more centred on acute and urgent situations than on preparing and planning ahead in the chronic and relatively stable phase, although not all cases that were discussed by him were a 'one-time event'. Some patients were hospitalised repeatedly in the same ward when exacerbations occurred, and in those cases there was a potential to discuss their plans after overcoming a crisis, before hospital discharge. Yet, from the given examples and from the answers to my explicit questions, his report exhibited no evidence of advance care planning and communication with patients about their wishes and preferences.

A different scenario from the one described above (in which Dr. Azriel was working), was revealed by a doctor who worked in the renal unit. Dr. Ash was the head of a large renal ward, comprising an acute inpatient unit as well as an outpatient dialysis unit. In the renal setting, patients were more likely to be known to physicians than in a medical ward; in the dialysis unit patients were treated repeatedly, three times a week for months and years, and in the inpatient unit some patients were hospitalised repeatedly due to chronic renal problems. It might therefore be expected that in the renal unit, the progress of a long term condition would be noticed and would be discussed; yet Dr. Ash said that advance care planning (ACP) was not practised at all in her ward. She added that she found it hard to discuss patients' requests to limit medical

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[64] To cross the bridge – to complete the mission. Here in the sense of communication.

care and to discuss EoL preferences more generally, and that she and her staff did not know how to do it.

From the accounts of the physicians, the culture of both inpatient wards (and the dialysis unit) seemed to create situations where decisions were made under pressure even if they could have been handled non-urgently in a more stable condition, i.e. between exacerbations or when changes occurred. A similar strategy (avoiding open and planned conversations) was elucidated from Dr. Agmon, who thought that most of her patients were not ready to handle the truth of their diagnosis of a cognitive impairment (predominantly due to Alzheimer's disease). She used an example to show me how she deliberately provided vague information because she thought that patients could not face the cruelty of a diagnosis of Alzheimer's disease:

> 'We say [to the patient]: "The memory is not so good, perhaps [it is] Alzheimer, could be, I am not sure". According to what they want to hear, we somehow say. And then there is this thing of "power of attorney for medical care" and this [is something that] we try to do. And then I say: "If CHAS VECHALILA[65], sometime [i.e. in the future] you don't remember [i.e. you lose the memory], if you won't be able, who would you like [to be your power of attorney]? Sometimes [patients say] "No. I don't need it now. Now I am all right". What can I do? [I know that] he is already not OK. We try very much to convince them [patients] to do it [i.e. to appoint a proxy decision maker] otherwise we put the family to trouble with [legal] guardianship that has financial implications as well' [Dr. Agmon].

Dr. Agmon said that it was difficult to convince patients who were newly diagnosed with Alzheimer's disease to appoint a relative as their power of attorney. It is perhaps not surprising that some patients seemed to understand, from the vague way in which their diagnosis was disclosed to them, that they did not have Alzheimer's disease at all, and saw no reason to appoint anyone to make decisions on their behalf.

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[65] CHAS VECHALILA- is equivalent to God forbid

Treatment refusals

Some physicians said that when patients refused treatments, they tried to make sure that the patient understood the implications of both using and refusing life-sustaining treatments. Dr. Barda for example, referred to COPD patients as 'acrobats who are walking on a thin rope'. He explained that contrary to some LTCs, while COPD patients may deteriorate dramatically and even die, they may just as dramatically recover and survive, until the next crisis. He said that he could more easily accept treatment refusals when he felt that the patient understood and was aware that they had a similar chance of dying as they had of recovering.

Perception of own communication competency

Three of the four hospital physicians expressed mainly discomfort from discussing EoL issues, especially with patients. Dr. Agmon shared uneasiness about communication both with patients and relatives regarding diagnosis and prognosis, as shown earlier. She felt she did not have the appropriate communication skills and thought that these issues scared most patients. Dr. Ash said explicitly that she and her staff did not know how to talk about EoL and that advance care planning came as a request from some patients, otherwise it was not brought up. Most of the physicians gave at least one example of a patient who asked direct questions, yet the same patient could not handle the direct answer:

> 'The fact that someone addressed me does not allow me to say everything. I mean, [that] sometimes, my experience is that many times he [patient] wants to hear encouragement, and this [i.e. asking about the future] is provocation to 'buy' encouragement. I don't have the 'recipe' how to distinguish. It is something intuitive' [Dr. Barda].

Some of the physicians seemed to use these examples as reasons for themselves as to why it was better, most of the time, not to initiate conversations on sensitive issues. Yet their discomfort seemed related to their difficulty to communicate about emotional issues as well.

Overall, the interviews with hospital physicians showed difficulty and often avoidance of discussing sensitive issues such as EoL plans. I found significant differences here from the descriptions provided by the GPs, who seemed to initiate communication even when it was not initiated by patients, and even when they found it hard to handle. Among the hospital participants, there were more expressions of incompetence in 'breaking bad news' and addressing sensitive issues with patients.

Communication among colleagues

Physicians in the outpatient setting did not share anything with me about collegial consultations regarding patients' wishes and care preferences, whereas in the inpatient setting within hospitals there was some indication of collegial discussions and shared decision making regarding EoL. Yet Dr. Agmon and Dr. Azriel described different local cultures, although they worked in the same hospital. Dr. Agmon relied on her past experience in an inpatient ward. She said that for decisions regarding withholding life-prolonging treatments in the ward, the policy was that three senior physicians had to sign the decision in the patient's file. She added that in her experience there was never a disagreement, and all medical decisions to withhold resuscitation were made unanimously. From listening to her, it seemed that discussion was quite limited:

> 'It never happened to us that for example we, the senior physicians that had to sign[66], were in disagreement. It hasn't happened. It looks as though we deal with things that are so difficult that we agree…, …There is no discussion. There is no discussion. The only thing there is, happens in the ward. If comes [a patient with] CVA and it is severe, and the patient is critical, [having] haemorrhage or something extensive, [then] comes the question whether to ventilate [mechanically] and then there is a discussion. The participants are the physicians who take part in the patient round, because if we decide not to resuscitate then three [senior] physicians must

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[66] In decisions regarding ventilation the policy was to have the signature of three senior physicians if there was a thought to withhold mechanical ventilation.

sign. And then, three of the [senior] physicians present sign. It is not really a discussion. It is sort of [agreement] among us' [Dr. Agmon].

On the other hand, Dr. Azriel described how physicians would discuss potential decisions in his ward, and said that he encouraged disagreement, saying:

'When we discuss a patient, it's kind of a habit that we acquired..., ...we give arguments 'for' and 'against', treatment or ventilation. Finally we try to reach a consensus. If we cannot reach a consensus and there is even one that says "no" [disagrees to withholding treatment], and this one, even [if he] is the youngest [junior] in the staff, we go for "do" [ventilate/treat] rather than the opposite.../ ...I personally have already internalised that I lead the ward, but without being the "know all dictator"' [Dr. Azriel].

The two examples differed in the openness and depth of discussion among colleagues yet, as could be seen in the previous sub-section, discussion with patients was difficult and partial in both instances. Apart from physicians and patients, there were relatives who were involved in the care and in decision making.

Another issue that was raised was the relationship with relatives in situations of EoL decision-making. According to Dr. Agmon and Dr. Azriel, disagreement could and did happen between physicians and relatives, and in such cases, they affirmed that the family's decision prevailed. When patients had cognitive impairment, communication occurred with relatives and medical decisions were always made after discussion with family members:

'But it definitely does happen that there is disagreement with the family..., ...It never happened to me that the family said one thing and I did another thing. I think that it hasn't happened to others [colleagues]' [Dr. Agmon].

Regarding disagreement among family members, in the (frequent) absence of ADs, Dr. Agmon said (similarly to Dr. Azriel) that in such cases the decision would be to opt for life-saving measures, even if only one relative preferred them.

To conclude, this subsection presented the context of the physicians' role regarding ADs, by providing details regarding the experiences of physicians among themselves, as well as with dying patients and their relatives. Although some of the physicians felt more comfortable communicating with patients who were interested and who initiated the exchange, it looked as though the participant GPs were the more committed to communicating with their patients and, overall, they felt more competent to do so. Hospital physicians, conversely, described limited communication in an acute setting that was focused on the immediate future even when there was a possibility to prepare for the longer term. In the outpatient clinics, although many patients were known to physicians for a while, planning for the future appeared difficult for the physicians. The trigger for communication was therefore mainly around practical actions (such as nominating a proxy decision maker for an incapacitated patient, or getting ready for lung transplantation). In the hospital setting the physicians seemed to perceive relatives' views or preferences as taking precedence over the physicians' views regarding EoL decisions when patients lost capacity. In the community it appeared more as a joint discussion led by the physician. One of the key differences between community and hospital physicians seemed to be that in the community, communication with patients and/or relatives was a process that started while the patient could still express themselves and often lasted long enough to build a relationship of trust with the relatives. Good relationships between physicians and patients and/or relatives were not always possible, but this issue will be addressed later in the chapter.

6.3 Physicians' experiences with ADs

After looking at the broader picture of physicians' involvement in EoL decisions and care we will proceed to look into their involvement with ADs, which is a specific issue in EoL care. This section looks at GPs and hospital physicians together, unless a specific distinction is made.

6.3.1 The "numbers" and knowledge regarding the 'Dying Patient Act' and ADs

No real numbers were available regarding physicians' experiences with actual AD documents. Most physicians knew little about ADs in general and had seen few if any such documents in their professional life. In hospital, it seemed rare to have met a patient with ADs and rarer still to use such a document in EoL decision making. Dr. Shalom for example said she knew three patients in her community who held ADs. Dr. Ash said that she had never encountered a renal patient with Ads, and Dr. Azriel and Dr. Agmon said that they had little experience with ADs.

Regarding their knowledge of the 'Dying Patient Act' (DPA) and ADs, Dr. Paz was the only one of the physicians who felt knowledgeable about the DPA and the legal AD form, as he said:

> 'Let's put it this way, today there is the law, the DPA, I know it well. I teach it to students and those who specialise [in family medicine]. [But] It didn't penetrate to the vast public in my opinion' [Dr. Paz].

The other physicians (although all of them had heard about the DPA) had various degrees of acquaintance, from none-at-all to some degree of knowledge. Most of them had pieces of information but overall they seemed to be missing quite a lot. For example, most were not aware that ADs were now legal in Israel, yet they knew something about the 6-month prognosis as a factor to apply ADs. Dr. Azriel and Dr. Agmon did not address ADs directly to allow me to assess how much they knew about this option and its legal aspects. Dr. Azriel said at one point that patients' requests are not limitlessly respected, but it was unclear whether he was expressing his views or his knowledge regarding the legal boundaries of ADs, when he said:

> 'We try very much to respect, unless there is reversibility to the illness and we have the impression that we are not going to prolong suffering. Then [i.e. in such case] we prefer to do [i.e. to treat] and not to

respect the document. But usually we do respect the patient's request' [Dr. Azriel].

6.3.2 Documents and declarations

Most of the physicians could point out limited experiences with patients' informal EoL requests, or relatives' requests on patients' behalf when they lost capacity. 'Informal' means to say that these requests were expressed orally, without being backed up with AD documents. Dr. Agmon said:

> 'I think that someone who wrote something, it happened, but very rarely. It happened in the ward. It regarded patients who came with severe CVA, elderly [patients], and their children said: "Here there is a letter, mother/father asked not to do anything, except of course from the very basic things"' [Dr. Agmon].

Dr. Barda said that the little experience he had with EoL wishes was with informal requests rather than with ADs. Even with Naomi, he did not remember having seen an AD document (though Naomi was certain that a copy of her ADs was in her patient file in the clinic). Dr. Shalom remembered around 3-4 patients (in a decade) who were hospitalized and asked to return home, to die at home. She added that this wish was expressed by patients who did not have ADs. All three GPs could only recall a few of their patients who had ADs.

Dr. Azriel said that he kept copies of the few AD documents he encountered in the ward-safe. Yet, it was not clear if, how and when these AD documents were used for EoL decisions of patients who lost capacity. The examples he gave for EoL decisions were mostly with patients who did not have ADs. Dr. Azriel raised the issue of accessibility to AD documents in patients' records, saying that now that the medical file was electronic, he faced a problem, because if he mentioned ADs in the follow up it would disappear from view in the following days. He did not have the option to scan the document into the electronic file and there was no system put in place to make a pop-up note in the electronic file, for everyone to see when they accessed the file. More

important than these practical problems, it was not clear if and how AD documents served decision making for people who lost capacity.

It was interesting that the three GPs said in various ways that they did not need AD documents in order to discuss ACPs with patients and relatives, nor in order to make EoL decisions when their patients lost capacity. Yet they also said that with patients who had ADs it was easier to communicate about their preferences toward EoL, not because of the document but because of the mental and emotional preparedness that came out of making it:

> '[it is] much more open [discussion] with those [patients] who wrote [ADs] or told me [their preferences] before. Those [with which] I raise it, [it's] much more closed and there is always this question how much they want to talk. You always have to **feel** [loud] it, because they haven't **discussed** death [with themselves yet]' [Dr. Yahalom].

The GPs emphasised that in the home setting the ability to respect patients' EoL wishes depended on the physician's philosophy of care and willingness rather than on formal AD documents. With some contradiction, they said that they preferred to know if a patient had an AD document, yet most of them did not attach high value to the document in the process of decision making, as Dr. Paz said:

> 'An AD connected with the right physician is very credible…, …In utmost discretion, in the private home of the patient there is a chance/ if the physician knows him [i.e. the patient] and agrees with him/ there is a chance that it will happen [i.e. fulfilling the patient's wishes]. That's the message: A person, in order for it [i.e. EoL wishes] to happen [i.e. to be fulfilled], needs a physician that believes in this [i.e. in palliative care], and not necessarily based on the [AD] forms. There is no need for these forms' [Dr. Paz].

All three GPs thought that ADs were much more relevant in the hospital setting where the patient is unknown, as are their priorities, as Dr. Paz articulated it:

'If there is no AD they [hospital physicians] will never
[i.e. they can't] respect it [i.e. a non-existent AD]. If
there is an AD there is a small chance that they will
implement [it], because after all, the person meant it [i.e.
expressed a wish]. In the hospital chances are low to
implement an AD' [Dr. Paz].

Regardless of AD documents, the GPs apparently discussed patients'
priorities when they felt the time was right, and they apparently matched the
way in which they discussed EoL wishes to every patient according to their
needs and capability, as they (the physicians) perceived this capability and
these needs.

It was interesting that Dr. Barda thought that even in the hospital he did not
need AD documents in order to abstain from life-prolonging treatments or to
give good palliative care. However, most of the examples he gave were of
patients with capacity who could say what they wanted and did not need ADs
for that.

The GPs described an approach of investigating what the patient wanted to
know and what their priorities were even when relationships were not long-
lasting. As mentioned earlier, home-hospice care usually lasted around a
fortnight. In some cases GPs were caring for dying patients who were not
registered in their surgeries but lived in proximity to their house, for example.
In these cases they only could get to know the patient in their last days of life.

The process of discovering what the patient wants to know was described by
some physicians as difficult, and most of them said that when the patient
initiates such conversation it is easier because:

'Most people who talk about it [their ADs], it is
something that they are talking with death anyway. Sort
of they have this kind of talk and then, they ah…. they
ah… they raise this point' [Dr. Yahalom].

In the relatively small experience with ADs, it seemed that in most cases the
patients addressed the physician regarding ADs when they were already ill.
Patients rarely came to discuss their AD document in good health. Most of the

EoL communication between GPs and patients was held without having made a formal AD-document.

6.3.3 Looking at changes of views and wishes

The three GPs and Dr. Barda (a pneumologist) referred to patients' changes of mind as an acceptable and rather expected occurrence. Dr. Yahalom described it as a constant challenge and viewed it as her role to check repeatedly with patients where they stood and if they wanted something different than they had before. For example, she thought that Ben's (Noa's husband) wish to hospitalise Noa was an example of such a change of a need. She perceived her challenge at that moment to be weighing up Noa's previous statements, in her current condition, and trying to hear her voice, but also trying to support Ben in his distress. Dr. Shalom also legitimized changes of standpoints, saying:

> 'It doesn't mean that they [patients who refuse treatments] don't change their minds. [this is] Legitimate. Sometimes they change their minds late and then the success chances with the valves [replacement] are lower' [Dr. Shalom].

Like Dr. Shalom, Dr. Barda also related to the diminished chances of helping patients when they changed their minds too late, saying:

> 'I also saw people who were very aware…, …people who were very determined with this wish [not to prolong life], that were 'well cooked'[67] on it, thought about it and were determined but in the last moments, when it was not a momentary [i.e. short] process in the emergency room, but when there was a continuous process and they gradually deteriorated in the ward, and then they were willing, cheaply to 'buy' the opposite scenario, that, OK, [they agree to mechanical] ventilation, when the chances to wake up from it was 60% that [chance] of a month

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[67] 'Well cooked' – a jargon expression that means that the person has thought a lot and was ready.

> earlier, and they **did** [loud] get tempted. They **were**
> willing to embrace the more invasive attitude, contrary to
> what they said before…, …I saw this not less than [I have
> seen] people that were determined till the last moment
> [to refuse mechanical ventilation]' [Dr. Barda].

Dr. Paz related to changes of views made in competency, saying that he flowed with the patients' 'here and now', and when a patient changed their mind he went along with the change. Using the example of Dov (the patient in CS7) regarding a change of views, Dr. Paz first said that Dov expressed 'paradoxical' (Dr. Paz's word) behaviours: on the one hand he was radical in his refusal of any life-saving measures in case of incapacity; yet he showed great distress at symptoms and wanted countless tests and imaging. Later in the interview, Dr. Paz said that he believed that as long as Dov maintained capacity he would seek every possible treatment due to his fear of being ill and his wish to preserve his healthy condition as far as he could. At that point in the interview, Dr. Paz viewed the behaviour under capacity and after losing capacity as being different, rather than contradictory.

6.3.4 Helping to make the AD document

From the seven physicians who took part in the study, three (Dr. Barda, Dr. Agmon and Dr. Ash) said that they had never seen a 'real' AD document, although some of them knew of patients who had made ADs. I found it intriguing that although Dr. Barda knew about the existence of such a document in Naomi's case he did not ask to see it, nor had he suggested putting it in her medical file. Four physicians had come across ADs in a variety of ways. Yet only one of them, Dr. Paz, said that he was involved in the making of ADs. He helped Dov to fill out the legal AD forms. Based on his experience, he pointed out that it was a very demanding task that required a few meetings and a significant investment of time, so much so that he was not ready to initiate it with patients unless they explicitly asked him for help:

> 'I want to tell you that to fill the AD document according
> to the law takes over an hour, certainly… certainly… and
> it's difficult. Over an hour… it may [require] few
> meetings till we complete [the process]… and then he

> [the patient] needs to bring the witnesses. That's why many times physicians… a physician who filled [helped to fill the document] once… won't volunteer again. It takes a long time. The documents are not simple at all, at all, at all' [Dr. Paz].

Dr. Paz mistakenly thought that the physician is responsible for the signature of the witnesses, whereas legally the physician has only one responsibility: to explain the different treatment options that appear in the document, in order to make sure that the person makes informed decisions. The rest of the process does not need the involvement of a physician.

Not only was it difficult to help patients fill in AD forms, but the GPs also thought that it was not necessary in order to respect patients' wishes in the home or nursing home setting. All the participating physicians said that they never raised the option of making ADs. It was always the patient who came to them with the idea, the knowledge and premeditation.

6.3.5 Communication about ADs

The three GPs said that they used the occasion when patients presented their ADs or shared the fact that they had such document as an opportunity to discuss patients' preferences and wishes with them. Dr. Yahalom and Dr. Paz seemed to discuss EoL preferences with patients under their care at EoL as a regular practice, especially with long-lasting relationships. For example, regarding his relationship with Dov, Dr. Paz said that he would feel comfortable helping to make decisions for Dov if he lost capacity. He had many discussions with Dov and felt that he understood the spirit of Dov's requests if he were in a condition where he lost capacity.

In contrast, Dr. Shalom said that such discussion was promoted mostly by patients rather than by her. In her experience it happened from time to time, not as a planned conversation, but as a reaction of patients to changing conditions. Apparently she held the view that if it did not come from the patient it would scare them. When I asked her about the possibility of communicating with elderly people in her community about their advance care plan she said for example:

'I think it would depress people. Perhaps it is my own
thoughts. I don't know. It seems to me like saying: "the
hangman is standing outside" or something of the sort'
[Dr. Shalom].

In the hospital setting, there was no such echo of discussions with patients
who came with an AD document for future decisions, although it was a golden
opportunity to learn what the patients' views were. Dr. Barda did say that he
used opportunities when he felt the patient was willing to prepare for their
future, to discuss their preferences if their condition deteriorated further. Some
examples related to conversations with relatives who presented ADs and
written letters on behalf of patients who had lost capacity, but none of the
examples were detailed enough to provide information about the
communication itself.

6.4 How did patients and relatives view the physicians' communication regarding EoL?

It may be regarded as not surprising that the three GPs who agreed to
participate in the study were viewed as very trustworthy by their patients and
by some of the relatives in regard to ADs and respecting EoL needs. In all
three cases a long-lasting relationship had been established, not only between
the patient and the physician but also with others around the patient. Most
often the GP took care of the patient and the spouse or even offspring that
lived in the same community. Dr. Yahalom, who stands at the heart of this
chapter (see Vignette 4 on page 172) was known both to Noa and to her
husband, because she visited Noa at home mostly in the presence of Ben. As
the GP herself described the interaction, it was often a conversation over non-
medical issues and interests, and after so many years a relationship had been
formed not only between the physician and the patient, but including Ben and
other members of the family as well. In the case of Yarden, the GP took care
of both Yarden and Koby, but she was also a member of the same small rural
community and therefore relationships went beyond pure patient-physician
ones. The same applied to the case of Dov who lived in a rural community,
but there were also professional relationships because Dov helped Dr. Paz
introduce computerised systems into the GP surgery, and thus relationships

were again beyond pure patient-physician ones. Although Yoni was no longer living in the village, and Dr. Paz was not practicing as a GP in that village anymore, Dov's trust in Dr. Paz was evident. This was also reflected by the fact that Yoni, who knew how Dov trusted Dr. Paz and how close he felt to him, expressed certainty that Dr. Paz would help him to make decisions regarding Dov, and that he could consult him even though he was not Dov's GP anymore.

I found differences between the deep trust of these patients in their physicians and Naomi's trust in her pulmonologist (lung specialist). Although she described her relationship with him as good, she felt that he had some difficulty in supporting her wishes not to be ventilated. She perceived hesitation in his evasive reaction when she tried to discuss her requests. Although Dr. Barda said (in his interview) that he could easily identify which patient was able to discuss openly and which was not, he also expressed some difficulty in communicating about prognoses, and about advance care plans. He said that Naomi was very determined and that he believed that she had clear idea what she wanted, yet he did not discuss the details with her, not even after her respiratory crisis (see synopsis of CS3). This ambiguity could decrease Naomi's trust in Dr. Barda's ability to support her wishes not to be mechanically ventilated. I suggest that this ambiguity was also demonstrated in the fact that even though Dr. Barda knew about Naomi's AD, he did not ask to see the document, did not recall seeing it, and did not initiate including Carol in a planned conversation to clarify things and to help all parties involved to reach the best possible outcomes in the next crisis. Overall, he did not seem to take any responsibility in preparing Naomi or accompanying her in her last phase of life, but was rather (at least partially) responsive to her requests.

At the other end of the spectrum of looking at the communication between patients and their physicians, stand the examples provided in CSs 2,5,6. In these cases, as will be shown next, patients perceived their physicians as irrelevant partners.

6.4.1 Missing physicians - absent from the study, or from the care?

As mentioned previously, only four physicians related to CSs took part in the study. In another three cases, either the patient refused to address the physician or the physician refused to participate. In these cases it appeared that this refusal may reflect the limited level of communication between the patient and the physician regarding EoL wishes.

Meira for example said that she did not have any individual physician who followed her in her treatments, and that her ADs were not known to her physicians. She also expressed a high level of distrust in the medical staff in the dialysis unit. Ehud said that he did not consider it possible to discuss his EoL plans and wishes with his physician at all because of different values, due to the fact that the physician was religious and Ehud was not. Shelly and Omri felt that communication with their physicians regarding anything that was not purely medical (such as treatments and tests) was out of the question due to the work overload. Omri described this in picturesque yet sad words:

> '[laughing:] It's not important to her [GP].../ ...you don't have a physician with whom you have 'soul conversation' [i.e. conversations regarding emotional aspects].../ ...there is nothing to say [i.e. to expect].../ ...well it [i.e. a GP] is not for plans. Who spoke about plans?.../ ...It's necessary but what can I do? [Let's say] I will go to the physician [and she will ask me:] "what do you want?" [Can I reply:] "Let's plan my life now"? [an interrogative tone]' [Omri, patient 5].

Patients reported that these physicians expressed impatience, frustration and anxiety. All patients were empathic to the distress of the physicians but they seemed abandoned in their emotional and physical distress. They felt unable to 'disturb' their physicians with 'nonsense' such as ADs, EoL wishes or emotional needs. In such an atmosphere it seemed impossible to ask physicians if they would take part in a study about ADs. Unfortunately I was not able to approach these physicians myself, therefore I could not gain their perspective on this. Yet, the mere difficulty of the participants in approaching

their physicians with issues that were important to them (such as ADs and future plans) is more problematic than the physicians' absence from the study. It demonstrated barriers in the patient-physician relationship, and in the degree of trust that these physicians would be their patients' advocates if they lost capacity.

To conclude the part of the chapter looking in greater detail at the experiences regarding ADs, the major findings showed little experience with ADs altogether and not one initiative of the participating physicians to suggest this option to a patient (yet, it should be underlined that Adam, patient 9, said that ADs were suggested to him by his geriatrician). There were more encounters with informal declarations than with formal documents, and there was one example of a physician who had helped a patient make an AD. The GPs referred to the possibility that patients might change their views and wishes as normal. They thought that they needed to 'go with the patient' and adapt to such changes, while taking the opportunity to discuss these changes with the patient. There was a noticeable difference between: (1) physicians who used the opportunity of being given ADs to discuss patients' preferences and to understand their fundamental intent; (2) physicians who related to the AD document as something quite simplistic, whether they filed it away in the patient's records or not. Physicians who felt comfortable communicating about sensitive issues were more prone to discuss ADs while those who felt uncomfortable mostly avoided such conversations.

6.5 Discussion

Several issues emerged from the findings of this chapter. These will be listed to note their presence, but not all will be discussed here due to length limitations of the thesis. Also, some issues are singled out elsewhere in the thesis, as will be indicated. Firstly, differences were seen between the participating GPs and the hospital physicians regarding perceptions of their role, and their communication styles and barriers around patients' EoL. GPs usually looked at the patients' whole illness process, and nearer death they focused on keeping patients in their home setting, as free of symptoms as they could. Hospital physicians on the other hand were more focused on acute events than on looking at illness trajectories as whole processes. They

therefore seemed less able to plan the last phase of life. They seemed reactive rather than proactive, needing *ad hoc* decisions at every juncture. Also, within the group of hospital physicians there were differences in local cultures of discussion among colleagues regarding EoL decisions. In some units there seemed to be a declared local policy, in others not, and this difference in itself seemed to reflect a lack of policy in the overarching health organisation (lack of policy in health organisations was also evident in the survey of health care professionals, as the next chapter will demonstrate). The relationship between physicians and patients' relatives, which appeared in the findings and seems crucial to EoL decision making, will be further discussed in the general discussion chapter.

Postulation about differences between patients coming from rural and urban locations derived from one interview alone. The GP stated that in the urban population it was less easy to bring up EoL issues, whereas in rural communities patients opened up to such conversations more easily. Another element contributing to this could also be that GPs in rural locations developed relationships with their patients that had a greater depth and trust. One statistical support for this claim comes from the latest 'population census' performed in Israel in 2008 by the Central Bureau of Statistics: While the rural population represented 8.2% of the total population in that census (Central Bureau of Statistics, 2009), the proportion of the rural population among 'legal-AD' holders, is 40% (Even, 2013) and similar differences appear from a study performed in the USA and which analysed data from 551,208 admissions to nursing homes during 2011 (Buchanan, Bolin, Wang et al., 2004). Differences between rural and urban populations could be related to other factors (such as different education levels, or physician-patient relationships as suggested above). Nevertheless this may be significant and it is perhaps an area for future research. Another important point made by one GP but also implied by other physicians was that it is more difficult to abstain from action than to be active (i.e. give medical treatments) because abstinence was perceived as contradictory to the medical education. This issue will not be discussed directly here, however it may be one of the factors influencing the low degree to which physicians initiate and/or actively participate in discussing advance care plans and ADs with patients, which will shortly be elaborated on. It may also be related to the fact that only in recent years has palliative care been incorporated into the speciality of family medicine in Israel, and many GPs are

not familiar with the palliative philosophy of care regarding life-limiting illnesses.

In the findings of the current project, there seemed to be a mutual expectation by patients and physicians that the 'other' would initiate sensitive conversations, such as the patient's preferences towards EoL. This has also been revealed in other studies. For example, Almack et al. (2012) report a study with patients who were estimated to be in their last year of life, and which included their relatives and their health carers. Among other things, the study looked at the initiation of conversations regarding preferences of the patients towards EoL. Regarding the question of who should initiate EoL discussion, many patients expected that such a discussion would be initiated by the physicians. Moreover, as supported elsewhere, apparently many of the patients did not want to discuss plans for future care (Almack et al., 2012; Bajwah, Koffman, Higginson et al., 2012; Fried, Bradley and Towle, 2003). Some patients, for example, express fear from 'the evil eye', meaning that they think that talking about death will bring it upon them earlier (Curtis, Patrick, Caldwell et al., 2000). Some patients want to keep open the possibility of a miracle (Detmar, Muller, Wever et al., 2001). Yet Fried et al. (2003) found that the closer to death patients perceive themselves to be, the larger the proportion is of patients who desire to have accurate prognostic information. In my findings all patients wanted their preferences to be known to their carers (both relatives and physicians). As it appeared, patients spoke with physicians who enabled EoL discussions, while others expressed distress and dissatisfaction because such conversations with their physicians seemed impossible. Advance directives were only part of the possible relevant EoL issues that patients needed to discuss with their physicians. Due to the evident gap between patients' levels of satisfaction at their physicians' accessibility to dialogue, I will address the communication barriers of physicians in greater detail. Yet in reading the next section, the reader is advised to keep in mind that when barriers to EoL discussion are mentioned, they mean to include ADs as an obvious part; there is no way to discuss ADs separately from the broader communication about EoL care.

6.5.1 Communication about end-of-life and ADs – are physicians self-protective or overprotecting their patients?

Almack et al. (2012) found that not only patients, but physicians too were often reluctant to initiate sensitive communication. Physicians in multiple studies share worries that, by such initiatives, they may put patients in distress and take away any hope they may have (Almack et al., 2012; Curtis et al., 2000; Steinhauser, Christakis, Clipp et al., 2001). But there are indications that concern for the patients is not the only reason why physicians do not initiate EoL conversations. In an article named: *'breaking bad news: why is it still so difficult?'*, which was published by an oncologist three decades ago, barriers that are attributed to the physicians' side of communicating about EoL were listed and explained (Buckman, 1984). Physicians' barriers were divided into two categories: (1) various fears; and (2) taking responsibility for the bad news itself. Among fears he included were: practising communication without being trained for it; starting an uncontrolled chain of reactions by the patient (especially emotional reactions) and by the self (physicians' emotions); and exposure during EoL conversations to physicians' own vulnerability and mortality. Buckman (1984) explained that some physicians embellish the truth when facing the patient, both to protect their patients as well as to defend themselves. Physicians may over-stress the positive aspects 'here and now' or may be tempted to reassure the patient that everything will be fine. Yet later, when treatments fail, these physicians feel that they have failed to fulfil the promise of a cure. Their only control over the situation at that point is by protecting the patient from knowing the truth. By hiding the truth from the patient, physicians are also protecting themselves from facing the patient at this sensitive time (Buckman, 1984).

Three decades later, there is further significant confirmation in research that breaking bad news is still difficult for most physicians, and many physicians feel ill-equipped to perform this task. Most physicians say that it is important to disclose information that will help patients prepare for their EoL, while avoiding such conversations in many cases (de Haes and Koedoot, 2003). Interestingly, studies that looked at barriers to EoL communication show that health-care professionals often name more barriers related to patients and health-care systems (Anselm, Palda, Guest et al., 2005; Curtis et al., 2000) and far fewer barriers related to their own fears (Hancock, Clayton, Parker et

al., 2007). This tendency to emphasise people other than the physicians was seen in the current findings as well.

Some physicians tend to view patients as 'not yet ready/not wanting to discuss EoL', more so than reports by these patients about their own readiness or desire (Curtis et al., 2000). Not all patients are ready or want to have EoL discussions, and those who do may wish to do it at various stages along the illness trajectory (Curtis et al., 2000; Fried et al., 2003; Kirk, Kirk and Kristjanson, 2004; Knauft, Nielsen, Engelberg et al., 2005). The philosophy of social research postulates countless variations in individuals' needs, and variety is indeed elucidated in research, mostly through qualitative research. Moreover, there is confirmation that patients' needs may change along the illness trajectory (Fried et al., 2003; Kirk et al., 2004; Knauft et al., 2005), which the GPs in the current findings viewed as normal and expected. Based on this identified social variation, guidelines in different countries and organisations suggest patient-centred communication and an on-going process of communication regarding needs of EoL care, in order to provide the best and most individualised care possible (Clayton, Hancock, Butow et al., 2007; National Institute for Clinical Excellence - NICE, 2004). Yet, regardless of these recommendations, evidence shows mainly one-off discussions (if any), rather than repeated encounters to discuss the end of patients' lives (Almack et al., 2012; Fried et al., 2003). Also, there is indication from different clinical specialties that some physicians assess their patients' needs to discuss EoL issues without asking specifically whether and what patients want to know (Curtis et al., 2000; Knauft et al., 2005). Furthermore, some physicians' assumptions about patients' needs are influenced by first impressions (patients who seem satisfied, educated or communicative) rather than on actually knowing those patients' needs (Street, Gordon and Haidet, 2007). Based on their assumptions, physicians may decide if and when to discuss with their patients, and how much information to provide (Hancock et al., 2007) and thus they may be imposing information that the patient is not yet ready to receive. Physicians who make assumptions regarding patients' readiness and/or emotional state are often inaccurate (Curtis et al., 2000; Ford, Fallowfield and Lewis, 1994). On the other hand, physicians who are patient-centred explore patients' needs by asking them explicitly and allowing them to express themselves. There is a growing body of evidence that patient-centred communication allows patients to express themselves as individuals,

and thus provides patients with the support and information that they specifically need with respect to their ability to receive that information. This is shown to produce better health outcomes (Jackson, 2005; Kaplan, Greenfield and Ware, 1989).

Unfortunately, not all physicians know how to individualise communication with patients. Without proper skills they are reluctant to broach sensitive issues and tend to emphasise medical information such as tests and treatment plans (Detmar et al., 2001). Sometimes avoidance of sensitive communication seems to be due to the dread of unknowingly harming the patient. It may also be chosen to self-protect the physician who feels ill-equipped to deal with the emotional exposure to his incompetency or - even worse - to his own mortality (Buckman, 1984).

Communication is known to be a skill that can be learned, and indeed communication skills are incorporated into the programs of health care disciplines in some countries (Steinhauser et al., 2001). It is recognised that physicians' fears are barriers to constructive and empathic communication with patients (National Institute for Clinical Excellence - NICE, 2004). However, there is developing evidence that teaching communication skills is effective (Back, Arnold, Baile et al., 2007; Butow, Cockburn, Girgis et al., 2008) and has positive influences on the rapport between physicians and patients, and on health outcomes (Arora, 2003). Currently, guidelines for EoL care emphasise that teaching communication skills to health care professions is imperative. Guidelines stress that communication education programs need to: include large components of experiential learning; allow for reflection and self-awareness; provide a safe environment for learning based on constructive feedback; be a process of learning over an extended period (National Institute for Clinical Excellence - NICE, 2004). It should be considered that in order to produce long-lasting learning of communication skills and to apply such guidelines, sufficient resources need to be allocated.

Much of the data in this chapter relates to communication. Good and longer-term communication promoted more patients' confidence while poor communication provoked mainly discomfort and distress in patients. I suggest that communication barriers related to physicians as well as to other health care professionals are one of the reasons for the rarity of treatment refusals witnessed by the participating physicians in this study. Feeling unskilled to

engage in sensitive communication, in addition to the commitment not to harm the patient, probably impedes many health care professionals from initiating EoL conversations, including wishes related to medical treatments in the last phase of life. The discomfort that was expressed here and in other research may be one of the explanations why physicians prefer not to initiate such conversations, although many admit that these conversations should be carried out and are important to patients and relatives (Steinhauser et al., 2001). Whether avoidance of communication at EoL is explained by patient's (over-)protection or by physician's self-protection, it mainly reflects these professionals' under-developed skills in communication. Providing physicians and other health care professionals with proper tools will give them better emotional readiness and communication skills. This will undoubtedly encourage them to communicate more and probably to initiate EoL discussions with patients and relatives more often, according to their patients' needs, with less fear and less vulnerability for both partners.

6.6 Conclusion

This chapter aimed to respond to three of the study's research questions. First, to explore the extent to which the expectations of patients with ADs are met by their formal carers during the delivery of care towards and at the end of life. This question received only limited testimony in the data. It is a question requiring further exploration in the future and which may require different approaches, perhaps using longitudinal studies. Second, it was intended to examine the potential contribution that ADs have in the palliative care of people with LTC, from the perspective of their physicians. Although some participating physicians had limited knowledge regarding ADs and how to use them, it was suggested by the participants that ADs may serve as a platform to discuss EoL preferences with patients on the one hand, or they may be used as intended, to represent incapacitated patients mainly in hospital settings where these patients are less well known than in the community. The third research question was to examine health professionals' knowledge and attitudes relating to ADs and their perceived role in the process of making ADs. This question produced the most copious data. The findings showed variety and breadth of experiences that overall elucidated a lack of knowledge regarding ADs specifically, as well as more broadly indicating a great deal of

missing knowledge in palliative care and communication skills. These findings can give additional support to previous evidence of communication barriers that need to be surmounted. They show quite clearly that in order to deal with ADs, health care professionals need to overcome communication barriers. Advance directives are part of EoL discussion and planning, but it is difficult to distinguish barriers specific to ADs as long as death and dying are mostly intimidating for health care professionals. Hopefully, with improvements in communication skills and less avoidance of communication around EoL there will be more room to focus on barriers that are related specifically to ADs.

The next chapter will provide additional support to the findings of this chapter, by adding the results of a survey of health care professionals regarding ADs.

CHAPTER 7: FINDINGS FROM THE SURVEY

7.1 Introduction

As mentioned in Chapter 3 (the methodology chapter), examining how advance directives (ADs) are viewed and understood by health care providers (HCPs) in the Israeli health system was viewed as complementary to the case-study element of my research. This angle was initially explored by Bentur (2008), who conducted her research after the enactment of the 'Dying Patient Act – 2005' (DPA) and the legalisation of ADs in Israel (The Dying Patient Act, 2005). Bentur (2008) used focus groups to explore geriatricians' and family physicians' knowledge of and attitudes towards ADs (Bentur, 2008). Her findings will be presented and compared with my study in the discussion part of this chapter. Bentur's (2008) study is of particular relevance because she suggested learning further about the current situation in Israel by using a larger sample, by including other health professions, and by looking at various clinical fields (Bentur, 2008). This was the aim of the quantitative element of my project, and it was intended to be achieved by surveying the existing ability (knowledge, attitudes and experiences) in the health system (various disciplines in different clinical fields) to deal with ADs. As will be revealed, only a limited sample could be reached within the data-collection period. This chapter will describe the findings of the survey and discuss those findings in relation to previous literature, especially Bentur's (2008) findings in Israel, and Schiff et al.'s (2006) findings in the UK. This chapter will also evaluate the survey's limitations and strengths.

7.2 Methods

7.2.1 The questionnaire - an overview

The questionnaire, based on one developed by Schiff et al. (2006), was adapted both linguistically and culturally (see Chapter 3 for details, and refer to Appendix E). It contained seven sections, composed of different numbers of questions in each part. Most were closed-ended questions, and some were open-ended. The closed-ended questions were of two types: one type in

which participants had to select the **most suitable answer** among the given choices, and another type in which they were asked to choose **all the options that were relevant** to them; they also had an additional option: *"other",* in which they could write choices that were not listed. There were a few screening questions that formed 'junctions' where participants for whom subsequent questions were irrelevant were referred to the next relevant section. The questionnaire addressed three main issues, listed below:

- *Knowledge* regarding the Israeli "Dying Patient Act – 2006" (which regulated ADs and provided a pro-forma[68] for making them) and regarding AD-related policy in the respondent's workplace.
- *Attitudes* toward: the concept of ADs; role perception of communicating about and helping to complete ADs; and the idea of a pro-forma for ADs.
- *Experience* with: communicating and helping to make ADs; caring for a patient who has an AD; and participating in carrying out an AD in a patient's dying process.

7.2.2 Recruitment

The recruitment plan, as well as the changes introduced in it, has been discussed in the methodology (Chapter 3). The actual recruitment happened during a national palliative care conference which addressed HCPs who care for people with a variety of long term conditions (LTCs)[69], in hospitals and in the community, and which took place in Israel, in February 2011.

7.2.3 Response

Seventy-seven HCPs agreed to fill in the questionnaire (90%). Eight individuals declined because: they felt uncomfortable with a questionnaire in Hebrew (n=4), they were giving an oral presentation at the same conference and were too tired to fill in the questionnaire (n=1), or they declined without explanation (n=3). Five of the 77 questionnaires filled in were excluded due to various reasons:

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[68] Pro-forma- i.e. a form or document of a standard type used in every situation, not designed especially for a particular situation (Encarta)

[69] Examples for LTCs considered: Cancer, neuro-degenerative conditions, organ failure (Renal /heart /lung).

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- Filled in by a spiritual counsellor (which was not one of the included disciplines) (n=1)
- Only odd pages were filled in (n=1)
- Too incomplete to be analysed (n=3)

The analysis that is presented in this chapter is therefore based on 72 completed questionnaires.

7.2.4 Data analysis

Data were analysed using SPSS statistical software, version 17. Analysis is mainly descriptive because of the fact that two of the disciplines (physicians and social workers) were under-represented (n=8 and n=7, respectively), and did not allow 'within and between group' comparisons or the use of statistical tests in a manner significant enough to compare the three disciplines. Consequently, the results in this chapter will relate to the whole sample and will include the three disciplines.

7.3 Results

7.3.1 The sample

The final sample (N=72) comprised 57 nurses (79%), 8 physicians (11%), and 7 social workers (10%), aged 28-70 (Mean=49.3; SD=9.8). The sample was uneven in other respects (see Table 13, below), such as gender (n=66, 92% females), profession (n=57, 79% nurses) and religion (n=66, 92% Jewish). The most common traits of the sample participants were: secular (n=49, 68%), from the field of oncology (n=37, 51%), worked in hospitals (n=35, 49%), and had over 11 years of professional experience (n=51, 71%).

Table 13: General description of the survey's sample (by profession)

		Profession			
		Physician	Nurse	Social worker	Total
Gender	Male	5	1	0	6 (8%)

	Female	3	56	7	66 (92%)
Religiosity	Religious	2	8	3	13 (18%)
	Traditional	1	7	0	8 (11%)
	Secular	3	42	4	49 (68%)
	None applicable	1	0	0	1 (1%)
Religion	Judaism	6	53	7	66 (92%)
	Islam	0	1	0	1 (1%)
	No religion	2	1	0	3 (4%)
	Other religion	0	1	0	1 (1%)
Medical domain	Oncology	1	35	1	37 (51%)
	Cardiology	0	1	0	1 (1%)
	Geriatric	5	10	5	20 (27%)
	Other domain	2	5	1	8 (11%)
	More than 1 domain	0	4	0	4 (6%)
Years of experience	1-5 years	1	7	3	11 (15%)
	6-10 years	0	9	1	10 (14%)
	11 years and above	7	41	3	51 (71%)
Place of work	Hospital	3	31	1	35 (49%)
	Geriatric institution	2	4	0	6 (8%)
	Community	2	13	3	18 (25%)
	Other	0	6	3	9 (13%)
	More than one	1	3	0	4 (6%)

7.3.2 Health professionals' knowledge, attitudes and experiences regarding ADs

The findings that emerged from the survey are first presented and then compared with prior evidence in the literature. The qualitative data provided in the answers to open-ended questions and other comments were summarised and added to the description of the quantitative data where relevant.

7.3.2.1 Knowledge

The Dying Patient Act (DPA)

All the participants (n=72, 100%) reported knowing about the existence of the DPA. Yet, 8 (11%) did not know its content although they had heard about it; 26 (36%) had participated in a lecture about the DPA; 46 (63%) had read it; 32 (45%) knew the appendices of the DPA[70]; 14 (20%) knew about the national pool for ADs in the Israeli Ministry of Health and 7 (10%) had taught about the DPA.

Institutional policy regarding AD

Most of the respondents (n=66, 92%) worked in health organisations. Of those, 13 (20%) answered 'yes' about the existence of an advance care plan (ACP) policy in their workplace, 38 (53%) answered 'no' and 15 (23%) answered 'not sure'. To the question whether AD or ACP forms were available in their workplace for patients, 44 (61%) replied 'no'; 12 (17%) replied 'don't know' and 10 (15%) replied 'yes'. Those who replied positively said that these forms related to 'various health conditions' (n= 9, 90%) or 'DNR'[71] (n=1, 10%). Of the 66 respondents who answered the question regarding the availability of an AD or ACP form in their institution, 10 (15%) reported that these forms were available, and most of the latter answered the open questions as well, which related to *content*, *strengths* and *weaknesses* of the forms (9, 9 and 7 comments, respectively) as detailed below.

Content of the ACP/AD forms in workplace as reported by respondents

In an open question regarding the health conditions that AD or ACP forms covered in their institutions, 9 of 10 (90%) respondents provided answers which addressed other issues as well. Two (20%) said that they did not know or did not remember the content, while others mentioned:

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[70] The appendices include the pro-forma for AD and/or for appointing a legal power of attorney, among other documents.

[71] DNR – A 'Do Not Resuscitate' order, to prevent cardio-pulmonary resuscitation efforts in case of cardiac or pulmonary failure.

- Health conditions covered by the form (mental incapacity and terminal illness)
- Medical interventions that can be refused or chosen ('wide range, down to the level of (i.e. including) antibiotic treatment', 'including the wish for inserting tubes into them')
- The possibility to nominate a legal power of attorney (LPA)

The view of HCPs regarding strengths of AD/ACP forms in their institution

To an open question regarding the strengths of the institution's AD/ACP form, 2 out of 9 answers (22%) were general (the positive aspect of the option to express wishes and to have a plan for end-of-life (EoL) in advance); 3 (33%) respondents said that they did not remember or know enough; while 3 others were more specific:

- The benefit of nominating a decision maker by the patient, rather than having to have the court nominate a legal guardian at a later date.
- The form being clear and detailed, covering all treatment possibilities (n=2, 22%).

The view of HCPs regarding weaknesses of AD/ACP forms in their institution

Respondents mentioned a few weaknesses regarding the form (ACP or AD) that existed in their workplace, in free text, saying that: (1) It is not applied in reality; (2) It is difficult to decide the right timing to carry it out; (3) The form was too long and detailed (n=2); (4) It did not detail enough hypothetical medical situations and it did not refer to DNR (n=2); (5) HCPs need to explain the forms to the patients.

Possible complexity around AD/ACP forms was illustrated by the fact that some respondents thought that patients depend on HCPs to explain the AD form to them, while others thought that it was difficult to understand the content themselves, suggesting that they may not be able to help patients on this matter when the need arises.

7.3.2.2 Attitudes

Two probing questions were addressed to the whole sample: (1) *'How do you feel about the use of ADs?'* (Answered by 71 (98%) of the respondents), and (2) *'Are there advantages to the use of ADs?'* (Answered by 72 (100%) of the respondents). Most respondents had positive attitudes to both questions (*see* Table 14 below). It is interesting that two respondents added notes beside the first question. One described embarrassment and confusion ('I don't know how I feel') and another wrote that it is important to allocate time for communication about ADs ('to give more space for this issue when communicating with the patient and his relatives').

Table 14: Health care providers' attitudes toward ADs

'How do you feel about the use of ADs?' (n=71)	'Are there advantages to the use of ADs?' (n=72)
Comfortable (52, 73%)	Yes (65, 90%)
Concerned (4, 6%)	No (1, 1.4%)
Not sure (15, 21%)	Not sure (6, 8%)

Health care providers' concerns related to the concept of ADs

The question, '*What could be worrying about ADs?*' was addressed to the entire sample and participants could choose all the applicable answers (out of six options) and add ones that were not listed. Seventy respondents (97%) answered this question. The rate of response ranged from 22 (31%) who ticked concern about the 'slippery slope'[72], to 48 (67%) who feared the gap between wishes expressed in ADs and the family or community's ability to execute them (see details in Table 15, below). There were 10 additional comments in the open category which are described and discussed later (Table 21, page 225).

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[72] 'Slippery slope' is an expression to describe the moral fear of a gradual process starting with allowing a change that seems relatively harmless to morality and gradually allowing further changes, resulting in currently unthinkable behaviours or norms becoming accepted.

Table 15: Concerns related to the concept of ADs (n=70)

Statement	n (%)
Wishes expressed in ADs cannot be fulfilled by the family or community	48 (67%)
Lack of uniform mechanism to deal with patients with ADs	34 (47%)
Potential for coercion by others	32 (44%)
Difference between coping in reality and the theoretical fears that led to formulating ADs	31 (43%)
People may complete ADs without understanding the implications of their decisions	30 (42%)
Option for shortening life – fear of the 'slippery slope' (see footnote on the previous page)	22 (31%)
Other (listed in Table 21, page 225)	11(15%)

Health care providers' positive attitudes toward the concept of ADs

In their response regarding the advantages of ADs, participants could choose all the applicable options and add ones that were not listed. The rate of positive response to all the suggested options was high (n=47-60, 66%-85%), and it is listed in greater detail in Table 16 (next page).

Attitudes toward communication about and helping to make ADs

Attitudes toward communication about ADs referred to participants who did not experience discussing or helping others to create ADs (n=36, 50%). They were asked *'What are possible explanations for not having experienced discussing ADs?'*, and were provided with a choice of answers. Twenty nine (81%) inexperienced respondents answered that no one had made such a request from them; 14 (39%) did not know how to do it; and 7 (19%) felt uncomfortable and explained their discomfort in free text:

- Such conversations may suggest that the treatment will not succeed (i.e. reflect pessimism).
- It is a sensitive issue and not pleasant to mention.
- HCPs fear the reaction of the person they talk to.
- HCPs lack knowledge about legal and other aspects of AD that are unclear.

Table 16: Positive aspects of ADs in HCPs' view (n=72)

Statement	n (%)
Provide a useful insight into someone's wishes to inform about a health-care choice	60 (85%)
Provide peace of mind for those concerned with losing the ability to communicate	60 (85%)
Provide a legal stance for someone's wishes when they can no longer express themselves	60 (85%)
Provide respect and humanism	58 (82%)
Help convey a person's wishes to his relatives	57 (80%)
Help an individual define his wishes for himself	54 (76%)
Aid communication and end-of-life care planning, and identify the AD-producer's fears	54 (76%)
Provide sense of control over life	51(72%)
Might reduce inappropriate hospital admissions of terminally ill patients	47 (66%)
Other (open responses): • Promote communication with family and reduce escapism when discussing EoL • Help cope with feelings of loss, closure and separation processes • Give a sense of control over dying • Provide reassurance to the staff that they may abstain from treatment • Reduce tensions among family members	3 (4%)

One participant (3%) said it was not his/her job, but no one (0%) said that it was against their belief. In the open category there were 7 additional *'explanations for not discussing ADs*':

(1) It is the responsibility of the social worker.

(2) Feeling rejection by the staff in addressing this issue.

(3) Not having the opportunity to do it in the current position (n=2).

(4) Lack of information for carers and patients and lack of public awareness of this issue.

(5) Feeling unknowledgeable about it (n=2) ('*I didn't encourage him to address me on this issue*').

(6) Not having the relevant forms.

The overall impression was a lack of confidence and tools to engage in such communication.

Attitudes toward the idea of pro-forma for ADs

The screening question was: *'Do you find a pro-forma for ADs useful?'*. The responses (n=71, 99%) were split between 3 categories: 'yes' (n=63, 88.7%); 'no' (n=4, 5.6%); 'not sure' (n=4, 5.6%). Those who replied positively or hesitated (n=67, 94%) were invited to list the positive aspects of a pro-forma for ADs and to list all the issues that should appear in such a pro-forma. The aspects suggested in the questionnaire were generally highly selected (by n=46-54, 69%-81% of the 67 respondents to this question), and details appear in Table 17 in the next page. One participant (1.5%), contrary to the others, supported an open form, which is personal and adapted to each individual. Issues that should appear in such a pro-forma were also relatively highly selected (by n=39-58, 61%-87% of the 67 respondents to this question). Yet, the option to include in the pro-forma: *'a request for an active ending of life in case of unbearable suffering from a terminal illness'* was the least selected, by 32 (47%) respondents.

In some of the open comments it was not clear whether respondents addressed the idea of a pro-forma specifically or ADs more generally. In the open category, additional suggestions were to include (in the pro-forma):

(1) Palliative care only
(2) Not to prolong life artificially if the illness reaches most of the vital organs (liver, kidneys and lungs)
(3) To enable artificial sedation if necessary

7.3.2.3 Experiences

Questions addressing the experiences of HCPs regarding ADs were threefold: (1) Discussing and helping to make AD documents; (2) caring for patients with ADs in general; and (3) experiencing AD implementation while the patient is under the care of the staff. Each of these experiences will now be expanded upon.

Table 17: Health care providers' views on positive aspects of AD pro-forma (n=67)

Statement	n (%)
Providing a tool to express the wishes of patients who have lost capacity	46 (69%)
Enabling uniformity that makes it easier for HCPs to deal with such a form ('forms a common and uniform language in a 'sea of terms'')	54 (81%)
Being easier to fill in	46 (69%)
Enabling the most commonly relevant medical conditions to be listed	48 (72%)
Helping educate HCPs on how to communicate about EoL issues ('understanding of the matter').	46 (69%)
• Other (open responses): • Helps prepare people for what they may expect • 'Balances expectations of patient/HCP/family' • '"Makes order" and puts emphasis in the proper places' • Explicitly exposes carers to the wishes of the patient • Enables one to help patients more professionally	7 (10%)

Discussing and helping with ADs

Thirty six participants (50%) answered that they had experienced discussing or helping to make ADs, most commonly by helping a patient (n=27, 75%); but also by helping relatives (n=11, 31%) and friends (n=5, 14%). The feelings that were explored were 'unpleasant' and 'pleasant' in nature. The unpleasant ones selected were: not knowing enough about the legal aspects (n=8, 22%); stress from dealing with end-of-life issues (n=5, 14%) and embarrassment (n=4, 11%). The pleasant feelings were: happiness at being able to help (n=22, 61%); comfort in own ability to help (n=10, 28%) and satisfaction (appeared in free text).

Caring for patients with ADs

Thirty six participants (50%) answered that they had experienced caring for patients with ADs, although for most of them (n=27, 79%) this was with three or less patients (Table 18, next page), and 2 (6%) did not answer with how many patients they had this experience. Of the 36 participants with experience, 27 (75%) replied to the question: *'Did the existence of ADs affect discussion about their medical condition with patients?'*: Nineteen (70%)

answered positively and 8 (30%) negatively (i.e. that it did not affect discussion). Those 19 who replied positively were asked to select which of the statements best described the effect of an existing AD on care: 16 of 19 (84%) found it easier to discuss EoL issues with patients; 14 (74%) found it easier to discuss EoL with patients' relatives; 5 (26%) spent more time discussing health issues with patients. However, some thought that the time they dedicated to communication with patients (n=7, 37%) and their relatives (n=4, 21%) was unreasonably increased. One (5%) respondent thought that the effect of ADs was only negative. This participant added in writing the emotional difficulty induced by the exposure to death and subsequent related thoughts.

Table 18: 'How many patients with ADs have you cared for?' (n=34)

Number of patients with ADs	N	%
1-3 patients	27	79%
4-6 patients	3	9%
7-9 patients	2	6%
> 10 patients	2	6%

Carrying out ADs while the patient is under staff's care

Twenty (28%) respondents answered that they had experienced AD implementation while caring for a patient. They were asked: (1) whether the AD was known to them before hand, and if so: whether it was kept in the patient's official record; (2) whether they consulted any source about legal issues regarding the AD, and if so what was the source of information; (3) whether the treatment differed, and if so in what way; and (4) was their overall experience with ADs that they made health care decisions easier, more difficult, or had no effect on them.

Table 19 (next page) demonstrates the flow of questions regarding experience with executing ADs, the categories of answer and relevant number of responses. Some of the questions were answered by fewer than 20 respondents, because they addressed those who had a specific experience. For those questions, the number of potential replies is indicated specifically (for example: *'What was the effect of this change?* (N=12)', see Table 19, below).

To the open question '*How did the treatment differ?*' 9 participants answered in free text, relating mostly to potentially invasive treatments that were spared from those patients (resuscitation, intubation, tracheostomies (n=2), mechanical ventilation), and antibiotics. Alternatively, they wrote that the patients were followed up by the staff to preserve their optimal condition until death; patients' wishes were respected and alterations in care were made accordingly, and health care staff was released from confusion around invasive ('tiring') procedures.

Table 19: Experiences with effecting ADs (N=20)

Were ADs known about before the time came to apply them?	never	n=0					
	sometimes	n=9					
	always	n=11	→ Was the document in the patient's record? (N=11) [*1]	(missing)	n=1		
				don't know	n=0		
				no	n=3		
				yes	n=7		
Were legal issues regarding ADs discussed with other sources?	(missing)	n=1					
	no	n=6					
	yes	n=13	Sources (various): Legal, ethical, organisational, professional				
Did the treatment differ from that given to other patients due to ADs?	(missing)	n=1					
	no	n=7					
	yes	n=12	→ How did the treatment differ? (open question)				
			→ What was the effect of this change? (N=12)	neutral	n=2		
				negative	n=1	→ In what way? (open question)	
				positive	n=9		
Overall effect of ADs on end-of-life decision-making	(missing)	n=2					
	no change	n=0					
	harder	n=2					
	easier	n=16					

*1: This question was incorrectly placed in the questionnaire and thus concealed (by error) from those who replied 'sometimes'

Interestingly, to the open question in what way was the effect of ADs on care negative, two answers were positive: '*The family fought for his wishes and they were respected!*'; '*More personal care with emphasis on quality of life and pain control*' and no open answer related to negative aspects. The positive aspects of having AD guidance for patients' care at end-of-life, as expressed in free text by 8 out of 10 respondents, are listed in Table 20, below. As one of the respondents added: '*This specific patient suffered less needle stabs and survived wondrously although treatment was suspended*'.

Table 20: Positive aspects of having ADs guidance for patient's care at end-of-life (N=8)

- Encouraging communication with patients and family members.

- Preventing unnecessary interventions ('less needle stabs')

- Preventing prolongation of suffering

- Encouraging deliberation prior to any intervention

- The staff and family know in advance the preferences of the patient for medical care

- The patient and family control their life, in contrast with the alternative offered by health staff

- More respectful death

- Staff are more calm

7.4 Discussion

7.4.1 Knowledge

The data showed that all the survey respondents knew something about the DPA, which determines the legal foundations for ADs in Israel, and this is different from Bentur's findings just a few years earlier (Bentur, 2008). In her study, there is evidence of ignorance of the DPA in general (illustrated by calling it a 'euthanasia law') and of ADs in particular: not one person in her study, which included 40 physicians, had seen the legal AD pro-forma prior to meeting the researcher (Bentur, 2008), whereas in my study 45% (32/72) said they knew about this document and 63% (45/72) said they had read the DPA. The data about policies regarding ADs and ACP in my survey showed a variety of policies (as well as 'no policy') in different institutions, and confusion about their availability and content, which may be illustrative of a problematic area. Similar confusion and lack of knowledge appeared among geriatricians in the UK although the ratios differed (Schiff et al., 2006). Statements about the complexity of the legal AD forms appeared in Bentur (2008), and some of her participants argued that this was done purposefully to discourage people from making ADs. Yet these were most probably preconceptions based on rumours, since no participant in Bentur's (2008) study had apparently seen

the legal AD form prior to her meeting with them. In addition to the different research tools, the major difference between the studies of Schiff et al. (2006) and Bentur (2008) was the timing of research: the study in the UK surveyed physicians prior to the enactment of the Mental Capacity Act, while the study in Israel investigated physicians after a similar legislation (Bentur, 2008; Schiff et al., 2006). Interestingly, the findings show greater familiarity in UK before legislation than in Israel after it. Yet four years later, as is evidenced by the current findings, it seems that knowledge of HCPs regarding ADs has started to take root, at least by PC professionals.

7.4.2 Attitudes

The fact that the majority of respondents (65, 90%) thought that ADs had advantages and 52 (73%) felt comfortable with the use of ADs does not imply simplicity or necessarily an achievement. All those who felt comfortable, except one, also pointed at potential worries with the use of ADs. Yet again, there were higher tendencies to select positive aspects than worrying ones. Both Schiff et al. (2006) and Bentur (2008) found positive attitudes alongside concerns regarding ADs, as I did. Schiff et al. (2006) reported that of the 713/779 (92%) of the geriatricians who saw advantages in the idea of ADs, two thirds (n=467) expressed concerns. The view that ADs are negative was rare in their study (2%) (Schiff et al., 2006). Bentur (2008) voiced ambiguity among the physicians that she interviewed, who expressed positive views about the idea of having ADs, but presented 'a long list of barriers and obstacles to their personal involvement… concerning the medical system… and… the law itself' (Bentur, 2008:363). I suggest that the findings of all three studies demonstrate not simply lack of knowledge about law and policy, but also an inherent complexity in ADs, which while they have many positive aspects, also create various difficulties for patients, relatives and health carers as well as health care institutions (hospitals, nursing homes and community services). This claim is supported in the previous chapters and will be discussed in the next chapter.

Different concerns were expressed in my study and the other two studies (Bentur, 2008; Schiff et al., 2006) (see Table 21, below). I have listed them side-by-side in the table to show them more clearly; however, I do not think

that they need to be compared but rather grouped together. They need to serve in their entirety as a platform (growing with additional concerns that may arise in future studies and in the field), to inform policy and practice.

Table 21: Concerns regarding the concept of ADs in open categories in three studies

My study	(Schiff et al., 2006)	(Bentur, 2008)
• Potential change in people's views in health and severe illness • Gaps between the wish of the patient and those of his relatives • Ambiguities and unclear role of health carers in executing ADs • Concern about people's motivation in making ADs • Unavailability of clear and simple information to the public at large • Unawareness or unavailability of ADs in relevant health care 'junctions' at the moment of critical decision-making.	• Validation of capacity at time of completion • Potential to miss undiagnosed depression • Extrapolation of views in living will that are similar but not identical to those situations that have been foreseen	• The medical role is to save life, not to withhold care • No guidelines are in place • Very time-consuming task • Patients may have fluctuations in mental state • Long, complicated document • Patients may have last minute regrets • Difficulty of determining a prognosis of <6 months, to allow the execution of ADs

The participants who had not been involved in discussing or creating ADs in my study were invited to explain their lack of experience. This was a new question that did not appear in the original survey (Schiff et al., 2006), and that was aimed at exploring attitudes toward communication about EoL or ADs. The answer 'no one has approached me with such a request' was selected often in my study, and appeared previously (Bentur, 2008). It is explained by respondents in my findings, mainly by lack of knowledge of how to communicate about ADs and EoL issues, and by embarrassment at such communication. Lack of knowledge and embarrassment were selected mainly by the same participants who claimed that no one had approached them. These findings strengthen the interrelatedness between ability and taking action in initiating communication about EoL issues. This was found in

previous studies as well (Bentur, 2008; Lipson et al., 2004; Schiff et al., 2006). Another support for this correlation comes from the findings of Cartwright, Onwuteaka-Philipsen, Williams et al. (2007), which looked at communication with terminally ill patients by 9,396 physicians from 7 countries and a variety of clinical domains. They found a higher level of communication around emotional and spiritual issues among those who had palliative-care training (Cartwright et al., 2007).

Communication barriers often appear to hinder HCPs from discussing EoL issues, ACPs and ADs. The communication competency (or incompetency) barrier is added to the complexity inherent in ADs, as was demonstrated in earlier chapters and as will be discussed in the general discussion and conclusion chapter (Chapter 8).

7.4.2.1 Attitudes toward the idea of a pro-forma for ADs and its content

In the parallel study (Schiff et al., 2006) there was little emphasis on the answers to the question regarding the idea of a pro-forma for ADs, and I would like to expand on this issue due to the responses I received regarding the benefits of using a standardised form. Among the benefits that were listed:

- An **educational** tool, for HCPs ('Understanding of the matter' and learning how to communicate better on these issues') as well as for patients (knowing what may lie ahead of them), to whom I also add the general public.
- A **communication** tool between patients, their relatives and HCPs, that may help balance the expectations of the parties involved and set the ground for open discussion. Some basic issues are clearly written out, and people can then develop ideas further rather than needing to 'reinvent the wheel'.
- **Familiarity** with the form was another issue that emerged from the data. Having a common uniform document makes it easier for those who will in due time need to consider ADs, especially within the time constrains of HCPs which appeared so problematic in my study and in others (Bentur,

2008). Such uniformity makes it easier to identify the 'extraordinary' since it is placed in designated parts of the form. For example, the pro-forma of the Israeli DPA has some personal open-ended parts where individuals can state anything that does not fit into other parts and ordinary categories, in *'personal orders that are not listed above'* (The Dying Patient Act, 2005: 76).

Contrary to the 'pros' of a standardised form for ADs, there are those who support the opposite, i.e. using open documents or other methods, such as audio-taped or audio-visual statements (Kendrick and Robinson, 2002; Moseley, Dobalian and Hatch, 2005), in which people can express their world views and EoL wishes with total freeness. The benefit of these options is that they permit a much greater freedom of expression, while drawbacks include, for example, greater difficulty for HCPs and relatives in extracting from such documents practical requests. In addition, it may be difficult to legalise statements that are not standardised, and this may call for the addition of non-standardised statements to formal ADs (Moseley et al., 2005).

7.4.3 Experiences

7.4.3.1 Discussing or helping with ADs

The overall experience in discussing or helping with constructing ADs appeared to be more satisfactory than worrying to the respondents, and was reported to be practiced by a relatively large proportion of the sample (n=36, 50%) in comparison with the study in the UK, in which only 6% (45/809) reported a similar experience (Schiff et al., 2006). Due to the difference in sample sizes, and the small scale size of my sample, it is difficult to compare the two, yet the difference in proportion (rather than in absolute numbers) is significant, and calls for further exploration. Possible reasons for the difference may be the fact that in the UK the sample included physicians, while my sample included those working in other disciplines, mostly nurses but also social workers. The latter sometimes view their role as including communication about EoL wishes, including the possibility of documenting them in writing (Black, 2006). The difference may be otherwise associated

with the palliative-care orientation of my sample as supported in previous research (Cartwright et al., 2007), although this information is not available in the parallel study (Schiff et al., 2006). In view of the current disproportion between my sample and that of Schiff et al.'s (2006), I find little significance in attempting a comparison between the findings from the UK and Israel. However, it is suggested that by using larger samples in the future, and by accumulating findings from physicians in Israel in significantly higher numbers than those presently attained, there will be more acceptable grounds for comparison (see Chapter 8 regarding steps in this direction).

7.4.3.2 Caring for patients with ADs

Thirty six participants (50%) in the current survey answered that they had experienced caring for patients with ADs. Most of them (n=29, 79%) reported little experience, with only 1-3 patients. In the UK the experience was 56% (454/811) and the extent of the experience was not explored (Schiff et al., 2006). The question regarding the scope of the experience was added to the current survey due to a preliminary estimation that experience with ADs in Israel is limited. The findings suggest that the knowledge that a patient had an AD seemed to motivate HCPs to communicate with the patient and their relatives. It was perceived as positive by most participants, yet it proved an added burden for HCPs because it demanded additional tasks in time that was allocated to other care tasks. End-of-life communication, although theoretically expected from HCPs (for example in the DPA), is not usually considered in the time allocated for patient encounters, especially with physicians. Nurses and social workers are not as yet allocated time for their encounters with patients in the same strict way as physicians. Time shortage was described by those participants who viewed the effect of having ADs as positive; a finding which proposes that a lack of time was not used as an excuse but was a genuine obstacle, at least in some cases, to communicating with patients in a meaningful way.

7.4.3.3 Carrying out ADs while the patient is under respondents' care

Findings from the current survey suggested that 56% of HCPs who experienced taking care of patients with an AD had done so when the AD was effected. In the UK, the reports were of 62% of the geriatricians who participated (Schiff et al., 2006). A previous study conducted in Israel regarding knowledge and attitudes of physicians about ADs (Bentur, 2008) did not report on physicians' experiences when ADs were executed. Schiff et al. (2006) reported that 39% of the physicians who experienced effecting an AD under their care felt that ADs directly affected treatments they provided, and 54% of them perceived the change as improving the care that was delivered (Schiff et al., 2006). In the current survey, 75% perceived the change of care due to the existence of an AD as positive. Responses to an open-ended question regarding the positive effects of having an AD for EoL decision-making were varied in both studies (my study and Schiff et al.'s 2006) and included: easier communication and a consensus between HCPs and relatives; helping to make decisions easier in difficult situations; and allowing palliative care rather than aggressive care, which was viewed as more respectful to the patient and more reassuring to the staff.

To summarise, the first part of the discussion analysed the findings regarding knowledge, attitudes and experience regarding ADs. Knowledge was greater than that found in a previous study (Bentur, 2008). Attitudes toward the concept of ADs were positive, yet there was evidence of a gap between attitudes and the perceived ability to engage in actions regarding ADs, such as communicating about them with patients. The experience of HCPs regarding ADs was positive. There was evidence of HCPs' positive feelings when they discussed ADs with their patients, and when ADs were discussed and applied in patients' EoL care. Yet HCPs experienced difficulties and burdens that raise the need for further exploration and a search for appropriate remedies. The next section will look at the limitations of the survey.

7.4.4 Limitations and biases of the survey

The main aims of surveys are to provide accurate measurements and the ability to generalise the findings from a sample to the larger population (Bruce, Pope and Stanistreet, 2008). This requires having: a clear idea of what we are looking for (i.e., what we want to measure); high-quality measurement tools that are able to measure exactly what we want to quantify; knowledge about the population that we want to survey; and effective tools to sample that population, in order not to have to measure it fully on the one hand, while being able to infer from the sample to the rest of the population with a high degree of assurance on the other (Bruce et al., 2008). Ideally, researchers should ensure that all these requirements are met, but in the real world some scenarios may differ, time and other resources may be short, and often researchers only answer these requirements in a partial way (Bruce et al., 2008). This in turn may reduce both accuracy and representativeness, but may still allow something meaningful to be learnt, even if it is neither perfect nor absolute.

In my study, I would maintain that the measurement tool did indeed measure what it was supposed to: the knowledge, attitudes and experiences of health professionals. The questionnaire was piloted in a previous study (Schiff et al., 2006) and a second time, after adapting it to the specific setting of my study, to improve its quality. The target population of HCPs who care for people with palliative-care needs was identified and known, and there were plans to sample it by using a postal survey, as was done in the previous study which resulted in a 57% response rate (Schiff et al., 2006). However, there was an obstacle to achieving that plan.

7.4.4.1 A small heterogeneous sample

While I was in the last preparatory steps, I was informed by a colleague that a postal survey has no chance of working in Israel[73]. This obstacle had to be dealt with in a very restricted time and budget frame, taking into consideration the fact that I was a lone researcher. The strategy was changed, as explained

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[73] I was told that HCPs throw surveys without opening them. I was advised to address teams in person and ask head nurses (ward sisters) to engage their staff to comply with my questionnaire.

in the methodology chapter, yet there was still an expectation for a large sample from several hundred participants in the conference where the survey was held (see Chapter 3). The fact that eventually I was not able to reach more than 85 participants was a major drawback, which I had not foreseen and which influenced the scale of this part of my project. Instead of recruiting a statistically significant sample of four groups of professions, I ended up with extremely uneven groups, two of which were too small in size for any statistical tests, and with no participation by psychologists. This hindered the possibility of generalising to the larger professional population, as well as of comparing between the disciplines. Moreover, being so small, the sub-groups of physicians and of social workers could also not be compared with the nurses' sub-group. I ended up relating to the sample as one entity, in spite of the fact that it was made up of three distinct professions. Had I been more experienced in research, and had I been familiar with the setting of this conference, I would have engaged ten colleagues to distribute the questionnaires among the conference participants. I presume that this would have yielded a larger sample.

The correction measures for sample problems that are offered in literature are based on large samples (Bruce et al., 2008; Iarossi, 2006; Seidman-Diamond, 2011). Unfortunately, I cannot provide a larger sample for the purpose of my study, but it is possible to learn from a small sample as well. The findings that were presented did highlight barriers and problems regarding knowledge, attitudes and experience with ADs. I suggest relating to the findings in two ways: (1) as a pilot to further studies that will use different time- and data-collection resources, to sample a more representative cohort that will indeed enable generalizability regarding the Israeli HCPs' abilities and needs regarding ADs; and (2) the current findings were used as triangulation for the findings in the qualitative part of my project, to deepen the understanding of the place and role of HCPs regarding ADs, as was envisioned in the first place.

Looking at the whole sample as one group, although three disciplines took part, is a limitation because the three disciplines not necessarily have same roles regarding ADs. In the study by Black (2006) for example, there was evidence that nurses viewed their role as being to describe life-saving treatments in as graphic a way as possible, to help patients grasp their

benefits and their costs and burdens. Social workers, on the other hand, viewed their role as facilitators for patients in the process of expressing their values and wishes (Black, 2006). Obviously, the role of physicians in EoL care is the most difficult because they are the ones who are responsible for medical decisions, both morally and legally. Recruiting larger groups of the four distinct disciplines (physicians, nurses, social workers and psychologists) in future research will enhance the learning that was possible from the current findings.

7.4.4.2 Self-report bias

One of the weaknesses of surveys is *self-report bias* that may occur due to respondents' tendency to wish to please the researchers and answer in the way they perceive as right, rather than being accurate (Donaldson and Grant-Vallone, 2002). This tendency, called 'social desirability' appears in various circumstances when respondents want to make a 'good impression' on the researcher. In the current study, the participants were HCPs with an affiliation to palliative care, and it may be that self-report bias was due to the wish to appear knowledgeable, or experienced with ADs. This could be enhanced if HCPs viewed ADs as part of good EoL practice and tools, as was the overall impression from the findings. Yet self-report bias is complex and is unlikely to be easily detected because it varies greatly from one question to another and depends on the interpretation of each respondent (Donaldson and Grant-Vallone, 2002). One partial remedy to this bias is to use at least two different data sources to improve validity (Donaldson and Grant-Vallone, 2002). In the current study, the survey was indeed one of two data sources, although they did not address exactly the same group of participants. Case studies included physicians, whereas the survey included three disciplines (physicians, nurses and social workers). Having two different data sources enabled a better assessment as to the knowledge, attitudes and experiences of HCPs regarding ADs in Israel at present, and partially compensated for the imperfections of the two data sets.

7.5 Conclusion

The aim of this chapter has been to present the findings of a small-scale survey that was conducted among palliative care HCPs in Israel in 2011. It provided an added aspect to the qualitative data by giving some evidence of the context in which ADs exist in Israel today. The findings show relatively positive attitudes toward the concept of ADs, and also some experience in helping create ADs as well as using them toward EoL, apparently with generally positive outcomes. Difficulties, barriers and critiques were also evident. These may hinder HCPs from discussing ADs with patients and relatives and limit the possibility of using ADs in EoL care of patients with LTCs. Limitations of surveys in general and of the current survey in particular were discussed, to enable the findings to be learnt from without hasty generalisation.

The findings of a similar survey that was conducted in the UK (Schiff et al., 2006) could realistically be only partially compared, due to different participants and a significant difference in sample sizes. Collaboration for further development of this is hoped to be achieved in the future.

The next chapter will be the last, and it will pull together the findings and emphasise the significance and contribution of this study to the available evidence surrounding ADs.

CHAPTER 8: GENERAL DISCUSSION AND CONCLUSION

8.1 Introduction

In this concluding chapter of my study I will draw together the findings to provide an overall picture of the project's contribution to the existing knowledge related to advance directives (ADs). It will show the significance and value of having a multitude of perspectives from the various relevant stakeholders on the phenomenon of ADs. It will demonstrate the meaning of making ADs as a statement rather than as a formal document. It will emphasise the process that ADs entail, conceptualising this as a 'relay', i.e. a number of consecutive steps which need to be well synchronised and connected in order to achieve the outcomes that AD-holders wish to achieve. It will underline that the best outcomes for the patient (and perhaps to other stakeholders as well) are based on team work, open and repeated communication, and mutual respect and knowledge. The chapter will also add to the understanding of the current ability of health care providers (HCPs) in Israel to deal with ADs. Health care providers are vital partners, to the meaningful development and enactment of ADs, for people who wish to utilise this tool to manage their end of life (EoL).

Subsequent sections of this chapter will be dedicated to the implications of my study and how it can lead to future research, and inform policy as well as clinical practice. I conclude the chapter by reflecting on my research, its limitations and other methodological aspects, to allow me, and potentially others, to learn from them.

8.2 The   main key findings – an 'AD-relay'

As in a relay race, in which the baton must be transferred from one runner to the next, a necessary transference of information and views also occurs in the 'relay' of ADs between the various stakeholders, so that the ADs may potentially be fulfilled. The word *potentially* refers to the understanding that good transference between all the stakeholders is a necessary step, although it is not always sufficient to assure the desired outcomes for the patient who writes an AD. The main findings of the study are related to the three main 'players' in the 'relay' of ADs: patients, relatives and HCPs. For clarity, these key findings will, at least initially, be divided accordingly.

8.2.1 The key findings related to the patients

8.2.1.1 Autonomy and its boundaries

The key issue discussed in Chapter 4 and echoed in Chapter 5 was the concept of *autonomy*, its limitations and complexity. All the patient-participants expressed a great desire, to live and die according to their own world view, and to make their own choices. Making an AD was one aspect of this philosophy. Yet in their interviews they provided many examples suggesting that autonomy is not totally based on an individual's free will, but is rather a 'relational autonomy', where people make decisions based on relationships with others around them. In most cases, their expressed determination to take full control over their living and dying existed alongside many concessions. These compromises were apparently made in order to fulfil the needs of an ill spouse, busy children, or grandchildren in need. Being part of a family appeared to put boundaries around the possibility of 'pure' autonomy; indeed these boundaries were often created by the patients themselves, as part of their commitment to their significant others.

In general, autonomy is limited by society, for example through laws which reflect the 'good' for society as a whole. A major finding was the wish of the patients to be able to control the timing of their death. All the patients knew that actively ending life was illegal in Israel, but expressed their disagreement with this fact and a wish to disobey this limitation, although this did not mean that they would eventually act on this wish. In their declarations during their

interviews, I found patients more constrained by meaningful personal relationships than by legal boundaries.

8.2.1.2 ADs as declarations rather than legal documents

The findings suggest that for the patients, ADs represented a declaration of their innermost wishes above all, rather than a legal document. Some of them were not aware of the legal status of ADs or their legal limitations and conditions; a finding which in itself is not new (see discussion in Chapter 4). However, what my findings add to existing evidence is the discovery that some patients did not remember what exactly was written in their AD documents, and some did not remember where they had placed the document. At first sight, this suggests disinterest, which is contradictory to other findings in this thesis regarding the patients and the way they perceive their situation and act upon it: being active and involved in their own care and life, and seeking control over their everyday lives till death. On further investigation however, it seemed that the exact words did not matter to the patients as much as the general idea (hence the term 'a declaration'). Once the idea was openly stated, apparently most patients did not feel the need to remain preoccupied with the documents, or remember exactly where they were placed. Patients did not express this directly but it was implied many times during their interviews.

8.2.1.3 The need to control death

One of the most significant findings of this study is the fact that all the patients who participated talked about the possibility of hastening death, either on their own or with the help of others, perhaps as a sign of the ultimate autonomy. Some shared accounts of the preparations they had undertaken to create the potential for this possibility. It appeared that these participants' fear of losing capacity to make decisions was worse than the fear of death. Moreover, their fear of losing physical independence while being lucid gravely concerned them. This finding did not arise from the aims of the study, from the inclusion criteria or from the questions I posed, yet it appeared in all ten interviews. I only asked about it when it was raised by the patients, in order to better

understand their perspective. This is significant, because it may suggest that the issue of controlled death was related with ADs in the minds of the patients, even though it is in complete contradiction with what the Dying Patient Act (DPA) permits (The Dying Patient Act, 2005).

Revisiting all the interviews with patient-participants showed that six patients raised the subject spontaneously, without any relevant preceding question having been asked. Others responded to a broader question regarding expectations from their AD document, or how they would like to handle health conditions that they spoke of. In addition, it did not arise in telephone calls with any of the participants, apart from one phone call (out of 110 callers) with an applicant who was not eventually included. This may indicate that such disclosure required face–to-face contact and the development of a certain amount of trust, for participants to feel able to reveal this information to me. This particular finding appears important in understanding the patients' accounts given here, even if it was not an explicit part of the study's aims. It reveals something about maintaining autonomy through control over the dying process. However, it would be valuable to continue to explore this issue, and to identify whether it applies to a small specific population or to the larger public. Further validation and investigation in larger groups is important in order to contextualize this finding, and to deepen our understanding of it. In spite of this, a systematic review by Monforte-Royo et al. (2012) provides interpretations of seven qualitative studies (including 155 patients in total) regarding patients' wishes to hasten death. In this review they identified a number of reasons provided by respondents regarding a desire to hasten death that were congruent with those found and discussed here, in Chapter 4. Six reasons were identified for this wish: a response to multi-dimensional suffering; disintegration of the 'person'; anticipatory fear of dying; a desire to live but not in this way; ending suffering; and, importantly, control over one's life (Monforte-Royo et al., 2012).

8.2.2 The key findings related to the patient-relative dyad

The key findings regarding the relatives and the patients as dyads, namely the first 'baton transmission' in the AD-relay, were fourfold:

1. Some relatives expressed fear, in the anticipation that they might make mistakes when enacting the patient's wishes, which seemed stressful to these relatives.

2. Simultaneously, most relatives reported feeling a moral obligation to become future decision makers for the patient, and did not conceive it possible to refuse that role, although it stressed them. This seemed to create the second layer of complication for patients and relatives.

3. Findings revealed conflicting commitments to self and to the 'other', both from the perspective of the patient and from the side of the relative, and this added a third layer of complexity to the communication between relatives and patients regarding ADs and EoL decisions (Figure 9, page 165).

4. The fourth layer of complication arises from evidence suggesting that the needs of patients and those of relatives appear to grow apart as death approaches, when the former want to 'be released from suffering' through death and the latter have an emotional need to keep the patients alive as much as possible.

These findings added to existing knowledge by exposing interrelated complexities, which intensify layer upon layer, and appear unresolvable. The first 'transmission of the baton' in the AD-relay seems almost insurmountable and chances for a successful transmission almost impossible to reach due to complexities inherent in relationships in general, rather than to specific persons or particular relationships. Chapter 5 highlighted the deep involvement of relationships in EoL decisions, and showed that in real life, autonomy is relational rather than 'pure' or 'free' (Dodds, 2000). This insight is important for policy and clinical practice, which both tend to over-emphasise the autonomy of the individual and often disregard the influence of relationships (Dodds, 2000).

8.2.3 The key findings related to the HCPs

There was considerable heterogeneity among the physicians in the study. While the numbers of physicians who were interviewed in the qualitative

phase formed a small group, they represented a multitude of fields, so that it was not possible to look for a relationship between fields and approaches. In the quantitative phase as well, the sample of HCPs who took part in the survey represented diverse clinical fields, although all were interested in palliative and end-of-life care. Variance has the potential for greater richness of data, yet simultaneously, due to limited numbers, it can only provide hints of evidence that may serve as tentative suggestions for further exploration. Thus, the findings of Chapters 6 and 7 are primarily focused on suggestions concerning the knowledge, attitudes and aptitude of HCPs regarding ADs, which will need to be explored further. Having acknowledged this, however, some noteworthy findings emerged, even if they were only reported by a small number of participants (Stake, 1995). Some added to (or confirmed) available evidence while others were more innovative. For example, one aspect that supports previous references (such as: Bentur, 2008) was the difficulty expressed by HCPs, especially physicians, regarding the possibility of abstaining from life-saving measures. Both in the survey and in the interviews it was raised as being contrary to medical education and to the moral professional commitment to save and preserve life. The innovative aspect is the fact that the data was collected from HCPs who practice EoL care and who are at the forefront of knowing about ADs. I assume that the findings from my survey reveal the highest level of knowledge and experience available to HCPs today in Israel. I also assume that other groups of non-palliative care oriented HCPs would have expressed less knowledge and less experience regarding the making and using of ADs in EoL decisions. This claim was initially supported by the qualitative findings regarding hospital physicians in Chapter 6.

8.2.3.1 Relationship with patient's relatives

The relationship between physicians and relatives around patients' ADs surfaced in various interviews, mainly with physicians and patients and much less so in interviews with relatives. Spouses knew their partners' (the patients) physicians, but most of the non-spouse relatives did not know and did not communicate with the latter. This is potentially problematic, given that the patients had an AD that clearly suggested that one day both parties (physician and relatives) might need to make joint decisions on behalf of the patient. It is

also problematic because relatives who care for ill patients have concerns and need information from HCPs, regarding: medications; what to expect as the illness advances; and reassurance for decisions that are made along the illness trajectory (Hebert, Schulz, Copeland et al., 2009). The relationship between physicians who lead the patients' medical care and patients' relatives is a necessary part in the 'AD-relay', which was proved in the current findings to be often missing.

In hospital settings, relatives were described by physicians as the most powerful players in EoL decisions regarding patients who lost capacity, almost to the point of removing all power from the physicians in EoL decisions. This is in contrast to relatives, who felt burdened and as such rather powerless when facing HCPs. Nonetheless, there was little evidence of discussion between relatives and hospital physicians. This may be due to both parties feeling powerless, or to other factors, but surely lack of communication contributed to relatives' disempowerment and difficulty to make informed decisions regarding incapacitated patients. Additionally, there were few indications in the findings that not only relatives but family physicians (GPs) as well found it difficult to approach hospital physicians to discuss their common patients. In few examples GPs shared the feeling that their patient suffered unnecessarily due to unwillingness of hospital physicians to consider the GP's input in medical decisions.

In rural community settings, the power of relatives was described by physicians as less dominant, and physicians described themselves as being much more active partners in decision making than their hospital counterparts. Perhaps from such perception of power-equality, physicians reported having had significant and repeated discussions with relatives of patients with and without capacity. This was supported by some patients' relatives. There was a hint that communication was different in rural and urban settings. Relatives who took part in case studies (CSs) in which a GP was included reported: positive experiences of communication with GPs, their feeling of empowerment by GPs, and their confidence in future support from those physicians regarding the moment when joint decisions may need to be made on behalf of patients. This was not the feeling of relatives of patients who lived in cities, who felt isolated in dealing with potential EoL decisions. Yet, this

distinction is a suggestion based on small scale exploration and needs testing in much larger groups of rural and urban patients and GP.

8.2.3.2 The 'absence' of physicians

One of the most potent and intriguing findings regarding the physicians in the interviews was the level of avoidance in terms of engaging in communication about patients' EoL wishes, which was mirrored by the reluctance of some physicians to participate in the study. Absence is a part of research, but here I emphasise the relevance of this attitude to the issue researched because relationships between physicians and patients are central to the ability to discuss ADs and EoL wishes for health care. The refusal of HCPs to participate in research is not surprising in itself. It is also perhaps not surprising that physicians declined to take part in a qualitative study which may have been perceived by many as 'not sufficiently scientific', especially when the study had been suggested to physicians due to the interest of the patient (participant) and not because of their own direct interest in the study. However, it was noticeable that the three physicians who had good communication with participating patients did make an effort to participate in the study. They expressed commitment and respect for the patient, which is not always present, and gave an example of 'putting the patient at the centre of care', regardless of their own interest (or disinterest) in my study. One other physician consented to be interviewed, not out of respect for the patient but because I had disclosed that I worked in the same institution.

It seems reasonable that when communication with their physicians was perceived by patients as poor, they felt embarrassed to ask physicians for a favour that had no impact on or relevance to their care, and which was perceived by patients as merely disturbing the physician. The methodological problem of giving voice to physicians who seem to be more communicative with patients and perhaps more patient-centred was discussed in Chapter 3, as well as the decisions taken to include additional physicians. The findings in Chapter 6 regarding physicians' communication show a greater variety than that which could be conveyed by the absence of physicians in the case studies. Hospital physicians who were added to the study did highlight difficulties and problems related to ADs. These may not have been the same

as those the absent physicians would have highlighted, yet their contribution balanced the voices expressed by the participating physicians through CSs. The 'absence' of physicians illustrates the isolation felt by patients in urban settings.

8.2.4 An overarching result: the 'falling baton' - communication difficulties among all stakeholders

The findings showed that all the above aspects influenced and could hinder the possibility of the eventual fulfilment of an AD document when it is required. Criticisers of ADs claim that they are largely unachievable, and that other strategies are needed for good EoL care and to ensure the best outcome of care for patients (Davison et al., 2010; Detering, Hancock, Reade et al., 2010; Jordens, Little, Kerridge et al., 2005). Supporters of ADs attempt to identify the various barriers and suggest solutions for them (Hammes, Rooney and Gundrum, 2010; Pautex et al., 2008). Both parties agree however that communication is essential for best EoL care, with or without ADs. The findings of this study added support to the importance of communication regarding ADs specifically, but also to EoL decision-making more generally, by gathering findings from the three major stakeholders in the process: patients, relatives and HCPs. By looking from three very different viewpoints, the depth and breadth of the data provide a significant contribution to the known evidence. It enables the development of a better understanding that ADs reflect a multitude of phases that are distinct: the maturation of the idea in the patient's mind; the process of making an AD document; the sharing of this idea with relatives, which is itself multi-facetted and may occur at different times; the sharing of the idea with HCPs; and discussing the patient's wishes between all three stakeholders, not once but repeatedly as illness progresses. However, the findings also showed that each of these phases in the 'AD-relay' is hard to achieve in its own right, while each step is also related to and dependent on the other steps. Each step that is not managed well enough jeopardises the odds of getting the whole process right, just as with the analogy of a baton falling in a relay race, that may happen each and every time the baton is transferred. Overall, one of the greatest hindrances seems to be the fact that patients often expect their HCPs to initiate discussion of EoL,

prognosis and options (McCormick and Conley, 1995; Murray, Kendall, Grant et al., 2007; Reid, McKenna, Fitzsimons et al., 2009), while their HCPs tend to expect exactly the opposite (Almack et al., 2012).

8.3 Future directions for research

Findings of the study suggest several new directions of investigation, which may improve our understanding of the complexities around ADs.

8.3.1 The illness experience and implications through the eye of the beholder

The findings presented in Chapter 4 demonstrated difficult experiences with various long term conditions (LTCs), showing that most patients experienced a multitude of physical and emotional symptoms which produced a burden. Emotional suffering was often related to loss of control, and mirrored a strong need to maintain the capacity to be autonomous. The anticipatory fear, of potential growing suffering, appeared overwhelming for the patients and seemed to be a driving force behind a search for operational solutions to prevent what they feared would happen. There was an indication of a particular fear of losing independence, which is subtly yet distinctly different from the fear of becoming a burden on others. A similar fear was described by Monforte-Royo and her colleagues (Monforte-Royo et al., 2012)

Findings from all the patients who took part in this study indicated that these patients were very active in the way they coped with their LTC: seeking information; taking full responsibility for the medical treatments and tests; and doing everything in their power to remain independent and productive in their daily lives. They all seemed to be able to enjoy life and wanted to carry on living as long as that 'joy of life' could be maintained, and as long as they could be meaningful to their significant others. All the patients expressed a strong determination to live according to their values and world views. The consensus of findings related to the patients as individuals and their coping strategies across the group of patients in the current study, suggests that people who take the initiative and make ADs may possess unique qualities

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and needs which may be distinct from those of the general public. A new perspective was highlighted here by focusing on patients near end-of-life (EoL) who hold an AD by their own choice, not because of an institutional policy or as a research intervention. This setting shed light on the profound motivation (or need?) of the participating patients to have such documentation, without being encouraged to do so. The question of personality was not one of the direct subjects of this study, and this is a tentative suggestion, nevertheless the remarkable consensus of the data suggests that this is an area worthy of further exploration. The relationship between personality and coping at EoL was explored around a different aspect, looking at the relationship between neuroticism and distress toward EoL (Chochinov, Kristjanson, Hack et al., 2006b) but no reference was found regarding personality and ADs.

8.3.2 The wish to control death

One important investigation is to look at the need that was highly evident in the current study: to control EoL to the point of preparing to shorten life. A deeper understanding of this issue may be sought by using larger groups of patients with ADs. My findings echo those which were identified in a recent systematic review that explored reasons for the wish to hasten death in seven qualitative studies (Monforte-Royo et al., 2012). Including larger samples in the future may permit comparisons between people with an AD and people who have not prepared an AD, or healthy and ill people with ADs, or patients with ADs at the onset of illness and those at an end stage of their illness. Future study in this domain may use a combination of research tools in order to triangulate findings from one method with those of another. This will enable to map the needs of people with ADs, by dividing them into subgroups and looking at the subtleties of their needs. Such investigation may reveal whether the findings of this study regarding the need to control death were coincidental, or whether they were related to the severity of the patient's illness, personal coping strategies, other factors, or a combination of several factors. The findings from this qualitative in-depth exploration serve as triggers and highlight an area that has until now been vague. They may, and hopefully will, serve as guides for further exploration and identification of people who make ADs. A possible relevant exploration that may stem from the findings of

my study is a psychological viewpoint. The findings inferred that the need to control dying by preparing an AD could be related to personality traits such as an 'internal locus of control'. The low number of people who hold ADs prompts a search for a potential relationship between personality and the act of making an AD.

8.3.3 Health care providers – Differences and similarities in role perception concerning ADs

My findings suggested that family physicians in rural and urban clinics may respond differently, and that physicians working in hospital perceive their role in ADs as being different from that of family physicians. This encourages further exploration of the difference between sub-groups of physicians, such as hospital and community physicians; exploration with much larger groups and multiple disciplines; and comparison of various clinical fields, as was previously recommended (Bentur, 2008). Future studies may look at ways to include larger groups of HCPs in a way that will enable a study of their knowledge, experience and attitudes and how these change (or not) over time. Larger samples will probably enable differentiation between the different disciplines and between various clinical fields, which may in turn influence educational schemes for HCPs regarding communication at EoL, advance care planning (ACP), and the legal aspects of EoL decisions.

A first step in the plan to map the present knowledge, attitudes and experiences around ADs in Israel occurred during June and July 2012. Three of my colleagues used the questionnaire adapted for this study (Appendix E in the hard copy of my thesis but see note now placed under Appendix E) to survey 58 additional HCPs from the oncology field at one heath centre in Israel, for a seminar in palliative care which was held in the University of Tel Aviv. This sets the ground for a collaboration which is planned for 2014 and which is planned to include additional medical fields at one of the largest health centres in Israel. It may also be possible to extend the investigation to other health centres in Israel, to compare hospital and community settings, and to look more specifically at large nursing facilities across the country. This mapping will act as a baseline measurement, before or in the initial steps of

considered interventions around ADs, vis-à-vis both HCPs and the elderly public.

8.3.4 ADs for people with strong religious beliefs and their faith leaders

In the current study only one participant identified herself as religious, and her participation as well as her Rabbi's allowed a glimpse to some of the complexities that religiosity may add to the phenomenon of ADs. From 110 applicants who called me after the advertisement of this study, only 3 identified themselves as religious, although there may have been others who did not identify themselves as such during the phone calls. The two remaining applicants did not fill the inclusion criteria. This low number of people who reported being religious, makes any exploration of the relationships between religiosity and ADs difficult to follow. It should be noted however that the overall percentage of AD holders in Israel is very low compared to the UK and USA for example, and this may be related to the specific Israeli context. Beyond this study, this issue could be explored perhaps by researching non-holders of ADs to better understand the reasons of reluctance to make an AD in the Israeli society. Furthermore it seems important to investigate to what degree faith-leaders perceive ADs as a tool for EoL decisions and whether and in what ways they might support this option for their followers. This perspective presumably will echo the strongest supporters of sanctity of life as an overriding value to any others in the Israeli society, based on Jewish 'HALACHA' and Laws of other religions as well. Including faith-leaders in future research may shed light on the widespread impression that ADs are contradictory to religion. It is not clear whether there is genuine contradiction with religion or with its interpretation. As mentioned earlier, I emphasize that the Israeli Dying Patient Act (DPA) enables to ask for full treatment in the AD legal document (see Appendix A, part B, page 264).

8.4 Implications for policy

As explained earlier in the literature review of this thesis, ADs were legally introduced into Israel in 2005, yet it is estimated that no more than 13,000

(0.16%) people in Israel hold a valid AD document, whether it is the legal one or LILACH's pro-forma (Even, 2013)[74]. My study supported a previous claim (Bentur, 2008) that HCPs as well as AD holders know little about ADs and about their legality and boundaries. Policy makers will need to decide whether ADs are indeed the best way to express EoL wishes for the event of capacity loss; if so, there will most definitely be a need to fully educate HCPs as well as the public about ADs. The majority of the public is not aware of the possibility and therefore cannot make an informed decision whether or not to use ADs. It is a legal right that needs to be known about. The literature chapter of this thesis presented debates around ADs, doubts about how realisable they may be, and suggestions that ACP is more achievable (Davison et al., 2010). The findings of both the qualitative and quantitative phases in my study emphasise deficiencies in communication tools around EoL preferences, with and without translating such communication into ADs or other documents. These findings add to previous ones (Bentur, 2008) to accentuate a clear need to allocate resources in order to equip HCPs with reasonable communication skills. In order to improve practice in Israel, health-providing institutions may need to establish policies regarding EoL care that will be known to all staff, whose implementation will be evaluated as part of general quality appraisals. This seems in line with the declared policy of the Israeli Ministry of Health from 2009, which set as its goal to implement palliative care across all LTCs nationwide by 2013 (Hozer Mankal, 2009), a goal which is only in the first steps of its implementation and for which no resources were allocated (Bentur et al., 2012).

Global health evaluations (World Health Organization, 2013b) forecast an increase in conditions such as dementia, in which mental decline precedes the decline of the body by many months and sometimes years, with no prospect of cure. This tendency may accentuate moral and legal debates that are increasingly appearing in the secular world, and which emerged in the current study. Countries may well need to re-consider legalising additional resources to manage EoL and allowing the control of death in a more active way, as has already happened in a few countries such as the Netherlands and a few states

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[74] Even stated that 20,000 individuals have written ADs through LILACH since 1987, but LILACH's spokesperson claimed that LILACH currently holds around 10,000 updated AD documents. 3000 ADs are kept in the national database for ADs, and there may be overlaps of the numbers in the two groups because some LILACH members preferred to fill the legal AD document after having filled the LILACH AD document.

in the USA. Perhaps in the future, society will need to challenge its definitions of what *life* is and what *death* is. For example, in addition to the existing definitions of *cardio-pulmonary death* and *brain death*, a need may arise to define a third form of death, such as *cognitive* or *cortex death.* A society which views quality of life as a value equal to sanctity of life, may consider that for some people who declare their wish in advance not to remain alive without capacity, when no cognitive activity whatsoever is possible, this constitutes a morally acceptable reason to declare that life has ended.

8.5 Implications for clinical practice

At the present time in Israel, questions regarding ADs are rarely initiated by HCPs when recording a patient's medical history (as part of hospital admissions). No questions are routinely asked about patients' wishes and preferences for care at EoL. In Israel, unlike in the USA, the patient is not offered the possibility of signing a 'do not attempt resuscitation' (DNAR) order, either. Palliative care settings as well as specific services for patients with LTCs[75] and facilities for the elderly should address the needs of patients who would like to have their EoL wishes clearly expressed, whether orally or in writing, formally or informally (Fernandes, 2008; Heyland, Barwich, Pichora et al., 2013). Health care providers who are responsible for the medical care of people with LTCs need to include communication regarding EoL preferences as appropriate, when such communication can affect EoL care, and when there is enough time to prepare ahead for a time when EoL decisions will be needed (Fernandes, 2008). This was described by too few of the HCPs who participated in the interviews as well as in the survey. There is evidence indicating that various barriers exist in initiating ACP conversations, even in countries where palliative care is quite developed. This was observed in nursing homes in the UK (Froggatt, Vaughan, Bernard et al., 2009), and in acute hospitals in Canada (Heyland et al., 2013). Yet there is also indication that intervention may improve HCPs ability and action to encourage patients to express their preferences for EoL care (Fernandes, 2008). Considering that the survey in the current study included palliative care professionals, even less communication may be expected from other HCPs. The call to address

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[75] Specific services, such as: renal; cardiac; lung and similar clinical services.

EoL issues in communication between HCPs and patients includes general internal medicine services, which provide much of the medical care for people with LTCs. Ignoring these issues until EoL occurs, as was disclosed by participating hospital physicians, can mean that decisions continue to be made in urgency and without much reflexion and consultation. On the other hand previous evidence shows that repeated discussions reassure patients that their wishes will be considered when they will no longer be able to take part in decision making, and improves outcomes for patients' EoL care (Fernandes, 2008).

The expectation that patients will raise these issues can often prevent communication, because patients, as was seen in this study, perceive HCPs' avoidance of the issue as deliberate, signalling either disinterest, lack of time or emotional or moral difficulty. There is no doubt that when patients and relatives do have an AD document, it should always trigger discussion with HCPs about its content and meaning for the patient, and the document must be included in the patient's medical record. However, this expectation is rarely met in Israel, and is still inadequately exercised in other countries (Heyland et al., 2013). Today, most patients' medical records in Israel are electronic, and this may facilitate an automated highlight to draw attention to the fact that a patient holds and AD, and may provide a quick link to its content. Such technology may facilitate educational and other improvement processes, and with specific policy and guidelines may promote the implementation of these recommendations.

8.6 Methodological reflection

My study had some limitations. Firstly, the available resources in terms of the time, budget, and human-power needed to carry out the research alone narrowed down some possibilities, compared with working in a research group. The ability to analyse transcripts (data) when working alone is very different from their analysis within a research team, where mutual validation is possible; the hundreds of hours spent undertaking one's own transcription of interviews is different from having this carried out professionally; having several researchers to hold the interviews can sometimes compensate for wasted time due to barriers (such as the publicity barrier that arose in this

study). Yet carrying out the research on my own was beneficial from other perspectives. The fact that I carried out all the interviews myself gave me important contextual details of the setting, and sometimes provoked new questions[76]; transcribing on my own allowed me to be completely immersed in the text, but also to retain the tones of voice and emotional expressions.

Had I had more time available for my data collection, I would have taken more time to choose at least ten patients at the very end of their lives, i.e. with an end-stage illness, rather than working under a very restricted timeline (resulting from publicity problems, see Chapter 3), which meant that I had to make some pragmatic choices about the patients selected for interview. With more time, I would have preferred to have had the opportunity to develop at least ten full case studies.

Another limitation was the fact that I did not meet relatives for a second time after the death of the patient. Having a 'before' and an 'after' viewpoint of the process would have improved understanding. This could have enabled me to learn about whether and how ADs influenced patients' EoL in reality, and also to compare their 'forecast' with the actual occurrence as experienced by relatives. Working in a research group might allow a longitudinal study to be conducted to provide such a complementary perspective.

Much learning and understanding occurred after I started analysing the findings. In fact, this learning has been on-going and has not yet ended. The first analysis was the first layer of learning. It was followed by writing up the chapters about the findings, which enabled an additional level of analysis and gave me an opportunity to gain deeper insight into the findings and the issue under investigation. Each finding chapter added depth, as well as hesitations, and questions. Discussing each chapter's findings in the light of previous evidence illuminated new aspects, and brought new questions.

If it was possible to go back to the participants now and meet them again, I would like to conduct another full interview with each of them, and I would ask many new questions that I was not aware of until the end of the writing up the research. Research process has its structure, and data collection has a time

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[76] For example experiencing Noa's interview while her mechanical ventilator stood in the room between us provoked questions about her everyday life and improved my understanding of the influence of her condition on her quality of life.

slot during the process. This golden window of opportunity can only provide what researchers are able to identify as important before and during the collection of the data. No one is able to predict where the findings will lead them, and what new questions will emerge from the answers to questions that were related to the study's objectives, after they are analysed.

I wish I could go back to the patients and share with them my understandings from the feelings they disclosed and the analysis of the findings. I would have hoped to help them to better handle the 'AD-relay' with their relatives and physicians, and to reach more satisfactory outcomes than those they feared would happen. This thought probably stems from my immense gratitude to the participants, who gave me their time and who opened their hearts so generously. This one-way giving from patients to me, who as a nurse is used to a relationship that usually flows in the opposite direction, is not taken for granted and was sometimes difficult for me to accept. This is also a huge personal lesson for me as a researcher who is also an HCP, and I cherish it.

8.6.1 Self-reflection

When I started planning this study I was asked by my supervisors to write my views about ADs. I wrote that I was in favour of the possibility and thought that it should be proposed to everyone, to enable those wishing to make an AD to do so. Nonetheless, I thought that making an AD was the need of a minority of the population, even in a secular society. The most evident change in my perception, from the beginning up to this point in time as I now write, is that I previously viewed making out an AD as a very straightforward, perhaps even one-dimensional task. It seemed that people needed to know about the possibility, those who wanted could prepare an AD, and then the EoL decisions of those possessing an AD would be clear and easier to make. After conducting the research and meeting people determined to have their wishes clearly stated, but who also demonstrated a multitude of barriers and obstacles, I now look at ADs in a different way. Undertaking this study enabled me to develop an understanding of how difficult it is to make ADs, and to communicate them to others. A long process of educating HCPs and the public seems to be needed in order to be able to communicate about EoL needs and wishes, and to be able to consider making decisions for individuals

who have lost capacity. Guided by the voices of relatives who took part in this study, I became much more aware of the difficulty of making decisions on behalf of another. Yet such situations will probably become more common because of the increasing prevalence of illnesses affecting cognitive ability. In the process of analysing the findings, I realised that discussing preferences is difficult for both patients and for their relatives, although it is an important issue to confront. It is part of preparing people to make EoL decisions on behalf of others, which often necessitates facilitation and on-going support before, during and after such decisions are taken. I realised how rarely HCPs provide such facilitation or support. I end this research study with much more awareness of the complexities around ADs and the low chances of completing the 'AD-relay' with satisfactory outcomes for all parties involved. This is not to say that my support for ADs has decreased, but rather that I acknowledge how much remains to be done in the fields of education, policy, and practice, to make ADs a more realistic option for those who wish. I perceive ACP, i.e. the communication and attempt to understand patients' values, fears, and most profound wishes, as more important than the writing of an AD document. I am not sure that rigid documents are the most appropriate tools to help HCPs and relatives make the best decisions on behalf of the patient. Perhaps adding a free statement based on open questions, which will be recorded orally or audio-visually, would better equip relatives and HCPs for difficult and unpredictable situations. I think that the major change from the beginning of my research study journey to its end is that I am more hesitant than I was, and have more questions than answers regarding ADs. I am much more aware of variance, subtleties and differences, and of the many layers that I was not aware of when I took the first step toward this study.

8.7 Conclusion

This study explored the meaning of ADs for patients facing EoL due to an LTC, and for other relevant stakeholders around them: relatives and HCPs. The rationale behind its design was that ADs are produced by an individual but are meant, by definition, to be executed by others, who are usually relatives and HCPs. Looking at the three main stakeholders facilitated a

comprehensive and deep understanding of the complexity of the phenomenon of ADs.

One aspect of understanding emerged from looking at the phenomenon as a process, and not simply as the one-time act of making an AD document. Advance directives were therefore viewed along the various steps: from preliminary thoughts about the option, to written statements regarding later EoL care, through the writing of the document, throughout the stages of sharing (or not) the document with other stakeholders, and culminating in examples of the actual use of the document in EoL care. This was achieved by in-depth one-to-one interviews of 27 participants, looking retrospectively at their individual processes.

To complete the understanding of the complexity, another tool was used to learn about the present state of knowledge, experience and attitudes among HCPs, without whom ADs cannot be executed. An investigation into the state of competency and readiness to deal with ADs in medical practice in Israel was perceived as complementary to the views gathered in the case-studies around individual patients. The survey was used as a means to triangulate some of the qualitative data that was collected during interviews, by providing an understanding related to the health system vis-à-vis ADs, in addition to individual physicians' views. This enables an initial mapping-out of the current situation and suggests recommendations for policy and practice. The survey sample was not as large as was hoped when the study was designed, but it included palliative care-oriented HCPs, who are more aware of EoL issues, the DPA and ADs than one would expect HCPs from other clinical fields to be. They can be viewed as the highest bench mark of aptitude in Israel today. Further data is planned to be collected in the near future, which will check this assumption and increase representation.

A key finding regarding the group of patient participants in this study was their wish to control their death, and this calls for further investigation as suggested.

Communication issues when addressing ADs constituted a further significant finding, that was present across all three groups of participants – in particular the finding that communication is often heavily compromised at different levels: between patients and relatives; patients and physicians; physicians

and patients' relatives; and between HCPs and their colleagues. A related finding was the lack of accurate information and understanding regarding ADs, their boundaries and their purpose, for all parties involved in the process. An additional barrier to the possibility of suggesting ADs to people towards EoL was the difficulty of many HCPs to discuss sensitive issues such as EoL preferences with patients.

On the whole, relatives were ambivalent toward the patients' ADs, because ADs reminded them of the approaching death of their loved ones, which was difficult to confront. It was also evident that communication was often evaded in order to avoid the burden of discussing dying and death.

In the review of the relevant literature in Chapter 2, ACP based on repeated communication between patients, relatives and HCPs was described and explained. I noted that many supporters of ACP view ADs as 'passé', criticising this tool as impractical, and giving reasons for this critique, such as: the fact that AD documents are often rigid; people can rarely sufficiently predict their EoL in order to make an AD document that will correspond to it; and therefore ADs are seldom able to address real-life situations accurately enough.

The significance of this study's findings is the emphasis they place on the importance and centrality of communication as a tool to prepare people for EoL, with or without ADs. They provide varied evidence regarding miscommunication and barriers to communication. They show that some of the most powerful barriers jeopardising the smooth 'transference of the baton', i.e. information and communication between the relevant 'players', are identical to the barriers to ACP.

I would like to challenge the antagonists of ADs by saying that while patients have full capacity, open and significant communication between patients, relatives and HCPs about EoL preferences and fears is the key and the challenge for ACP as well as for ADs. Repeated communication will help EoL decisions to be made on behalf of the patient once capacity is lost, because the subtleties of these patients' wishes will most probably already have been discussed in relation to others' experiences, whether in the family or in the media.

I would also suggest that ADs are perhaps not needed by everybody, especially in the Israeli context. The influence of faith and faith leaders could only be addressed in a limited way in my study; only one case study was developed around a religious patient-participant, and only a few HCP participants in the survey were religious. The data of both study phases suggests no apparent contradiction between holding an AD and being religious. However indirect comments made by interviewees (both secular and religious) in the qualitative phase elucidated sensitivities and prejudices that need to be further examined with religious people who hold ADs. This would enable an appreciation of the extent to which the evidence from this study applies to the wider Israeli context and in other settings globally.

It may be that most of the public in Israel do not need or want to make an AD or to plan their EoL care in advance, yet everyone is entitled to know about the possibility and everybody is entitled to have the opportunity to prepare for their approaching EoL. Advance directives are not an aim but a tool, which cannot be complete without ACP, but may be added to ACP if and when people so wish.

This study is significant because it provides a voice to a small group of people who may have different needs from those of the majority of the population, and who wish to remain in control even when approaching death. Their needs are ill addressed in Israel, and perhaps also in other countries. Although the study was held in Israel, the findings suggest that people who want to make ADs have a unique need to control their lives and EoL, and perhaps need to have unique solutions in addition to the ones available in most countries in the world today. Certainly they need a lot of support and guidance, which is still seldom available to them.

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APPENDIX A: ADVANCE DIRECTIVES AS TO FUTURE MEDICAL CARE OF A DYING PATIENT

The **official** English version (Based on the Israeli 'Dying Patient Act, 2005'; Paragraph 31). Available at:

(http://www.health.gov.il/DocLib/doa_1_0708e.pdf)

This form is to be filled and completed by persons wishing to give advance directives[1] as to their future medical care —
  (1) requesting that medical procedures commonly performed in Israel <u>not</u> be performed on him/her (see Box A), or
  (2) requesting that life-prolonging medical procedures <u>be</u> performed, even if unjustified in the given circumstances (see Box B)

I, the undersigned, _____, ID.No. _____, year of birth_____, address_____
being competent as defined by The Dying Patient Law, 2005 (hereafter — The Dying Patient Law), hereby issue, under the provisions of the Dying Patients Law, advance medical directives:

For the purpose of issuing advance medical directives I declare as follows:
(a) (1) <u>My current medical state is</u>:

    ☐ Generally healthy

    ☐ It has been determined that I am a Dying patient

  (2) I have received medical information[2] from _____.
     The said information is as follows: (to be completed by a specialist physician, physician or nurse, as the case may be)

     _____
     _____
     _____

(b)   I am aware that these directives shall come into effect, that is, that the medical care given me shall conform to these directives, only once it has been determined that I am Dying Patient, and I have been declared incompetent **and I am suffering significantly**, all the foregoing within the meaning of the Dying Patient law.

_____

[1] Advance Medical Directives are issued by a competent person, and state his wishes as to his future medical care should he become terminally illa dying patient, and incompetent, or terminally ill (death imminent)a dying patient in final satge, and incompetent.

[2] Medical Information: (1)   A specialist physician shall give a person confirmed to be terminally ill information about his medical condition, including medical information about his condition which is relevant to his issuing directives, and medical information he may reasonably require for issuing advance medical directives.
       (2)   A physician or nurse shall give a person not confirmed to be terminally ill medical information, which he may reasonably require for issuing advance medical directives.

(c) I am aware that if it has been determined that I am Dying, but have not been declared incompetent, that my expressed wishes shall take precedence over the provisions of these directives.

(d) I am aware that I may alter or cancel these medical directives at any time, as long as I have not been declared incompetent within the meaning of the law; the cancellation shall take the form of new medical directives or a completed cancellation form, as provided in Appendix 4.

(e) I am aware that these medical directives shall remain valid for five years or for a period not exceeding five years, namely until: _____ (A date maybe specified here not more than five years from the date the advance medical directives form is signed). After the end of the said period a Responsible Physician may (but not must) take these directives into account, unless they were cancelled by me.

Box A: ADVANCE MEDICAL DIRECTIVES <u>NOT</u> TO PERFORM LIFE-PROLONGING MEDICAL PROCEDURES			
A1.	(1)	I am aware that only if I reach a state of 'significant suffering', as defined by me below, and shall be a dying patient, and incompetent, will procedures not be performed on me in accordance with the advance medical directives in this document; significant suffering, as I define it, is—	
		(Check [in the box] whichever of the following (one or more) defines significant suffering for you):	
		☐ requiring to be artificially fed / nourished	
		☐ I am unconscious	
		☐ I am quadriplegic (paralyzed in all 4 limbs)	
		☐ a state of dementia	
		☐ I require any of the following treatments: _____ _____ _____	
		☐ I am in one of the following states / conditions– _____ _____ _____	
	(2)	I am aware that if I have not defined in Clause A1(1) above what I consider to be significant suffering, I shall be considered as being in a state of significantly suffering only if I am experiencing pain or suffering which a reasonable person would be ready to make a great effort to avoid or eliminate, even at the cost of significant injury to his	

		quality of life or life expectancy, and that only if I am in that state, and am also a dying aptient and incompetent, will these advance medical directives be followed.	

A2. Should I reach a dying patient state these are the procedures I wish not to be performed / to be performed on me:

			[Cross out what does not apply]
	(a)	Resuscitation in any possible way	Do not perform/ Perform
	(b)	Resuscitation by external cardiac massage	Do not perform/ Perform
	(c)	Resuscitation by endotracheal intubation	Do not perform/ Perform
	(d)	Resuscitation by administering resuscitation drugs	Do not perform/ Perform
	(e)	Resuscitation by electric shock	Do not perform/ Perform
	(f)	Connection to a ventilator with a timer (Temporary artificial breathing machine)	Do not perform/ Perform
		If this procedure is to be performed, please specify for how long it is to be maintained: _____ days/weeks/months/without time limit (Cross out what does not apply)	
	(g)	Dialysis	Do not perform/ Perform
		If this procedure is to be performed, should it be halted if the dialysis is proving to have no useful effect?	Do not perform/ Perform
	(h)	Major surgery (e.g. amputating a necrotic limb, removing a necrotic internal organ)	Do not perform/ Perform
	(i)	Minor surgery (e.g. amputating a necrotic finger)	Do not perform/ Perform
	(j)	Radiotherapy for malignant diseases	Do not perform/ Perform
	(k)	Chemotherapy for malignant diseases	Do not perform/ Perform
	(l)	Antibiotic treatment for severe septicemia resistant to regular antibiotic treatment	Do not perform/ Perform
	(m)	Diagnostic tests (blood, X-rays, cardiac monitor)	Do not perform/ Perform

A3. Should I be a dying patient in Final Stage, these are the procedures I wish not to be performed / to be performed on me:**

			[Cross out what does not apply]
	(a)	Resuscitation in any possible way	Do not perform/ Perform
	(b)	Resuscitation by external cardiac massage	Do not perform/

			Perform
	(c)	Resuscitation by endotracheal intubation	Do not perform/ Perform
	(d)	Resuscitation by administering resuscitation drugs	Do not perform/ Perform
	(e)	Resuscitation by electric shock	Do not perform/ Perform
	(f)	Connection to a ventilator with a timer (Temporary artificial breathing machine)	Do not perform/ Perform
		If this procedure is to be performed, please specify for how long it is to be maintained: _____ days/weeks/months/without time limit (Cross out what does not apply)	
	(g)	Dialysis	Do not perform/ Perform
		If this procedure is to be performed, should it be halted if the dialysis is proving to have no useful effect?	Do not perform/ Perform
	(h)	Major surgery (e.g. amputating a necrotic limb, removing a necrotic internal organ)	Do not perform/ Perform
	(i)	Minor surgery (e.g. amputating a necrotic finger)	Do not perform/ Perform
	(j)	Radiotherapy for malignant diseases	Do not perform/ Perform
	(k)	Chemotherapy for malignant diseases	Do not perform/ Perform
	(l)	Antibiotic treatment for severe septicemia resistant to regular antibiotic treatment	Do not perform/ Perform
	(m)	Diagnostic tests (blood, X-rays, cardiac monitor)	Do not perform/ Perform
	(n)	Routine procedures, e.g. giving antibiotics, blood & blood products	Do not perform/ Perform
	(o)	Treating intercurent illnesses, e.g. administering insulin	Do not perform/ Perform
	(p)	Giving food and liquids artificially	Do not perform/ Perform
	(q)	Giving palliative treatment and drugs	Do not perform/ Perform

** With regard to the subsidiary procedures specified in clauses (n) – (q) above, the Dying Patient Act, 2005, states that directions that they not be performed can apply in the case of an incompetent Dying Patient in Final Stage, only if he is suffering significantly.

A4. Instructions for other Emergency Situations***:
[Complete section A4 only if you have directives for an emergency situation other than the ones mentioned above.]

_____
_____
_____

A5. Personal Directions not mentioned above			

_____
_____
_____
_____

B. ADVANCE MEDICAL DIRECTIVES THAT EXCEPTIONAL MEDICAL PROCEDURES **BE PERFORMED,** EVEN WHEN THE ATTENDING PHYSICIANS CONSIDER THEM UNJUSTIFIED IN THE GIVEN CIRCUMSTANCES

B1.	Every possible medical procedure that can prolong my life, is to be preformed, even if the said procedures will cause me additional suffering and even if my attending physicians consider the procedures unjustifiable. It is my firm request that my physicians: perform full resuscitation, endotracheal intubation, connect me to a ventilator (artificial breathing machine), perform dialysis, chemotherapy, radiotherapy, administer antibiotics, blood and blood products, food and liquids, in any manner possible and as part of any medical procedure capable of prolonging my life.	
	▪ These directives shall apply when I am - (Either or both boxes may be checked)	□ A dying patient (up to 6 months life expectancy)
		□ A Dying Patient in Final Stage (up to 2 weeks life expectancy)
	▪ These directives include / do not include experimental procedures. (Cross out what does not apply)	
B2.	**Instructions for other Emergency Situations**: [Complete this section only if you have directions for an emergency situation other than the ones enumerated above.]	
	_____ _____ _____	
B3.	**Personal directions not mentioned above:**	
	_____ _____ _____	
C.	(1) In addition to these advance medical directives I have given a Surrogacy Appointment, and I direct my attending physicians to act in accordance with both the said Surrogacy Appointment and these medical directives	□ Check this box if Surrogacy Appointment was given
	(2) I hereby direct that, in case of a contradiction between my advance medical directive and a directive of my appointed surrogate,	

		precedence shall go to -	
		☐ My advance medical directives	☐ My appointed Surrogate
	(3)	I am aware that, in the absence of directions under Article C2 above, concerning a contradiction between these advance medical directives and the said surrogacy appointment, the directives shall take precedence. However - if the surrogacy appointment shall have been given a considerable time after the directives, then an institutional Committee shall decide the precedence between them.	
	4.	Further instructions concerning a contradiction between an advance medical directive and a directive my appointed Surrogate:	
		_____ _____ _____	

*** Emergency situation — a situation in which immediate treatment must be given if the patient is not to die.

DECLARATION AND SIGNATURE

Informing other persons of advance medical directives:
[There is no duty to inform other persons, but doing so increases the chances that your directives will be effectively and correctly observed. (<u>If you have not informed another person</u> go directly to the next section - Signature)

I hereby declare that I have talked with the persons noted below about this document and that **I have given them/ have not given them** (Cross out whichever does not apply) a copy of this document:

For each box checked, give name, address and telephone number of the person/persons informed.

☐ Spouse/ life partner
_____
_____
Tel:_____

☐ Other Relative
_____
_____
Tel:_____

☐ A Doctor
_____
_____
Tel:_____

☐ Attorney / Lawyer
_____
_____
Tel:_____

☐ Rabbi/priest/ Kadi
_____
_____
Tel:_____

☐ Other person
_____
_____
Tel:_____

Signature of Person Issuing these Advance Medical Directives
(The signatory must sign in the presence of 2 witnesses)

I sign this document after deap and careful consideration and of my own free and autonomous will, and not in consequence of any familial, social or other pressure.

Signature: _____ Tel. no. (landline): _____
Tel. no. (mobile):_____ Date: _____

[Should the issuer of these directives not speak or read Hebrew, please attach a written authorization of the person who translated for him/her the explanations and directives in the document.]

Signature of Witnesses
(The 2 witnesses must sign in each other's presence)

We, the undersigned, witness that the above signatory of this document —

☐ Is personally known to us

☐ Identified himself/herself to us by means of an identifying document which included a photo of the signatory
   [Check one of the two above boxes]

o Signed this document in our presence and that he/she appears to us fully aware and speaking to the point, and that there is no sign of any pressure brought to bear on him/her.
o <u>Further</u>: I declare that I do not hold the signatory's surrogacy appointment, nor am I a candidate to do so, nor do I have any economic or other interests involving the signatory.
   (A witness may not be one that has economic or other interests involving the signatory, including a family member who has economic or other such interests` However, a doctor or a nurse may be witnesses)

Witness: Name: _____ Id. no. _____
Address:_____
Tel. no. (landline): _____Tel. no. (mobile):_____
Signature: _____ Date: _____

Witness: Name: _____ Id. no. _____
Address:_____
Tel. no. (landline): _____Tel. no. (mobile):_____
Signature: _____ Date: _____

Signature of Person who Gave the Signatory Medical Information

(1)   To be completed if it has been determined that the issuer of these directives is a Dying Patient:

I, _____, a specialist physician, hereby confirm that I wrote the précis of medical information and on (date) _____ gave Mr./ Ms. _____ an explanation of his/her medical condition, including medical information about his/her condition which is relevant to his/her issuing directives and also medical information he/she may reasonably require for issuing advance medical directives. I also confirm that I explained to him/her the medical terms used in this form and that it was my impression that he/she understood the information I gave him/her.

Name: _____ Id. no. _____
Address:_____
Tel. no. (landline): _____Tel. no. (mobile):_____
Signature: _____ Date: _____

(2)   To be completed if it has <u>not</u> been determined that the issuer of these directives is a Dying patient:

I, _____, a physician/ registered nurse, [Cross out whichever does not apply], hereby confirm that I wrote the précis of medical information and on (date) _____ gave Mr./ Ms. _____ medical information about his/her condition he/she may reasonably require for issuing advance medical directives. I also confirm that I explained to him/her the medical terms used in this form and that it was my impression that he/she understood that information I gave him/her.

Name: _____ Id. no. _____
Address:_____
Tel. no. (landline): _____Tel. no. (mobile):_____
Signature: _____ Date: _____

APPENDIX B: ETHICAL APPROVAL

Received from Rambam Medical Centre Institutional Review Board

Helsinki Committee
RAMBAM
Health Care Campus
P. O. Box 9602
Haifa 31096
Tel: 04-8543501
Fax:04-8542520

RAMBAM
Health Care
Campus

09 May , 2010

This is to confirm that the study No. 0188-10-RMB "The meaning of ADs
for people with long term conditions – (Protocol vers 1 dated April 01,
2010)" ,
Principal Investigator – Mrs. Tikva Meron, Rambam Medical Center,
Was approved on April 21, 2010 by the Helsinki Committee of the
Rambam Medical Center, Haifa, Israel.

<u>The voting members of the Helsinki Committee were</u>:

Moshe Berant, MD, (M)	Head, Helsinki Committee
Amihai Rubin MD, (M)	Head, Helsinki Committee (Co-Chairman)
Ami Safran (M)	Lawyer, Haifa
Menahem Nahir, MD, (M)	Dept. of Rheumatology
Norberto Krivoy, MD, (M)	Head, Clinical Pharmacology Unit
Salim Haddad, Dr., (M)	Director of Pharmacy
Ilana Oren, MD, (F)	Head, Immunodepression-related
	Infections Unit, Hematology Institute

Sincerely,

Dolly Haddad
Coordinator, Helsinki Committee

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APPENDIX C: THE ADVERT IN THE 'LILACH' BULLETIN

(The original advert was in Hebrew and the attached form is an adapted English version that was used for discussion and agreement with my supervisors)

University of Nottingham
School of Nursing, Midwifery & Physiotherapy
Room B53, B Floor
Medical School
Queen's Medical Centre
Nottingham
NG7 2UH
UK

Dear LILACH member,

This letter is sent to you as a member of LILACH organisation, and I thank you for your attention.

My name is Tikva Meron. I am an oncology nurse and a clinical specialist in palliative care, currently doing doctoral studies in palliative and end of life care in the University of Nottingham (UK). As part of my studies I am researching the meaning of advance directives to people with life threatening illnesses such as: Cancer, MND, AIDS, heart\kidney\liver\lung failure.

In this research study, I am seeking to talk to people who have a life threatening illness about advance directives. I want to find out what people think about the idea of having an AD and how, if they already have an AD, do they hope it will be used. This research will enable to broaden and open for the public, the knowledge and discussion that are needed for coping with these issues, and will add to the research body of knowledge.

If you have made an AD or, if you have thought about this but decided not to make an AD, I would be very thankful to have your consent to meet and discuss this with you at time and location of your choice.

If you are interested in participating, please contact me by e-mail: t_meron@hotmail.com or by phone: 052-3488453, to receive more information and see if you can be included in the research.

Thank you for reading this letter.

Regards,

Tikva Meron, MSc.

APPENDIX D: PATIENT-PARTICIPANT'S INFORMATION SHEET

(the original information sheet was in Hebrew)

University of Nottingham

School of Nursing, Midwifery & Physiotherapy
Room B53, B Floor
Medical School
Queen's Medical Centre
Nottingham
NG7 2UH
UK

The University of
Nottingham

Title of Project: The meaning of advance directives for people with long term conditions

Patient Information Sheet

Dear LILACH member,

My name is Tikva Meron, an Oncology nurse in Israel since 1991 and currently doing a PhD degree related to Palliative and End of Life care in the University of Nottingham (UK). As part of my studies I am researching **the meaning of advance directives for people with long term conditions.**
Before you decide whether to take part in this research it is important for you to understand why it is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish to. Ask me if there is anything that is not clear or if you would like more information.

Background

You have recorded what your preferences and wishes for future care and treatment might be if you become unable to make decisions for yourself. These are called advance directives (or living wills).
This study is looking to understand the meaning of having advance directives for people who have a long term condition. It will take place in Israel between September 2010 and June 2011.

What does the study involve?

The research involves an interview of around 1-2 hours. In the interview, I would like to ask you some questions about your experiences of writing advance directives and your views about their contribution to your care.

The interview will be held in a place of **your choice** that will be quiet enough to enable communication. For the research purpose the interview will be recorded with an audio-tape, and I may take notes during the conversation.

After your interview, I will ask your permission to approach people involved in advising or helping you with your advance directive, so that I can invite them to take part in an interview. This might be a relative, your physician, and\or a lawyer. It is important that you feel free to accept or refuse some or all. This will have no effect on the quality of your participation.

In some cases and if you will be interested, there could be more than one interview.

Why have you been addressed?

You have been addressed because you have made advance directives and currently cope with an advanced state of a long term condition.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form in two copies, one of which to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What are the possible disadvantages of taking part?

Thinking about one's illness and the plans you have made for when your illness gets worse can be difficult. For some people it can invoke feelings of worry and sadness, and it may make make you recall experiences of bereavement. On the other hand the interview may be an opportunity for you to share and express important issues in a safe and private environment, which can be rewarding and supportive.

In case you are left with any discomfort and feel distressed after the interview, it may be useful to get the support you need, from a family member, a friend, or the support service where you are cared for. I would appreciate it if you could let me know if such an event occurred.

Who can I complain to?

In case you have a complaint on anything to do with the study, you should contact the Ethics Committee Secretary, Mrs. Doly Hadad [Rambam Medical Center, tel: CONTACT DETAILS].

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept on a password protected database and is strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the research study?

The research results will be published as part of a PhD (doctoral) thesis at the University of Nottingham possibly by the end of 2012. It will be published in professional journals as well. You will not be identified in any report or publication.

Who has reviewed the study?

This study has been reviewed and approved by my supervisors, Prof. Seymour and Dr. Almack; by the University of Nottingham Nursing school confirmation board and the Helsinki ethical research committee in the Rambam Medical Centre, Haifa.

Contact for Further Information

For further information and\or if you agree to participate please contact Tikva Meron, mobile number: 052-3488453. e-mail: t_meron@hotmail.com

Thank you for reading this.

Tikva Meron, nurse, Msc.

APPENDIX E: THE QUESTIONNAIRE FOR HEALTH CARE PROVIDERS

(Adapted with permission from Rebekah Schiff, the first author of Schiff et al., (2006).

Note: The questionnaire which was included in this appendix for the purpose of doctoral defence has been removed from the e-thesis document in order to safeguard copyright; the original questionnaire has not been published and I did not seek permission to publish it.

If interest arises in the precise content of the adapted questionnaire, specific measures will be taken to ask permission from Schiff et al. prior to sharing the questionnaire that was used for this research.