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Abstract

As a nurse in palliative care I have noticed that a gap sometimes exists between the understanding of healthcare professionals and of our palliative-care clients regarding the clients' lived experience and their perception of quality of life under those circumstances. As the main aim of palliative care is, however, to contribute to people's quality of life, I felt impelled to explore the phenomenon from the patients' point of view. The purpose is to provide healthcare professionals with a deeper insight into this experience, and thereby empower them to become more able to support their clients towards a better quality of life.

The research approach was the Vancouver School of Doing Phenomenology, since its aim is oriented towards the construction of understanding by grasping the meaning of a phenomenon. The participants were seen as co-researchers and were selected through purposeful sampling, and the data collection was carried out through dialogues with ten co-researchers with different incurable, life-threatening diseases, a total of fifteen dialogues. The data analysis was thematic.

The study revealed that fatal illness has had deep social, physical and personal effects on the co-researchers, who use a variety of resources to make their lives easier. Increased symptoms often reminded them of the gravity of their disease and provoked anxiety attacks and existential concerns. It transpired that a positive frame of mind, hope and faith, as well as the feeling of having a role and a purpose, had a positive influence on quality of life, and support from family was crucial. Another important factor was whether or not they received adequate social services; most of them felt that pursuing their rights was too cumbersome and complicated, and that it was hard to live on the benefits they received. A professional and supportive approach from healthcare personnel had a positive influence on quality of life, but when health personnel

appeared to be uninterested or rushed, this was discouraging. The co-researchers' need for 'human contact' with healthcare professionals was clear, and their experiences of care from specialised palliative nurses were strikingly positive.

Despite their physical burden and deterioration, and a life 'consisting of getting bad news,' the co-researchers' profound need for going on with as meaningful a life as possible, and in society with others, was clear, and is reflected in the study's overriding theme: 'Remember that I am still alive.'

**I dedicate this dissertation to the memory of my parents,
Bjarni Hólmgrímsson and Sigríður Guðmundsdóttir.
Their optimism, tenacity and courage are my guide.**

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Contents

Statement of authorship and verification	II
Abstract	III
Dedication	V
Acknowledgements	VI
Chapter 1 : Introduction	1
1.1 Research question	1
1.2 Purpose of the study	1
1.3 Background to the study	2
1.4 Significance to nursing and the researcher's position	3
1.5 Summary	4
Chapter 2 : Literature review	5
2.1 Introduction	5
2.2 Literature search	5
2.3 Key terms	6
2.4 Literature review	7
2.4.1 The experience of living with an incurable, life-threatening disease	7
2.4.2 Influences on perceived quality of life when living with incurable, life-threatening disease and facing impending death	11
2.5 Summary	12
Chapter 3 : Research design : methodology and methods	13
3.1 Introduction	13
3.2 Philosophical underpinnings of the study	13
3.2.1 The ontology and epistemology of phenomenology	14
3.3 Methodology and philosophical underpinnings	15
3.3.1 Phenomenology	15
3.3.2 The Vancouver School of Doing Phenomenology	16
3.4 Methods used for sampling, data collection and analysis	18
3.4.1 Sampling	18
3.4.2 Data collection	19
3.4.3 Data analysis	19
3.5 Trustworthiness, rigour of the study	19
3.6 Ethical issues	21
3.7 Summary	22

Chapter 4 : Data collection and analysis	23
4.1 Introduction	23
4.2 Access and permission for data collection	23
4.3 Data collection and analysis	23
4.3.1 Selecting co-researchers	24
4.3.2 Collection and analysis of data	26
4.4 Ethical concerns	30
4.5 Summary	31
 Chapter 5 : Findings	 32
5.1 Introduction	32
5.2 A phenomenological description	32
5.2.1 The experience of living with an incurable, life-threatening disease	32
5.2.2 Positive and negative influences on perceived quality of life	35
5.3 The lived experience of living with an incurable, life-threatening disease	38
5.3.1 Personal reaction	39
5.3.1.1 Mixed initial response	39
5.3.1.2 Anger	40
5.3.1.3 Psychological distress / depression	41
5.3.1.4 Anxiety attacks / existential crisis	42
5.3.1.5 New view of life, inner strength	43
5.3.2 Social effects of the disease	43
5.3.2.1 Positive effects on relations with family and friends	44
5.3.2.2 Negative effects on relations with family and friends	44
5.3.2.3 Decreased ability to work	45
5.3.2.4 Poor financial situation	46
5.3.3 Negative physical effects of the disease or the treatment	47
5.3.3.1 Problems with fatigue	48
5.3.3.2 Pain	48
5.3.3.3 Eating / digestive problems	49
5.3.3.4 Cardiovascular problems	50
5.3.3.5 Other physical problems	50
5.3.4 Resources	51
5.3.4.1 Fighting back	51
5.3.4.2 Conscious changes in attitude toward life	52

5.3.4.3 Use of humour	53
5.3.4.4 Finding strength in faith	53
5.3.4.5 Denial	54
5.4 Positive and negative influences on perceived quality of life	55
5.4.1 Positive thinking, hope and faith vs. negative thinking, hopelessness and lack of faith	55
5.4.2 To have a role and sense of purpose vs. feeling purposeless	56
5.4.3 Support from family and friends vs. lack of support	57
5.4.4 Public social intervention vs. lack of public social intervention	57
5.4.5 Professionalism vs. lack of professionalism within the healthcare system	59
5.4.5.1 Specialised palliative care vs. lack of such care	59
5.4.5.2 Conduct of healthcare personnel: Professional and supportive vs. unprofessional and discouraging	61
5.4.5.3 Professional resources and security vs. lack of these	62
5.5 Summary	64
Chapter 6 : Discussion	65
6.1 Introduction	65
6.2 The model: The essential structure of living with an incurable, life- threatening disease	66
6.3 The overriding theme: ‘Remember that I am still alive’	66
6.4 The lived experience of living with incurable, life-threatening disease	67
6.5 <i>Internal factors</i> influencing perceived quality of life when living with an incurable, life-threatening disease	71
6.6 <i>External factors</i> influencing perceived quality of life when living with an incurable, life-threatening disease	73
6.7 Limitations and strengths of the study	76
6.8 Summary	77
Chapter 7 : Conclusion	78
7.1 Introduction	78
7.2 Implications and recommendations for practice	78
7.3 Recommendations for further research	83
7.4 Concluding comments	83

Appendices	85
References	111
Bibliography	132
Research methodology	132
Palliative care	136
Miscellaneous articles	142

List of tables and figures

Tables

Table 1 Definition of key terms	6
Table 2 Examples of qualitative studies in palliative care, conducted from the patient's perspective	9
Table 3 The 12 basic steps of the Vancouver School of Doing Phenomenology	18
Table 4 Characteristics of the co-researchers	25
Table 5 The lived experience of living with an incurable, life-threatening disease	38
Table 6 Examples of negative <i>physical</i> effects of the disease and/or treatment	47
Table 7 Professionalism vs. lack of professionalism in healthcare	59
Table 8 Summary of co-researchers' ideas on ideal healthcare service	79
Table 9 Co-researchers' advices to other people who might be in a similar situation to theirs.	82
Table 10 Recommendations for further research	83

Figures

Figure 1 Temporal overlapping of literature search, data collection and data analysis in the Vancouver School of Doing Phenomenology	6
Figure 2 The 'struggle' of trying to cope and enjoy life when facing impending death; 'it's a huge struggle'	34
Figure 3 The essential structure of living with an incurable, life-threatening disease and positive and negative influences on perceived quality of life under those circumstances	37

Chapter 1

Introduction

This phenomenological study explores the lived experience of living with an incurable, life-threatening disease, and positive and negative influences on perceived quality of life under those circumstances.

As a nurse in palliative care I have noticed that sometimes there is a gap between the understanding of healthcare professionals and of our palliative-care clients regarding the clients' lived experience and perception of quality of life under the circumstances. As the main aim with palliative care is, however, to contribute to people's quality of life, I felt impelled to explore the phenomenon from the patients' point of view.

1.1 Research question

The research question of this study is: 'What is the essential structure of living with an incurable, life-threatening disease, and what has positive and negative influence on perceived quality of life under those circumstances?'

1.2 Purpose of the study

The purpose of the study is to contribute to our understanding of what it is like to live with an incurable, life-threatening disease, and what has positive and negative effects on perceived quality of life under the circumstances. The findings will hopefully provide healthcare professionals with a deeper insight into what it is like to be actually living under these circumstances, and thereby empower them to become more able to support their clients towards a better quality of life.

1.3 Background to the study

Researches within palliative care have widely been perceived as being ethically problematic, not least when including patients as participants (Barnett, 2001; Lee and Kristjanson, 2003; Terry *et al.*, 2006a). In the 1990s nurses were increasingly asked to provide evidence of their nursing care in order to establish their 'worth' within the palliative-care team, and most studies from that time address service delivery and the role of the palliative-care nurse (Wilkes, 1998; Wilkes *et al.*, 2000; Frogatt *et al.*, 2003). Later on, user involvement was suggested as part of a good research practice (Wright *et al.*, 2006), and it has been recommended that in future studies, palliative-care patients themselves be invited to participate (Frogatt *et al.*, 2003; Johnston *et al.*, 2005; Terry *et al.*, 2006a). In a study where research priorities among nurses within cancer care were explored, quality of life was assigned the highest priority (Rustøen and Schjølberg, 2000). An evaluative review of qualitative research in palliative care revealed that academics seem to dominate the author lists. However, palliative-care professionals should be encouraged to conduct studies within the spectrum, in order to strengthen the applicability of the findings for practice (Frogatt *et al.*, 2003). I see the phenomenological research which I, as a nurse within palliative care, conduct in collaboration with individuals with an incurable, life-threatening disease, as a response to the above recommendations. In my view my study also harmonises with the compilation of the World Health Organization (WHO), where it is pointed out that fields needing more in-depth studies include, among other things, the social and psychological aspects of palliative care (Davies and Higginson, 2004b).

People with cancer are more likely to receive specialised palliative care than those with other life-threatening diseases (Skilbeck *et al.*, 1998; Skilbeck and Payne, 2005; Daley *et al.*, 2006; Rosenwax and McNamara, 2006), although it is widely acknowledged that the latter group also has a great need for specialised palliative care (Boyd *et al.*, 2004; Andersen *et al.*, 2005; Hughes *et al.*, 2005; Skilbeck and Payne, 2005; Daley *et al.*,

2006; Fraser *et al.*, 2006; Hudson *et al.*, 2006; Willems *et al.*, 2006). Most of my clients within palliative care have advanced cancer but, as there are also individuals suffering from other incurable diseases, I found it meaningful to invite people with different diseases to participate in the study, thus endeavouring to 'reflect the reality.' I find this especially important, as people with cancer are more often participants in palliative care studies (Frogatt *et al.*, 2003), and I agree with Skilbeck and Payne (2005) who find it unrealistic to plan all palliative care on models of care developed for people with cancer.

1.4 Significance to nursing and the researcher's position

Palliative care is a global public health issue, as millions of people worldwide suffer from life-threatening diseases (Sepúlveda *et al.*, 2002). The need for palliative care emerges therefore within almost every field of nursing practice and should always be centred upon the personal needs of each client and her / his family (WHO, 2002).¹ I agree with Dingwall *et al.* (1998), who pointed out the relations between personal intervention, as needed within palliative care, and qualitative inquiry, which provides useful information at an individual level instead of on a population level. In light of this, the Vancouver School of Doing Phenomenology was chosen as a method. The School can provide a systematic explication of human experiences through mediating the unfamiliar to an understanding (Halldórsdóttir, 2000), and empathic understandings gained through our participation in the created worlds can eventually change our nursing practice (Koch, 1998). By moving beyond the surface and connecting with depths of common but unique human experience (Chinn and Kramer, 1999), the findings can be valuable in their direct applicability to practice (Rose *et al.*, 1995), influencing thoughtful, reflective care through revealing the meanings of human experiences (Van der Zalm and Bergum, 2000). In my view, the findings gained by the method of the Vancouver School may therefore prove advantageous in strengthening

¹ I emphasise that although both patient and family are the units of care within palliative care, the focus of this study is on patients' experiences.

the empathic and deliberate professional approach that is needed in order to fulfil the aims of palliative care.

1.5 Summary

The need for palliative care emerges within almost every field of nursing practice, and it should always be centred upon each client's personal needs. I have noticed that a disparity sometimes exists between the understanding of healthcare professionals and that of palliative-care clients regarding the clients' lived experience and perception of quality of life. I felt impelled to explore the phenomenon from the clients' point of view, using a qualitative approach in order to deepen our empathic understanding of the phenomenon under study.

Chapter 2

Literature review

2.1. Introduction

Although palliative-care research has been perceived as ethically problematic, many studies of palliative care have been conducted over the years, and these underpin the care provided today. In this chapter I will describe the literature search I carried out before and throughout the research process, present the key terms of the study and review the literature relevant to my research question.

2.2 Literature search

The literature search was carried out within several databases using combinations of the terms ‘incurable,’ ‘life-threatening,’ ‘quality of life,’ ‘palliative care,’ ‘terminal care,’ and ‘hospice care.’ Most of the articles I found by using these terms, addressed people with advanced cancer, and hence terms related to other incurable diseases were added to the search. In order to ensure broadmindedness I included some literature from the viewpoint of patients’ families and of healthcare professionals as well. Finally, I read through the index of several volumes of the ‘International Journal of Palliative Nursing.’

This study is guided by the method of the Vancouver School of Doing Phenomenology. Within that School, reading literature is recommended before and in parallel with the enquiry so that the enquirer may be more broadminded and receptive to what the co-researchers are saying (Halldórsdóttir, 2000). Therefore, the literature search, data collection and data analysis run concurrently through the research process, with an ongoing literature search after the data analysis, corresponding to the findings (figure 1).

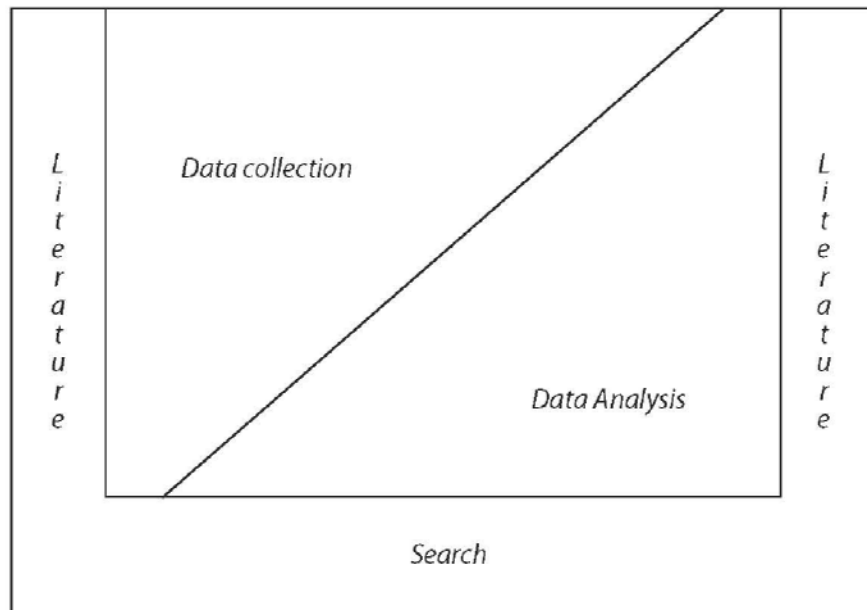


Figure 1

Temporal overlapping of literature search, data collection and data analysis in the Vancouver School of Doing Phenomenology (Reference: Halldórsdóttir, 2000, p.62).

2.3 Key terms

The definitions of the key terms as they are used in this dissertation are presented in table 1.

An incurable and life-threatening disease

The individual has a progressive disease which cannot be cured and he/she may or will die due to the disease in the near future.

Quality of life

Will be defined by the co-researchers themselves.

Table 1 Definition of key terms

2.4 Literature review

2.4.1 The experience of living with an incurable, life-threatening disease

Because of our familiarity with our culture and society through our *being-in-the-world*, certain aspects may be concealed because of their taken-for-granted nature (Plager, 1994). This could refer to the formerly taken-for-granted idea (before the 1970s) that it was in the best interests of palliative-care patients to be protected from knowledge of their prognosis and impending death (Burns and Grove, 2001). Care at that time was based on natural sciences and authoritative knowledge, with the emphasis on physical problems according to Cartesian dualism, and the person was not viewed as ‘a whole’ (Jordan, 1997; Björnsdóttir, 2005). An extensive qualitative study conducted in the 1960s (Glaser and Strauss, 1965; Glaser and Strauss, 1968; Glaser and Strauss, 1971) revealed, however, that this ‘protection’ – not telling the individuals that they were terminally ill – led to loneliness and isolation for them. These results brought about a new *gestalt* within palliative care (Burns and Grove, 2001). Kübler-Ross’ (1969) ‘stage theory’ of the process of denial, anger, bargaining, depression and acceptance within the dying person became well known, and has been widely used within palliative care ever since. Thus the above-mentioned studies made significant contributions to clinical practice (Copp, 1998), as did the enquiry of Saunders, the founder of the first modern nursing hospice in 1967 (Saunders, 2001). It gradually came to be acknowledged that individuals had the right to know about their condition and their prognosis, and this right was established by law in Iceland 1997 (Alþingi [The Icelandic Parliament], 1997). It was also stipulated that individuals’ autonomy should be respected, and that they and their closest relatives have the right to receive spiritual, social and religious support.

The above-mentioned evolution within palliative care called for a more complex knowledge base and skills among healthcare professionals. The experience of living with dying is difficult and frightening for most people (Copp, 1997), and palliative

healthcare professionals have to be able to assist individuals when it comes to integrating dying into their lifestyles (McCormick and Conley, 1995), modelling upon their personal coping skills (Sheldon, 2003). Current theories of death and dying have been criticized for not taking sufficient account of the dying individual's own perspective and values (Copp, 1998). Kübler-Ross's stage theory has been criticized for assuming too mechanistic an approach, with the person moving through the same universal stages (Copp, 1998), and for being used to 'categorize' instead of 'opening up people's experiences' (Frank, 1991). The current understanding of how people experience the end of life seems to derive in relatively large part from the viewpoint of health care professionals and family members (Davies *et al.*, 1995; Frogatt *et al.*, 2003; Vig and Pearlman, 2003; Hickman *et al.*, 2004; Terry *et al.*, 2006b). The palliative-care qualitative research review of Frogatt *et al.* 1990-1999 (2003) revealed that the patients themselves had been participants in only 26% of the reviewed studies. Professionals participated most frequently, although patients formed a large proportion of the focus of the studies. This coincides with a literature review of the trends within palliative care nursing research from 1987-1996, where it emerged that the main focus of reviewed studies was on nurses, while 24% were related to patients (Wilkes, 1998). It has been pointed out that palliative-care studies conducted in collaboration with patients as co-researchers remains an under-developed area of research activity (Wright *et al.*, 2006), and indeed the review of research in palliative care by Frogatt *et al.* (2003) revealed that only 0.5% of the articles were identified as reporting qualitative research with the focus on the context of death, dying or bereavement.

Although no research with the same focus and approach as applied in my study was found, various specific aspects of palliative-care patients' perspectives have been investigated using qualitative methods in recent years. Examples of these are presented in table 2.

Focus of study	Methodology/Participants	Reference
Perspectives on dying and the care of dying patients	'Interviews' / 6 patients with life-threatening illness	McCormick and Conley, 1995
Experience of living – dying in a nursing home	Ethnographic / 13 residents in a nursing home, all with terminal cancer	Engle <i>et al.</i> , 1998
The meaning of the lived experience of hope in patients with cancer in palliative home care	Phenomenological - hermeneutic / 11 patients with incurable cancer	Benzein <i>et al.</i> , 2001
Health promotion: the perception of therapeutic interaction with the palliative nurse in the primary care setting	Phenomenological / 12 patients with incurable cancer	Richardson, 2002
Expectations and experiences of specialist palliative care	Secondary qualitative data analysis / 37 palliative-care patients	Seymour <i>et al.</i> , 2003
Areas of priority in terminally-ill peoples' lives	Grounded theory / 10 patients with terminal cancer	Carter <i>et al.</i> , 2004
Approaches to clinical conversations	Grounded theory / 11 patients with terminal disease	Clover <i>et al.</i> , 2004
Ideas and attitudes of patients with end-stage cardiac failure concerning dying	A prospective, qualitative case study / 31 patients with advanced heart failure	Willems <i>et al.</i> , 2004
Nature of suffering and its relief	'Qualitative inquiry' / 26 patients with terminal cancer	Daneault <i>et al.</i> , 2004
Hospitalized patients' experience of suffering	Phenomenological / 12 patients with incurable cancer	Rydahl-Hansen, 2005
Existential issues	'A qualitative assessment' / 40 patients with advanced and incurable cancer	Blinderman and Cherny, 2005
Evaluation of supportive care	Focus groups / 8 patients with progressive cancer	Fincham <i>et al.</i> , 2005
Experiences of attending a particular hospice service and how terminal illness affects quality of life	'Goldfish bowl'/'a free flowing conversation in groups' / 34 patients with cancer	Kennett and Payne, 2005
Living with advanced cancer	Interpretive phenomenology / 7 patients with advanced cancer	Coyle, 2006
Patient work in end-stage heart failure	Prospective longitudinal multiple case study / 31 patients with end-stage heart failure	Willems <i>et al.</i> , 2006

Table 2 | Examples of qualitative studies in palliative care, conducted from the patient's perspective

The focus of the studies by Engle *et al.* (1998) and Coyle (2006) lies among other things on *living* with ‘terminal’ or ‘advanced’ disease, and may thus be likened to the present study’s focus on *lived experience of living with an incurable, life-threatening disease*. The findings of Engle *et al.* (1998) reveal patients’ experience of inadequate pain relief, as well as their need for fellowship and faith in order to improve their well-being. Participants used, among other things, humour and ‘withdrawal from the situation’ as coping strategies, and a minority expressed anxiety about dying. The participants in Coyle’s study (2006) tried to orient themselves to their disease and maintain control, among other things by trying to keep things ‘just as they always were.’ They tried to create a system of support and safety, strove to find meaning in what was happening, and created a legacy, which in a sense formed a bridge for them ‘between existence and nonexistence’ (p.272).

The other studies in table 2 have provided palliative care with rich and valuable information about diverse aspects of the subject, and will be addressed to some extent in relation to the findings in chapter 6.²

Qualitative studies which explore perspectives of both patients and their families and / or health professionals, on different aspects of palliative care have also been conducted (Copp, 1997; Taylor *et al.*, 2001; Boyd *et al.*, 2004; Mok and Chiu, 2004; Murray *et al.*, 2004; Francke and Willems, 2005; Hughes *et al.*, 2005; Low *et al.*, 2005; Waldrop *et al.*, 2005; Johnston and Smith, 2006; McIlfatrick, 2006; Terry *et al.*, 2006b), but will not be discussed further here.

² Because of a word limit in this dissertation, these other studies in table 2 will not be discussed further in this chapter.

2.4.2 Influences on perceived quality of life when living with incurable, life-threatening disease and facing impending death

The primary goal of palliative care is to reduce suffering and carefully support individuals to live as meaningfully and actively as possible until the end of life, and thereby to improve their and their families' quality of life (World Health Organization, 2002). Within palliative care, dying is regarded as a normal process (Davies and Higginson, 2004a), and the emphasis shifts from the hope for cure, to hope for quality of life (Vig and Pearlman, 2003). This makes the patient's quality of life within palliative care the principal focus of care, more than in most other nursing fields (Axelsson and Sjöden, 1998; Annells and Koch, 2001).

In my literature search I found several recent descriptive studies in which quality of life among palliative-care patients was investigated (Axelsson and Sjöden, 1998; McMillan and Weitzner, 1998; Annells and Koch, 2001; Sahlberg-Blom *et al*, 2001; Boström *et al.*, 2003a; Boström *et al.*, 2003b; Peters and Sellick, 2006; Yan and King-Fong, 2006). All of these studies dealt with standard instruments / questionnaires measuring patients' quality of life, and all participants but one had cancer. The findings of one qualitative study of quality of life indicate that standardized instruments can provide information about the quality of life of a group as a whole, but will probably not address the specific concerns of each participant (Cohen and Leis, 2002). This inspired me to plan my phenomenological approach to go 'beyond' the standard measurements, as did the findings of another qualitative study, where it is deemed important that professionals be familiar with their clients' experiences of living with terminal illness in order to maximize their quality of life (Vig and Pearlman, 2003). As the concept of quality of life is subjective, I found it helpful to approach the subject matter by asking my co-researchers about *positive and negative influences on their perceived quality of life*. Knowing these factors is a prerequisite for responding to them, endeavouring to establish a base for improved quality of life of the palliative-care client.

2.5 Summary

In recent decades individuals with incurable, life-threatening diseases have progressed from being passive receivers of health care service, deprived of the right to know about their condition / prognosis, to being valued persons with the right to receive spiritual, social and religious support when facing their death. Although this has called for a complex knowledge base in palliative care, current understandings seem to be drawn in relatively large part from the viewpoint of health care professionals / family members. Various specific aspects of palliative-care patients' perspectives have been investigated. By opening discussions with my co-researchers through broad questions about their overall experience, I hoped they would sense the opportunity to express themselves openly about experiences immediately meaningful to them. The next chapter will describe the methodology and methods of the research, and ethical issues will be discussed.

Chapter 3

Research design: methodology and methods

3.1 Introduction

The literature review on living with an incurable, life-threatening disease was presented in the last chapter. Now the design of the research, its philosophical underpinnings, the methodology and methods will be described. Furthermore, the trustworthiness and ethical issues concerning qualitative studies will be discussed.

3.2 Philosophical underpinnings of the study

A paradigm is a set of basic beliefs or world views that guide the inquirers in ontologically and epistemologically fundamental ways, as well as in their choices of a method (Guba and Lincoln, 1998). The paradigm underpinning my study is the constructivist-interpretivist paradigm, as I see this particular paradigm as the basis for holistic palliative-care, since the inquiry within this paradigm often leads to meaningful and refreshing discoveries about human beings and the world (Leininger, 1992), unifying rather than fragmenting the meaning of being human (Kretlow, 1990). In my view this makes an enquiry rooted in this paradigm suitable when it comes to studying the lived experience of living with an incurable, life-threatening disease. On that basis, the method of the Vancouver School of Doing Phenomenology, which is based on an interpretation of phenomenological philosophy (Halldórsdóttir, 2000), has been chosen to carry out the study.

In my view, it can be argued that palliative care today, as well as the Vancouver School, is rooted in the constructivist-interpretivist paradigm, since it corresponds with the paradigm's questions on the nature of understanding and meaning, and the emphasis is on the client's experience and perception of the illness (Draper, 1996). The quality of care will be seen 'in the light of the relationship between a unique nurse and a unique

patient' (Gastmans, 1998, p. 1317). Nurses are engaged with patients as persons whilst themselves being persons (Elcock, 1997) who are aware of conflicts of values within themselves, and between themselves and their clients (Johns, 1995). This refers to the existentialist viewpoint of the constructivist-interpretivist paradigm; understanding is possible because we have our 'being-in-the-world,' with a shared background of understandings, and are thus dialogic beings (Taylor, 1991; Crotty, 1998).

3.2.1 The ontology and epistemology of phenomenology

Ontology deals with the nature of reality (Guba and Lincoln, 1998). It is 'the study of being,' concerned with 'what is,' and with the nature of existence and the structure of reality as such (Crotty, 1998). The Vancouver School's ontology supports the views of the moderate realist, 'believing in one real reality while embracing multiple co-existing realities within the subjective domain' (Halldórsdóttir, 2000, p. 54). The world 'is there' whether human beings are conscious of it or not, and the multiple co-existing realities are grounded in people's constructed meaning about the world (Crotty, 1998). Meaning emerges then because of the unitary relation between human beings (Johnson, 2000).

Epistemology deals with the nature of knowledge, or what can be known and how knowledge can be created, as well as pertaining to the relationship between the researcher and the participant (Guba and Lincoln, 1998; Chinn and Kramer, 1999). The aim of creating knowledge within the constructivist-interpretivist paradigm is not to predict or generalize, but rather to gain insight and '*crystallise the essential structure of the phenomenon*' (Halldórsdóttir, 2000, p. 50). It is assumed that people construct ideas about the world and make sense of those constructions in a context, creating knowledge through construction but not finding or discovering it (Schwandt, 2000). The investigator and her / his co-researcher are interactively linked and the findings are

‘literally created’ through the research process (Guba and Lincoln, 1998). The epistemology of the Vancouver School is therefore transactional (Halldórsdóttir, 2000).

The conventional distinction between ontology and epistemology, which is prominent and clear within the positivistic paradigm, disappears within the constructivist-interpretivist paradigm (Guba and Lincoln, 1998). Since the social reality consists of people’s experiences and understandings, knowledge of reality is the knowledge of those experiences and understandings (Porter, 2000).

3.3 Methodology and philosophical underpinnings

3.3.1. Phenomenology

Edmund Husserl (1859-1938), the founder of phenomenology, introduced the concept of ‘life-world’ or ‘lived experience’ and brought to light the ultimate structures of the consciousness or ‘the essences’ (Koch, 1995; Holloway, 2005). His position was epistemological and the emphasis was on description (Fjelland and Gjengedal, 1994). Husserl’s ideology was a historical reaction to the positivist approach in studying human experience (Omery, 1983; Spiegelberg, 1984), giving the phenomena deeper attention than they had received within empiricism (Spiegelberg, 1984).

Martin Heidegger (1889-1976), a student of Husserl, shifted towards considering ontological problems (Leonard, 1994; Holloway, 2005), making human ‘being’ the nucleus, rather than pure consciousness (Omery and Mack, 1995). Heidegger developed hermeneutic phenomenology in order to uncover what it means to be a human being (Plager, 1994). The philosophies of phenomenology and hermeneutics have indeed been connected, as each presupposes the other (Hall, 2000): hermeneutics is constructed on the basis of phenomenology and phenomenology is the premise of hermeneutics (Ricoeur, 1990). Heidegger emphasized being-in-the-world as the basic human

structure (Omery and Mack, 1995), with death as the ultimate and fundamental meaning-giving possibility (Johnson, 2000).

It is arguable that in palliative care, knowledge originated from the positivistic paradigm serves as a base on which to construct holistic nursing care, as it provides us with various facts of symptoms, prognoses and other important factors in planning the care. When it comes, however, to accomplishing the essence of holistic palliative care, I believe in the art of communicating with and relating to the client, guided by principles of ethics. In my view, this may be likened to the desirable talent of the researcher within the constructivist-interpretivist phenomenological enquiry, making that approach valuable for examining and recognising the lived experience which is commonly taken for granted (Holloway and Wheeler, 1996), and shedding light on difficult and hidden issues in a rich and valuable way (Seymour and Ingleton, 2005). To perceive what it is like to go through a particular experience is basically a prerequisite for being able to assist the person who is going through the experience (Halldórsdóttir, 2003). It has indeed been suggested that phenomenology and nursing are congruent because of the humanistic underpinnings of both (Smith, 1989; Rose *et al.*, 1995), and that holistic nursing should be explored by methods that appreciate people's lived experience (Wilkes, 1991).

3.3.2. The Vancouver School of Doing Phenomenology

The Vancouver School is primarily influenced by the phenomenological writings of Anderson, Colaizzi and Spiegelberg and the writings of Ricoeur (hermeneutic / interpretive phenomenology) and Schwandt (constructivism) (Halldórsdóttir, 2000; Halldórsdóttir, 2003). The methodology of the Vancouver School is a blend of description, interpretation, clarification and construction (Halldórsdóttir, 2000). Its aims are oriented towards the construction of understanding by grasping the meaning of a phenomenon through the hermeneutic circle of understanding, describing lived

experience in depth, and the meaning it has for the persons from their point of view (Halldórsdóttir, 2000).

Within the School, creating knowledge is a transactional process between the researcher and the co-researcher. It has been described how an enquirer and a research participant construct and interpret their meanings while working toward increased information and sophistication through their dialogue (Guba and Lincoln, 1998), until they achieve the ‘fusion of horizons’ as portrayed by Gadamer (1986). By ‘sharing’ in this way, and participating in things, we enrich them and they become larger (Gadamer, 1984). I interpret this as the fountain of knowledge-creation which is a direct result of the empowering communication that takes place between the researcher and the co-researcher, or their ‘dance of dialogue’ as Halldórsdóttir (1996) put it in her discussion of the Vancouver School.

The researchers within the Vancouver School have to know the art of being open, receptive and able to think beyond their preconceptions, in order to see the world afresh from the research participant’s point of view. This is the prerequisite for gaining understanding; the enquirer and the research participant must make sense of the data in a meaningful way (Halldórsdóttir, 2000). Through *being-in-the world*, the researcher takes an emic stance. He / she is a participant rather than an observer in order to acquire an ‘insider’s perspective’ through mutual construction and interpretation. Thus knowledge is gained through the dialogue of two experts, the researcher and the research participant, who is an expert on the actual lived experience. Within the School the research participants are seen as co-researchers, as there is reverence for them as experts in the lived experience (Halldórsdóttir, 2000).

3.4 Methods used for sampling, data collection and analysis

The research process within the Vancouver School consists of 12 basic steps (see table 3). The seven basic stages of '*silence, reflection, identification, selection, interpretation, construction and verification*' are followed again and again throughout the process (Halldórsdóttir, 2000, p.56).

• Step 1	Selecting dialogue partners (the sample).
• Step 2	First, there is silence (before entering the dialogue).
• Step 3	Participating in a dialogue (data collection).
• Step 4	Sharpened awareness of words (data analysis).
• Step 5	Beginning consideration of essences (coding).
• Step 6	Constructing the essential structure of the phenomenon for each case (individual case constructions).
• Step 7	Verifying the single case construction with the co-researcher.
• Step 8	Constructing the essential structure of the phenomenon from all the cases (metasynthesis of all the different case constructions).
• Step 9	Comparing the essential structure with the data.
• Step 10	Identifying the over-riding theme which describes the phenomenon (interpreting the meaning of the phenomenon).
• Step 11	Verifying the essential structure (the findings) with some research participants.
• Step 12	Writing up the findings.

(Reference: Halldórsdóttir, 2000, p. 57)

Table 3 The 12 basic steps of the Vancouver School of Doing Phenomenology

3.4.1 Sampling

The first of the 12 basic steps of the research process is to select the co-researchers. A prerequisite for participation is that they have experienced the phenomenon (living with an incurable, life-threatening disease) and are willing to discuss their experience. As it is important that they can reflect upon the experience to gain a deeper understanding of the phenomenon (Halldórsdóttir, 2003), it is also a condition of participation that *at least* six months (preferably longer) must have elapsed since the co-researchers were diagnosed as incurable.

The co-researchers are selected through purposeful sampling, seeking richness of data about the phenomenon (Morse, 1991), as many as are needed to obtain saturation in the discussion of the phenomenon. In accordance with the principles of purposeful sampling, the sample is heterogeneous, so individuals with both typical and atypical experience are sought (Morse, 1991).

3.4.2 Data collection

Data is gathered through *unstructured interviews* or *dialogues* (Halldórsdóttir, 2000); by terming a communication a ‘dialogue’ emphasis is placed on the mutual construction of meaning (Benner, 1994). The aim within the Vancouver School is to create knowledge through a transactional process between the researcher and the co-researcher, and to gain insight through ‘crystallising the essential structure’ of the lived experience (Halldórsdóttir, 2000).

3.4.3 Data analysis

The process of data analysis begins concurrently with the data collection and involves repeated listening to the dialogues while transcribing them, followed by reading and rereading the transcribed dialogue. It is important for the process of analysis to immerse oneself in the data, ‘letting it soak in’ by attentive listening and reading. It is essential to allow for ‘living with the data’ in this way, for as long as is needed in order to perceive the essence of each and every discussed lived experience (Halldórsdóttir, 2000). When no new themes appear within the data, the saturation point has been achieved and additional data are not required (Tuckett, 2004).

3.5 Trustworthiness, rigour of the study

Qualitative methods have been criticised for lack of rigour when measured against the positivist tradition of validity and reliability (Seale, 2001). It has, however, been

pointed out that using evaluation criteria from the positivistic paradigm of enquiry can be problematic when evaluating a naturalistic enquiry, due to the different philosophical underpinnings of these paradigms (Lincoln and Guba, 1985; Koch and Harrington, 1998; Cutcliffe and McKenna, 1999), and the concepts of validity and reliability were replaced by Lincoln and Guba (1985) by the terms of *credibility*, *transferability* and *dependability*, which have been widely used since in the evaluation of qualitative studies (Maggs-Rapport, 2001).

In order to assess the trustworthiness and credibility of a qualitative study it is necessary to audit the research process by which the findings have been achieved, making it feasible for the reader to determine the justifiability of the analytical comments, or claims, which have been made (Horsburgh, 2003). In particular, a detailed decision trail concerning the selection of research methods, and an audit trail respecting the analytical process, should be provided (Slevin and Sines, 1999). If the research is well signposted, readers should be able to travel through the worlds of the participants and the researcher, and be able to decide for themselves whether the text is credible (Koch and Harrington, 1998). In order to improve the trustworthiness of the research it is recommended that a reflexive journal be kept during the whole research process (Lincoln and Guba, 1985).

When the methodology of the Vancouver School is followed, the audit trail of the research process is relatively transparent (see 4.3.2). The trustworthiness of a study within the School is, among other things, enhanced by verifying each single case construction with the respective co-researcher (Halldórsdóttir, 2000). Furthermore, within the School constant reflexivity on the part of the researcher is regarded as essential, in order to enhance the rigour of the study.

3.6 Ethical issues

In terms of codes of ethics, an endeavour has to be made to safeguard the co-researchers' dignity and privacy (Christians, 2000), respect their autonomy (Merrell and Williams, 1995), and secure confidentiality, among other things by giving them pseudonyms (Halldórsdóttir, 2000). All information on co-researchers and recorded data must be kept confidential and in secure places inaccessible to others, and ultimately be destroyed.

My co-researchers are seen as particularly vulnerable in that they live with an incurable, life-threatening disease. There are conflicting opinions regarding whether it is appropriate to conduct research with people in this situation and, if so, how it should be done in an appropriate, ethical way (Barnett, 2001; Addington-Hall, 2002; Dean and McClement, 2002; Lee and Kristjanson, 2003; Kristjanson and Coyle, 2005; Ferrel and Grant, 2006; Terry *et al.*, 2006a). Palliative-care patients' indisposition, discomfort, distress and emotional intensity due to their knowledge of impending death have been cited as reasons for not 'involving them' in research (Dean and McClement, 2002), and it has even been regarded as abhorrent to invite them to participate in research (Lee and Kristjanson, 2003; MacDonald and Weijer, 2005; Terry *et al.* 2006a). Hence it seems to be presumed that these people's lives are 'saturated' with nothing but tremendous suffering. In my view, this could be interpreted as meaning that they are seen more as 'dying' than as 'living' or 'being-in-the-world,' which could eventually evoke a feeling of abandonment within the terminally-ill person, as described by Lynch and Abraham (2002).

As a nurse within palliative care I find it pivotal that these individuals, like others, should have the opportunity to participate in studies. I regard them as *the true experts in this particular lived experience* and I therefore find it crucial that they have the

opportunity to make an impact within the field. Gaining an understanding of the experience from their point of view should in my view be valued as fundamental in order to deepen insight into the phenomenon and hopefully thereby serve to found the basis for enhancing their quality of life. In my view, an authoritarian over-protectiveness should not apply in the process of knowledge creation any more than in the care itself. Patients with advanced diseases have in fact expressed their enjoyment of participating in research (McCormick and Conley, 1995; Blinderman and Cherny, 2005; Johnston and Smith, 2006), and it has even been pointed out that the fear of involving terminally-ill patients in research may be an issue for professionals rather than the patients (Johnston and Smith, 2006; Terry *et al.*, 2006a).

However, when it is taken into account that my co-researchers are going through a tragic experience, I deem moral knowledge (cf. Chinn and Kramer, 1999) on my part as a researcher to be highly valuable, and agree with Seymour and Ingleton (2005), who maintain that ethical behaviour is a dynamic and interpersonal activity. The potent, moral 'inner strength' of the researcher can, in my view, eventually result in more appropriate and deliberate communication with co-researchers and, furthermore, increase the likelihood of managing to solve situational ethical problems that may arise in the field (Guba and Lincoln, 1998; Grinyer, 2001).

3.7 Summary

In this chapter the philosophical underpinnings of the study, the constructivist-interpretivist paradigm, was presented, as well as phenomenology and the method of the Vancouver School of Doing Phenomenology, which is the method that guides my study. Then the trustworthiness and ethical concerns of qualitative studies were discussed. The next chapter will describe how data collection and analysis were conducted.

Chapter 4

Data collection and analysis

4.1 Introduction

The philosophical underpinnings, methodology and methods of the study have been introduced. I will now describe how the collection and the analysis of the data were carried out.

4.2 Access and permission for data collection

Those who intend to conduct a study in Iceland involving participation by human beings and concerning health issues are obliged to first seek the consent of the National Bioethics Committee (Alpingi, 1997). I obtained ethical clearance and permission for my research from the committee (Appendix 1) and also notified the Icelandic Data Protection Committee of the study (Appendix 2).

In order to ensure demographic variation within the sample, I asked nurses in several different places in Iceland to collaborate on gaining verbal consent from those who fitted my criteria (see 4.3.1), and were willing to receive an introductory letter about the research, in which I invited them to participate (Appendix 3). Those who had questions about potential participation in the study were invited to contact me to receive further explanations, and those who decided to participate were asked to sign an informed-consent form for participation in the study (Appendix 4).

4.3 Data collection and analysis

The data collection was conducted from March to September 2006, and was carried out through dialogues with ten co-researchers, a total of fifteen dialogues. The duration of each dialogue varied from 45 to 150 minutes. The dialogues took place at a time and in

a private, comfortable location chosen by each co-researcher. Most of the dialogues were carried out in the co-researchers' homes, two in co-researchers' workplaces, two in an apartment available to me and one in a hospital. One diary was also submitted as a source.

4.3.1 Selecting co-researchers

The co-researchers in the study were selected through purposeful sampling (Morse, 1991). Individuals (men and women) 18 years and older, who had been diagnosed with incurable, life-threatening disease at least six months before, who were interested in having dialogues on their experience and felt well enough to do so, were invited to participate.

I emphasised to the nurses who assisted me in finding co-researchers the importance of proposing participation only to individuals who were fully aware of the incurable and life-threatening nature of the illness.

It turned out that several more individuals than were needed offered to participate. Those who were not included in the study were sent a letter in which I expressed my gratitude for their invitation to participate, and invited them to contact me if there were any points they wished to make or discuss (Appendix 5).³

The characteristics of the co-researchers are presented in table 4.

³ None of them contacted me. Before sending those letters, I ascertained (through professional contacts) if the persons were still alive; two were deceased, and no letter was sent to them.

Category	
Total number of co-researchers	10
Sex	
Female	5
Male	5
Nationality and race:	
Icelandic	All
White / Caucasian	All
Born in the years between:	
1960-1970	2
1950-1960	2
1940-1950	3
1930-1940	2
1910-1920	1
Living with:	
Various types of advanced cancer	5
Chronic obstructive airway disease (COAD) / respiratory failure	2
Coronary heart disease	1
Diabetes 1 / coronary heart disease	1
Motor neurone disease (MND)	1

Table 4 | Characteristics of the co-researchers

In accordance with the principles of purposeful sampling, individuals with both typical and atypical experience were sought (Morse, 1991). One co-researcher was severely allergic to various medications, and two had already ‘died,’ or been through cardiac arrest and resuscitation. One co-researcher had motor neurone disease (MND), which is a relatively rare disease (Andersen *et al.*, 2005). The time which had elapsed since the diagnosis of an incurable life-threatening disease was variable. Six of the co-researchers had lived with the certainty of the incurable, life-threatening nature of their illness for six months to two-and-a-half years, while the remaining four had lived with this certainty for four to ten years. Four co-researchers have now passed away.

4.3.2 Collection and analysis of data

The process of the data collection and analysis in my study will be traced following the 12 steps of the Vancouver School as showed below. The first step of the process dealt with selecting co-researchers, and has already been described.

Step 2 *First, there is silence* (before entering the dialogue).

I allowed for silent moments of reflection before I entered the dialogues, preparing myself for being receptive and ready to think beyond preconceptions and see the world from the co-researcher's point of view (Halldórsdóttir, 2000). In order to develop openness and sensitivity towards the co-researchers' horizons (Halldórsdóttir, 2000), I reflected on the pre-understandings I had as a self-interpreting being (Benner, 1994) and as a nurse within palliative care. As a facilitator of multi-voice construction (Guba and Lincoln, 1998), I prepared myself for being creative and thinking abstractly, in order to be able to add to the mutual construction of new knowledge (Morse, 1991; Guba and Lincoln, 1998). I felt prepared to meet my co-researchers in their homes, as I am used to dialogues with people in similar situation within palliative home healthcare. As recommended by Lincoln and Guba (1985), I kept a reflexive journal during the whole research process in order to enhance the trustworthiness of the study.

Step 3 *Participating in a dialogue* (data collection).

I initiated the dialogues with broad questions about the co-researchers' experience. I encouraged them to tell their stories frankly in their own words (Benner, 1994), and used probing to ask further questions. I endeavoured to listen with the 'totality of my being' (Colaizzi, 1978), moving from the whole to the parts and back to the whole within the circle of understanding (Fleming *et al.*, 2003). I wondered and asked for opinions and allowed myself to feel confused and in conflict (Oiler, 1982) in order to prevent 'premature closure' (Lincoln and Guba, 1985), keeping in mind the assumption of Wheatley (2002), that if I refuse to be confused I might not be as creative. When closing the dialogues I consulted with my co-researchers for any future recommendations on ideal palliative care service and I ended by asking them if they had any good advice they would like to

share with other people who might be in a similar situation to theirs. In order to promote accuracy, I finally asked the co-researchers to sum up our discussion.

The co-researchers turned out to be willing, and appreciated the opportunity to share and discuss their unique experience and submit valuable criticism and recommendations, among other things concerning the healthcare- and social-service system.

I had two dialogues with five of the co-researchers, and I decided in consultation with the others that one dialogue would suffice, because they had either already managed to present rich enough data, lived very far away, or the saturation point of the study had been achieved, as was the case after the first dialogue with the tenth co-researcher.

Step 4 *Sharpened awareness of words (data analysis).*

The process of data analysis began concurrently with the data collection, so I tried to sharpen my awareness of words right from the beginning (Halldórsdóttir, 2000). For accuracy, the dialogues were audiotaped and then transcribed verbatim along with all non-verbal expression, such as laughing, hesitation and silences. The data analysis involved repeated listening to the dialogues when transcribing, followed by reading and rereading the transcribed dialogue. I endeavoured to immerse myself in the data, 'letting it soak in' by attentive listening and reading, allowing for 'living with the data' in this way for several weeks to perceive the essence of each and every discussed lived experience (Halldórsdóttir, 2000).

Step 5 *Beginning consideration of essences (coding).*

I analysed each dialogue in order to gradually identify the essence of the phenomenon investigated. First I read the transcribed dialogues without noting, but when rereading I started to identify key statements, and to construct and code themes of key statements (Halldórsdóttir, 2000). Then I used the themes in probing during the other dialogues.

Step 6 *Constructing the essential structure of the phenomenon for each case* (individual case constructions).

Through reflection and the use of abstract thought processes (reasoning, intuition and introspection) (Halldórsdóttir, 2000), I gradually started to group key statements and themes together in order to make each construction true to the lived experience of the respective individual. I followed the cyclic process of the seven basic stages within the Vancouver School: silence, reflection, identification, selection, interpretation, construction and verification (Halldórsdóttir, 2000).

Step 7 *Verifying the single case construction with the co-researcher.*

In order to prevent making a selective choice of data, and to enhance the trustworthiness of the study, each case construction was verified with the respective co-researcher. I did this in my second dialogue with those I interviewed twice, by showing them the draft of their case construction presenting the key themes, and asking for verification or criticism. I phoned those whom I interviewed once and gained their permission to meet them again to show them their case construction for verification, or not. All verified my case constructions. In the case of two co-researchers the verification was carried out by phone. They were happy with my clarification over the phone, and declined my offer to send them the draft. One of the co-researchers passed away before I was able to seek her verification.

Step 8 *Constructing the essential structure of the phenomenon from all the cases* (metasynthesis of all the different case constructions).

The essential structure of the lived experience of living with incurable, life-threatening disease was constructed from all the cases through the comparison of the dialogues, seeking out ‘the common threads,’ as well as the differences within the lived experience (Halldórsdóttir, 2000). I kept in mind that the data were intended to mediate the unfamiliar to an understanding, so that those who are interested in supporting individuals within palliative care, could gain a deeper understanding of how it is to actually live (Halldórsdóttir, 2000) with an incurable, life-threatening

disease, and thereby become more able to support the individuals towards a better quality of life.

Step 9 *Comparing the essential structure with the data.*

I compared the essential structures with the transcripts, in order to ascertain whether the themes fitted the actual data. I was able to confirm all the main themes with each co-researcher, and each subtheme with most co-researchers.

Step 10 *Identifying the over-riding theme which describes the phenomenon*

When I had constructed the essential structures from the dialogues, the over-riding theme emerged, simple and clear: 'Remember that I am still alive.' It represents their desire to go on living as actively as possible, with their focus on *life* instead of *death*. The theme reminds us of the basic need of the co-researchers to go on living as persons who matter in human relationships with others, despite the shadow of impending death.

Step 11 *Verifying the essential structure (the findings) with some research participants.*

In order to further strengthen the trustworthiness of the study I verified the essential structure of the phenomenon with one of my co-researchers, in order to ascertain that he recognised in it the description of his own lived experience (Halldórsdóttir, 2000). For the same reason I decided to ask one non-participant with an incurable, life-threatening disease to read the findings in order to see if he would find them credible. I received verification from both of them.

Step 12 *Writing up the findings.*

To ensure the reporting of the actual lived experience beyond the 'common threads,' the voices of all the co-researchers emerged as direct quotations in the findings (Halldórsdóttir, 2003). This is especially important, as what makes an experience real is its particulars (Frank, 1991), and patients have described it as frustrating when their experience is not valued in itself but only measured against an average (Frank, 1991).

4.4 Ethical concerns

I was aware of the importance of safeguarding my co-researchers' rights, and took into consideration their vulnerability.

In the introductory letter (Appendix 3) it was specified that the co-researchers could choose not to discuss any delicate matters. It was also made clear that they could withdraw at any time during the study without giving any explanation, and that this would under no circumstances affect the treatment or service provided. It was specified that if the dialogues evoked uncomfortable feelings, which the co-researchers wanted to discuss further, they could contact me, or another professional who had been assigned to provide follow-up if needed (Appendix 6).⁴ All the co-researchers signed the informed-consent letter before participating (Appendix 4).

The co-researchers chose a place and time for our dialogues, with privacy in mind. I endeavoured to secure their confidentiality and anonymity, among other things by assigning them pseudonyms (Halldórsdóttir, 2000) and omitting their occupation, age and any exact description of the disease each had. The very small population of the Icelandic nation, around 300 thousand people, is a problem when it comes to presenting some of the findings. In some cases, only a few individuals suffer from each disease at any particular time, and also, when the co-researchers described some physical effects / symptoms or incidents, I anticipated that some of those accounts might eventually be recognised by respective healthcare professionals, unless I acted to prevent this. In the light of that, I deemed it essential in some cases *not even to specify the pseudonyms* in the findings in chapter 5.

⁴ None of the co-researchers asked for follow-up.

I applied methods of data processing accepted by the Vancouver School. I alone dealt with all components of the research and had access to the research data. Recordings will be destroyed after the submission of the dissertation.

As there have been conflicting opinions regarding whether it is appropriate to conduct research with palliative-care patients (see discussion in 3.6), I asked all my co-researchers, following our dialogues, about their experience of their participation. Everybody expressed their satisfaction: 'I want to do all I can to share my experience and knowledge with others... I hope I may sow a seed somewhere.' Some of them described positive effects: 'You learn to express yourself about it,' 'I feel much better... after having the opportunity to speak to you,' and 'it's enjoyable to talk about it... if someone may get some benefit from what I'm saying, I think the information from me is worth it.' Several of the co-researchers declared their contentment with the fact that they themselves were participants in the study, instead of their relatives / healthcare professionals: 'No-one can know how I feel except me... I'm the one who's experiencing it,' and as another co-researcher put it: 'It.... helps me to know that someone's studying the matter... please include my viewpoint, not just that of the health professionals.'

4.5 Summary

The process of data collection and analysis, guided by the method of the Vancouver School, has now been described. Furthermore, it was reported how ethical concerns related to the study were dealt with. In the next chapter the findings of the study will be presented.

Chapter 5

Findings

5.1. Introduction

In this chapter I will present the findings. I start with a phenomenological description which summarises the findings, and will then present the essential structure of living with an incurable, life-threatening disease and what has positive and negative influences on perceived quality of life under those circumstances.

5.2 A phenomenological description

5.2.1 The experience of living with an incurable, life-threatening disease

For most co-researchers, being diagnosed with an incurable, life-threatening disease was a traumatic experience, and life has not been the same afterwards. Their illness has extensive social consequences: bonds with family and friends change, either for better or worse, while reduced ability to work may lead to financial problems.

All co-researchers experienced negative physical effects and symptoms which varied from slight to severe and unbearable, especially pain and the feeling of exhaustion.

The personal responses of the co-researchers to illness were diverse in nature, although for most of them becoming ill was traumatic. Deep-seated anger was experienced by those who had been seeking medical help for a long time before being diagnosed, while all had times of mental distress, and some experienced depression. It is clear from the findings that physical discomfort can entail social discomfort, lead to loneliness and reduce ability to work, which may give rise to financial difficulties, which in turn contributes to various problems such as anxiety and depression. It is also clear that anxiety and depression are conducive to loneliness and isolation. Thus all these symptoms are interrelated, and must be examined using a holistic approach.

The co-researchers used various strategies to help themselves live with their changed circumstances. Most were inspired to fight the illness, and decided that they would try to get as much as possible from life, in spite of their ill-health: they focused on *life* rather than *death*, of which they had suddenly been made more aware, but they did not anticipate dying in the very near future. Many consciously changed their attitude to life, in order to cope better with the situation: they lived their lives one day at a time, used humour to keep their spirits up, and denial was sometimes helpful. Most had faith which helped them deal with difficult times.

Using resources in the above-mentioned way was a certain relief for most co-researchers. It made them able to live more meaningfully, sometimes even until symptoms increased or new ones arose, which often reminded co-researchers of the gravity of their illness, and thereby provoked anxiety attacks and existential crisis because they perceived their condition as deteriorating. Increased symptoms therefore really changed the ‘reality’ for the individuals, who tried to call upon their former resources, or find new ones, whilst healthcare professionals managed their symptoms. When comparing the co-researchers’ descriptions of this experience, I sensed this as a cyclical process, with intermittent periods of stability of variable duration, with personal resources and efficient symptom management ‘providing a temporary shelter.’⁵ This cyclical process could be presented in the following way (figure 2).

⁵ The oldest co-researcher’s experience, however, is not consistent with the model, as she had in a sense ‘wished for’ the fatal illness, thus reminding us how varied emotional reactions can be.

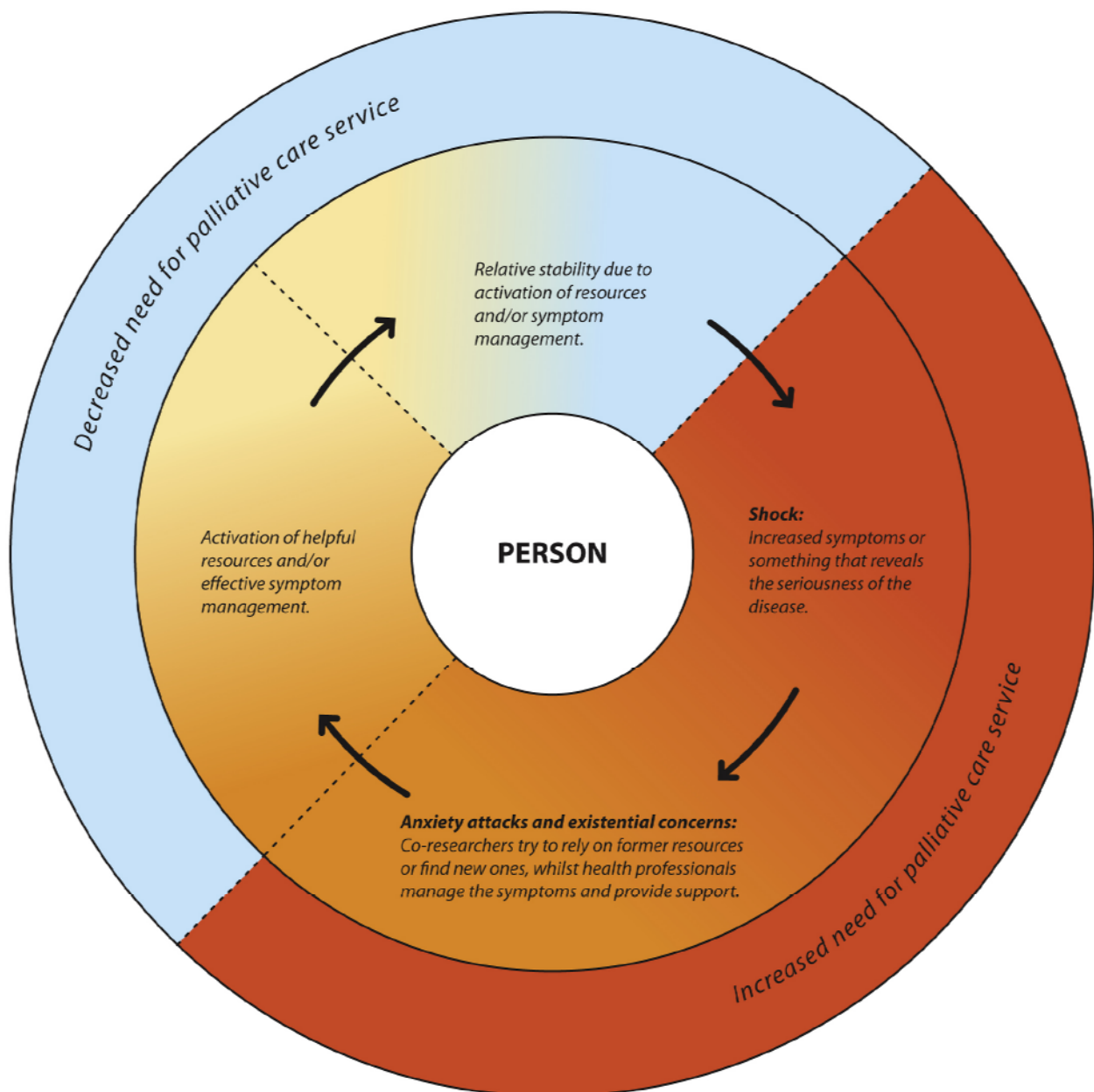


Figure 2

The 'struggle' of trying to cope and enjoy life when facing impending death; 'it's a huge struggle' (Forrest, II, 11).
The periods vary in duration at different times.

Despite deteriorating condition and anxiety attacks along their illness trajectory, most co-researchers found that they saw life in a new light, and felt that they had grown through the difficult experience. Some even got more out of life than before, in some sense.

5.2.2. Positive and negative influences on perceived quality of life

The dialogues with the co-researchers revealed that both *internal* and *external* factors can have a crucial influence on quality of life.

Most felt that positive thinking, hope and faith were factors which were conducive to better quality of life. It was also deeply meaningful for them to sense a purpose and have a role in life, and to have the support of family and friends.

Many co-researchers had experienced difficulties with pursuing their rights within the social security system. The expenditure of energy and time in ‘wrestling with the system’ had a major negative impact on their quality of life; in addition, when they did not receive the support they expected they experienced disappointment and even financial difficulties, which had a severe negative impact on their quality of life.

Professionalism within the healthcare system had great and positive influence upon the quality of life of co-researchers, while lack of professionalism had a negative, discouraging impact. Personal service and a supportive manner from professionals had an invigorating effect; when co-researchers felt secure within the healthcare system, and when they experienced a fast, professional response to their symptoms, this had a crucial and positive effect upon their quality of life. By the same token, when healthcare services did not meet expectations, and when the co-researchers felt that healthcare professionals lacked time, or even interest, this had a negative impact. Receiving specialised palliative nursing care at home had especially positive influence

and provided sense of security, among other things because of good symptomatic treatment and the fact that nurses were available 24 hours a day. Co-researchers' needs for palliative care are dynamic, and figure 2 (p.34) illustrates when it could be fortunate to increase palliative-care service in order to respond to their needs.

The essential structure of the co-researchers' lived experience of living with an incurable, life-threatening disease, and what has positive and negative influences on perceived quality of life under the circumstances, can be presented in the following way (figure 3).

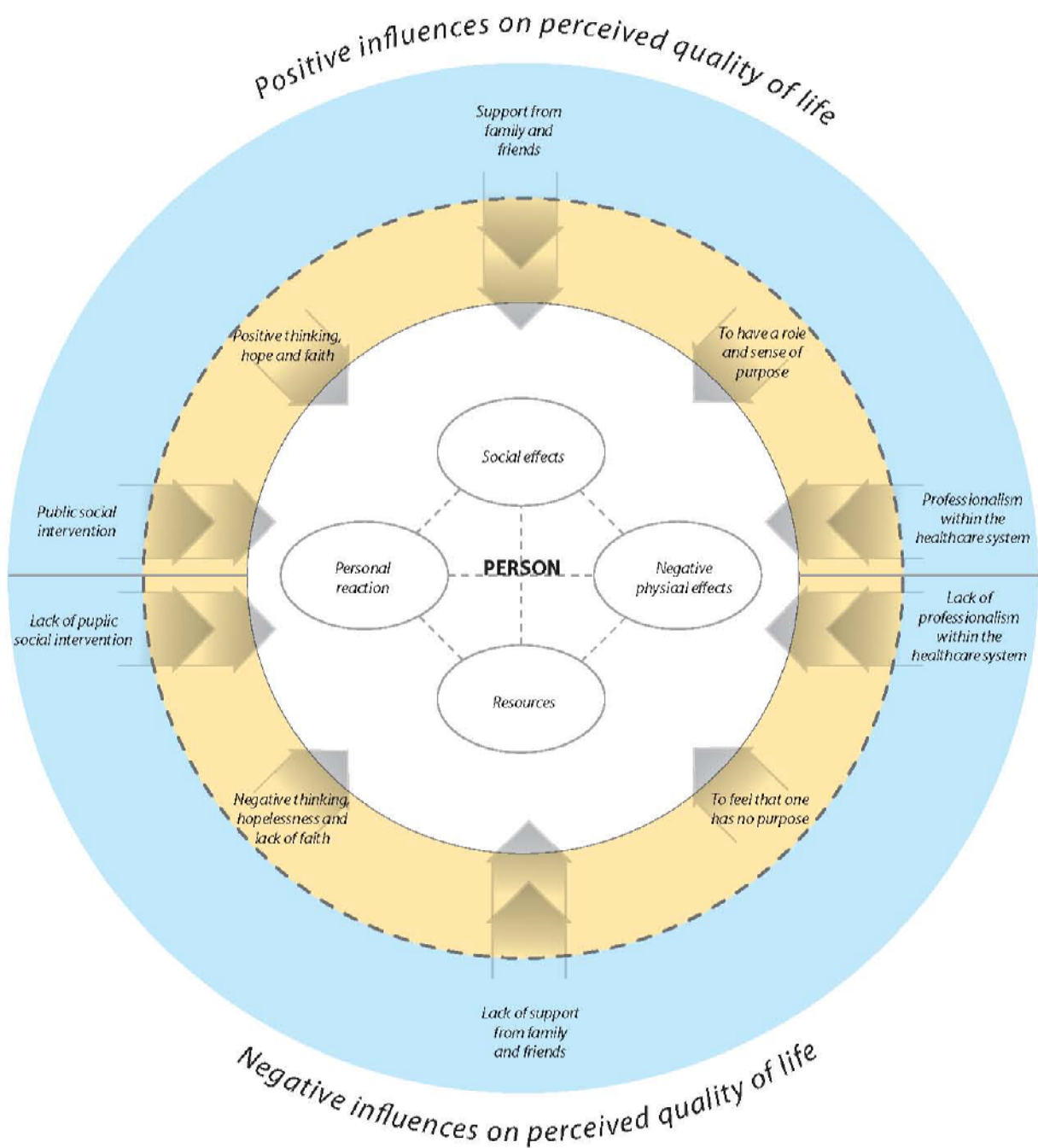


Figure 3

The essential structure of living with an incurable, life-threatening disease, and positive and negative influences on perceived quality of life under those circumstances.

Clarification: The internal and external factors are interrelated and dynamic, affecting each other in the same way as the person's condition and attitude can diversely affect these factors.

- *Internal factors*
- *External factors*

5.3 The lived experience of living with an incurable, life-threatening disease

Four main themes of the experience were analysed, each of which was recognised by the co-researchers. Table 5 presents the analytical framework of this lived experience. The themes influence each other, and do not represent a process, but a constantly-evolving experience, as the individual's state varies between the following conditions at different times.

Personal reaction	<i>Social</i> effects of the disease	Negative <i>physical</i> effects of the disease and/or treatment	Resources
Mixed initial response	Positive effects on relations with family and friends	Problems with fatigue	Fighting back
Anger	Negative effects on relations with family and friends	Pain	Conscious changes in attitude toward life
Psychological distress / depression	Decreased ability to work	Eating / digestive problems	Use of humour
Anxiety attacks / existential crisis	Poor financial situation	Cardiovascular problems	Finding strength in faith
New view of life, inner strength		Other physical problems	Denial

Table 5 The lived experience of living with an incurable, life-threatening disease

The themes, along with relevant sub-themes, will now be described.⁶

⁶ Direct quotations from co-researchers are identified using their pseudonyms, followed by Roman numeral I or II, according to whether the quotation is from the first or second dialogue with the respective co-researcher. The Roman numeral is followed by the page number from the dialogue. Three dots (...) indicate that text has been omitted.

5.3.1 Personal reaction

The co-researchers' initial response to their diagnosis varied greatly, from relief (one co-researcher) to massive shock for most of them. Anger was noticeable in the case of two co-researchers, and it emerged that for most of them mental distress and anxiety attacks were common. Majority of the co-researchers described a new view of life / greater maturity, which brought them increased peace, although they continued to experience anxiety attacks now and then, especially if they experienced their condition as deteriorating.

5.3.1.1 Mixed initial response

The co-researchers' initial response to their diagnosis varied greatly, but was a massive shock for most of them.

For Norman the process of diagnosis itself, which took three months, was a very difficult time: '...the worst time is really before you're diagnosed... that time is appalling' (Norman, I,1). He likened the actual diagnosis to a 'massive punch in the face,' which was followed by fear of death.

George had been consulting physicians for three years due to pain and debility. He described having felt a strange sense of relief initially, when diagnosed with advanced cancer: 'Very strange... Of course it shows how wretched I'd been feeling for a long time... you lose your, self-respect...' (II,2). But anger soon took over: anger that he had not met with a more professional response to his symptoms, so that he would have had a chance of being cured.

For Joan, being diagnosed with metastases was a severe shock, as she knew then that there was no hope for cure: '...I'd quite rejected the idea that it might come back... it was a huge, huge shock when I got the diagnosis... it knocked me flat...' (Joan, I,1).

The eldest co-researcher, on the other hand, responded quite differently to the recurrence of her cancer: 'I thought that perhaps I had really (laughs) wished for it... in some way' (Irma, I,8); she had to 'die of something.'

5.3.1.2 Anger

Deep-seated anger was expressed primarily by the two co-researchers who had repeatedly sought medical advice, but were not diagnosed until too late.

George had many unpleasant symptoms for a long time before being diagnosed with advanced cancer. He went to his GP, for instance, due to blood in his urine, over two years before he was diagnosed:

He should have sent me straight to a [specialist]... he'd have found it right away (II,8). I was so damned angry that it could have... gone so far... I felt a great, deep anger (I,5). To start with, the anger keeps you going.. then despair follows, and then grief... and then you simply break down' (George, I,3).

According to George the anger was accompanied by 'great arrogance,' and he did not open up emotionally to his family: 'I was just resisting it in every way, putting on airs, being unpleasant... As soon as you... relinquish the anger and.. arrogance... people can start talking to you...' (I,4).

Joan too was very angry, and could not find a way out of it:

I'm terribly angry, I'm angry, I'm angry, I'm angry... (I,29), ...I went to doctors again and again... Why didn't anyone do anything? Why was I simply admitted [each time] overnight... and then thrown out? (I,31). It's such a shame, I really can't... I see red (raises voice), I get so angry, I really shouldn't even talk about it (I,32).

One of them made a complaint to the Director of Health, but without result. The other felt it was pointless to complain. Both spoke of a 'medical mafia' in this context. '... they [doctors] defend each other to the death' (Joan, I,32).

5.3.1.3 Psychological distress / depression

Being diagnosed with an incurable, life-threatening disease was accompanied by great mental strain, which often leads to mental distress and even depression.

I'm... scared... I'm not resigned to dying... so young. I've always imagined, like most people... that I'd see my children grow up... (I,7), ...I sometimes cry, and say: 'Why can't I have everything as it was?' I want my life back (pause)... as it was... (I,15). It's... depression... I'm... awfully negative (Joan, I,17).

As George grew more and more debilitated, without being diagnosed, he grew increasingly depressed: '...of course depression is one of the consequences of being ill all the time' (I,2). This was accompanied by shame at not performing well at work; at that time he did not know that he had an incurable cancer:

I woke up in the morning with my wife ... then... [I] went back to sleep, and sometimes I slept until the middle of the day (I,3), ..then I got out of the house before she came home, because I couldn't look her in the face, being so feeble... I even pretended I was coming home from work. I felt terrible (II,1).

Lack of concentration and forgetfulness were also symptoms experienced by many co-researchers: 'I'm awfully forgetful, I think it may have something to do with ...the strain ... (Joan, I,13), '...I thought I had Alzheimer's.. I was forgetting so much... I have terrible trouble concentrating' (Forrest, I,35).

5.3.1.4 Anxiety attacks / existential crisis

The majority of the co-researchers described how fear and anxiety regarding their illness could have a negative impact on their daily lives: 'It gives me so much anxiety...' (Susanne, I,3). 'Of course you feel anxiety... you know that you're alone when you die... no matter how many people are around you, you're alone in going through that... process...' (George, I,12).

Many described feeling quite well, and then being struck by anguish without warning: 'Sometimes...you are simply overwhelmed by some terror: 'This isn't a nightmare... it's... real life!' And there's nothing you can do about it...' (Joan, I,3-4), '...it comes over me again and again... I can't control it' (Joan, I,25).

Anxiety attacks often occurred in connection with physical symptoms, especially when co-researchers thought the symptoms were indications of deteriorating condition, as they often did. Rachael described being overwhelmed by anxiety attacks and existential concerns when she experiences pain: '...it's like having a rock on top of me... I can't cope with it. I try to persuade myself, and say: 'It's not the cancer,' but somehow I feel I'm going to die just like that (snaps fingers) of cancer... (II,9). The anxiety is also linked to attacks of pain in Benjamin's case: '...I can't catch my breath... and I simply go stiff... and I get so terribly... frightened. Total panic'(II,16-17).

George described how he felt during anxiety attacks: 'You feel afraid of death... afraid to be alone, and afraid to go to sleep... you feel death is just around the corner' (II,3). Joan described being caught up in a vicious circle of isolation when she felt worst: '...when it gets hold of me, and the terror... comes over me, I withdraw into my shell... can't talk... as if I'm on edge with myself ... I'm so scared... I don't answer the phone...' (I,11).

5.3.1.5 New view of life, inner strength

A majority of the co-researchers described attaining a new view of life and an inner strength through their difficulties: 'I've started seeing life differently... really, thinking of one day at a time. Trying to enjoy it as much as possible... I think... you grow...' (Susanne, I,4). George feels the same: 'I've learnt a lot from this happening to me... it allows you to grow... in ways you wouldn't, except through this struggle, it's a huge struggle' (II,11). Forrest too has made his peace with the situation: 'Since it had to happen to me, it was a good thing, because my attitude to life... has changed...I'm much more positive...' (I,8).

Benjamin feels that he would have missed out on 'a lot of growth and mind-broadening' if he had not had to deal with the disease:

I can really be much more contented... with my life... happy and at peace, and really quite well-behaved... at last (laughs) (I,11-12), ...it's good to realise how much life... is worth. To have to face an enemy that is far beyond your strength... but to be able to enjoy being alive, for the time you have... (I,19). Probably you would call it... growth, it took me a long time... my attitude to life has changed... I'm... much more tranquil.. (I,32).

And Irma is level-headed and at peace with her long life: 'There's no anxiety in me... I really feel more of a desire to get it over with, before I start being a burden on the family' (I,3-4).

5.3.2 Social effects of the disease

Being diagnosed with an incurable, life-threatening disease has deep social effects for the individual and his / her family. The illness may have positive or negative effects upon bonds with family and friends. It is clear from the findings that individuals need to be 'alive and part of society,' to continue to have a purpose in life, to keep on working

as long as possible, and to have the support of family and friends. It is also clear that illness can have severe financial consequences, especially for younger co-researchers who have more financial and family obligations.

5.3.2.1 Positive effects on relations with family and friends

Most co-researchers described how family relations grew stronger through the experience of the disease: the family became closer, and the importance of family became clearer to the co-researchers. For some of them this process started soon after diagnosis, as in the case of Norman: ‘We’ve been sort of...trying to... enjoy the time we have. The family’s been talking, discussing things...’ (I,2), ‘[it] has brought us all together...’ (I,5).

For others it took more time before the family’s connections began to grow stronger. After several months of anger, anxiety and difficulties with communication, relations changed within George’s family:

...then I decided to.. live with them, for them... It is, of course the focus of life... real quality of life (I,16), ‘...your people... are so important to you... And you start nurturing those relationships... This illness has brought us together... (I,19).

Forrest described new friendships developing *due to* the illness, among a group of people with cancer. A strong sense of solidarity developed: ‘...there’s a lot of happiness, and lots of courage in them... great friendship.. a lot of hugs and trust’ (I,31). Barbara and Susanne also mentioned neighbours, whom they had known little before they were ill, but who had been caring during their illness.

5.3.2.2 Negative effects on relations with family and friends

Some co-researchers described how the illness had a negative effect upon bonds with family and friends.

George described major difficulties in his marriage, which began after he fell ill. He had an affair which led to divorce, after which he had a relationship with the woman for a time: 'It's an example of how you can react to death... that you haven't got long to live... I intended... to simply start a new life' (I,6-7).

Joan's husband probably could not take the strain arising from her illness, as he left her: '...then my husband walked out... he'd found another woman... [The illness has] had an enormous effect on home life... it's really like a time bomb, this home' (I,3). She said the tension in the home burst out in arguments and 'blame... I'm often caught between the children. And they blame me.. It can... be very difficult' (I,17).

Benjamin found it hard to control his temper initially. At that time he often lost his temper with his family, which was 'pure hell to experience' (I,9).

Some co-researchers described how their ties with workmates and some friends declined as the illness progressed: '... it dwindles... over time, everybody's very interested to start with...' (Joan, I,15), '...my colleagues were very active at first...(pause) but that's changed... You gradually get forgotten and buried' (Forrest, I,20).

5.3.2.3 Decreased ability to work

One co-researcher had retired before the illness, one was able to work until he retired, and two managed to keep on working, but only part-time, and with much flexibility from their employers. The six remaining co-researchers had to give up their work, five of them immediately after they were diagnosed. This was due either to the disease or weakness, or to medication. The two who continued to work said that it was very rewarding, while most of those who had to give up work felt it acutely. It increased

their sense of being ‘outsiders in society.’ Forrest was one of them: ‘I lost my job.. which was a shock... I was really forced to resign, I had no choice’ (Forrest, I,3). Barbara’s experience was similar: ‘I [went] into hospital, and I never went back to work. There was no chance.... Employers simply aren’t keen to employ people in poor health’ (I,5). By the same token, Joan experienced a sudden and overwhelming transformation: Life hasn’t been the same [after] that phone call... I haven’t been to work (I,1)... I lost a lot when I had to give up [work] (I,15).

5.3.2.4 Poor financial situation

Severe illness and reduced or non-existent ability to work had a grave impact on several families of the co-researchers. Five of the co-researchers discussed their worries about their finances; four of them had slight to severe financial problems: ‘I have only those 120,000 crowns [GBP 916]... It doesn’t go far, when you have to make payments on your home and everything. You can’t make ends meet... I have no chance’ (Joan, I,19). Forrest has the same experience: ‘Then you have to try somehow to live on it, I can’t live on it’ (II,12).

Rachael feels that the social security system is ‘terrible.’ I feel the system leads to people having to sell their home [and]... then rent from the government, so...[the authorities] always get their money back! (II,14). George and his family have had very difficult financial experiences due to his illness: ‘In the end our home was auctioned off [due to non-payment]... Today we have nothing...we’ve had such huge financial losses...’ (I,5).

5.3.3 Negative physical effects of the disease or the treatment

All the co-researchers mentioned some degree of negative physical effects.⁷ ‘Your life consists... of getting... bad news: ‘It’s grown or... spread more.’ And, naturally enough, you simply long to... hear something positive... simply peace’ (Joan, I,3). Norman has the same experience: ‘...It’s one blow after another, always losing something ... it’s a terrible effort... not to just to take to your bed and die’ (I,7).

Table 6 shows negative *physical* effects of disease and / or treatment mentioned during dialogues with the co-researchers, providing some insight into their lived experience. The table is not exhaustive.

Problems with fatigue	From tiredness to exhaustion, even with impaired mobility and /or temporary unconsciousness.
Pain	From slight pain with slight disturbing effects to unbearable torment.
Eating / digestive problems	Lack of appetite. Nausea. Vomiting. Problems with swallowing. Constipation. Diarrhoea. Ileus. Problems with ileostomy. Encopresis.
Cardiovascular problems	Atrial fibrillation. Circulatory problems. Embolism. Bleeding from tumours. Sores on hands and feet. Coronary thrombosis. Cardiac arrest.
Other physical problems	Sleep disturbances. Hair loss. Temporary poor sight. Retention of urine. Difficulties with speech. Phlegm and breathlessness. Infections . Anaphylaxis and shock. Burnt mucous membranes. Paraneoplastic fever. Feeling of coldness. Impotence. Fracture due to metastasis. Amputation. Paralysis.

Table 6 | Examples of negative *physical* effects of the disease and/or treatment

⁷ As explained in chapter 4.4, I judge it to be essential in some cases *not even to reveal the pseudonyms* of the co-researchers in order to protect their identity within the small population of Iceland. In those instances I will quote ‘NN’ in this chapter.

5.3.3.1 Problems with fatigue

All the co-researchers experienced growing debility as the disease progressed, and three had even lost consciousness.

‘You’re tired, awfully tired’ (Joan, I,3), ‘...I’m always terribly tired’ (George, I,1), : ‘...I sometimes think I need to give myself a kick in the behind to get through the day...[one] simply has no strength...’ (Susanne, I,2).

Forrest was left in a severely weakened state by treatment and procedures: ‘I was very weak... I could hardly get out of bed, I could just make it to the toilet, with assistance. I had to be lowered onto it’ (II,4), ‘...I [became] seriously ill... I was unconscious for two days’ (II,9).

Joan is also severely restricted by her lack of strength: ‘It’s left its mark on me... I’m so tired, I’m like an old woman’ (I,9), ‘...I go to the toilet, and I’m found there after half an hour, asleep’ (I,13).

Benjamin has tried to ignore his fatigue, in order to be able to continue to work: ‘Maybe the debility has... had quite an impact on me. You’re really tormenting yourself, forcing yourself to go on’ (II,11).

5.3.3.2 Pain

Benjamin sums up the views of most of the co-researchers when he says:

It affects every part of you to have pain.... You’re trying to do the things you have to... under some enormous strain. You can’t enjoy it and you’re always... thinking: ‘I’ll do it tomorrow...’ but then tomorrow’s no better. It gets very wearing in the long run’ (II,1).

Rachael suffered severe pain when she underwent chemotherapy: 'I couldn't lie still, and I couldn't sit... I couldn't do anything, there was... always constant pain' (I,11). Until she received service from a specialised palliative-care team, she was refused adequate analgesia, as she 'wasn't supposed to have so much pain.' She said she had been on the point of getting down on her '...knees to beg for morphine for the pain' (I,10). Joan too suffered great pain when she started treatment: '...I couldn't lie down, I couldn't sit, I couldn't stand, there was no way I could be. The pain was all over the body, I thought it was supposed to be like this, I had never underwent treatment before...' (I,2).

Benjamin describes his pain thus: 'Then... I wished... I'd die... it was simply too much for me, I wept like a child,...[it was] absolutely awful pain... I was shouting out...' (II,8).

5.3.3.3 Eating / digestive problems

Several co-researchers had experienced loss of appetite, temporary nausea and even vomiting: 'Then this awful vomiting started... very bad nausea, I vomited continually... I was so ill sometimes that I couldn't speak...' (Joan, I,1-2). Three co-researchers had experienced dysphagia, two of them temporarily, but the third had permanent difficulties with swallowing.

Problems with control of bowel movements were commonly experienced by the co-researchers, with either constipation or diarrhoea. One co-researcher had to have an ileostomy, which was hard to get used to: the bag 'wouldn't stay on, it was always leaking, and all sorts of problems' (NN, II,5). One co-researcher experienced distressing ongoing leakage of faeces, and therefore had to wear an incontinence pad, which exacerbated his isolation (NN, I,22).

5.3.3.4 Cardiovascular problems

Cardiovascular problems ranged from atrial fibrillation, circulatory disturbance, thrombosis and bleeding, leading to severe and uncomfortable symptoms, to sores on hands and feet, life-threatening coronary thrombosis and cardiac arrest.

Two co-researchers had been through the difficult experience of cardiac arrest and resuscitation. One of them had little awareness of the experience, while the experience was difficult for the other one, who experienced dyspnoea and severe pain before the cardiac arrest. During the cardiac arrest, he felt he experienced 'life after death,' perceiving people... and it was a good feeling: '...I simply experienced enormous peace... what you call death, I suppose?' (NN, II,4). After he was 'brought back,' he experienced great pain, as well as anxiety that he might again go into cardiac arrest due to an acute allergy to medication.

5.3.3.5 Other physical problems

Other physical problems that co-researchers had experienced were miscellaneous, such as sleep disturbances, hair loss, temporary poor sight, retention of urine, difficulties with speech, breathlessness and accumulation of mucus in the respiratory tract: 'The mucus is sometimes almost killing me... this.. really irritates me' (Susanne, I,7-8).

Several co-researchers had experienced severe infections, such as pneumonia and infections of a surgical wound, and one developed life-threatening sepsis which almost cost her her life.

One of the co-researchers had undergone anaphylaxis and shock, one had dealt with burnt mucous membranes and another had suffered from paraneoplastic fever: '...I always felt freezing cold... I slept in a thick woolly sweater and woolly socks' (NN, I,2).

Two co-researchers discussed their impotence. In one case, there is no possibility of improvement: ‘...it’s a bit damaging, of course... for one’s image of masculinity’ (NN, I,22). After years of hesitance, the other eventually discussed his total impotence with his doctor, who was able to help him to some degree.

One of the co-researchers sustained a painful fracture due to metastasis, one experienced progressive paralysis, and another had undergone an amputation, which was quite a shock for him, followed by severe suffering and demanding rehabilitation.

5.3.4 Resources

The co-researchers used a range of resources in order to cope with changed circumstances in their lives. Most showed a fighting spirit: they consciously tried to change their attitude to life, used humour and denial when needed, and most of them sought strength in their faith.

5.3.4.1 Fighting back

Co-researchers were unanimous about the importance of keeping the focus ‘on life’ instead of ‘on death,’ of the importance of not just waiting for death to come, but trying by all means to react to the process and their lives or, as Norman put it: ‘... it was a matter of either taking to my bed and dying, or fighting back and enjoying life...’ (I,2). ‘I’m fighting, I’m not waiting’ (Joan, I,28), and Rachael is convinced: ‘I... wouldn’t have survived my illness, except for stubbornness... I intended... to live’ (II,18).

Most co-researchers do not bargain for dying in the near future. Joan’s family and friends have on the other hand tended to focus on her death, and her children’s loss, which has been hard and irritating for her: ‘I’m fighting back, don’t they understand? I

haven't admitted defeat, it's not over till it's over!... I'm fighting for my life, [but] people are wondering... whether I've started planning my funeral!' (I,28).

Some co-researchers find it helpful to use metaphor to express their thoughts about their disease and their resistance to it. Forrest, for instance, uses the metaphor of war: '...I haven't lost any battles yet.. but the war's not over' (I;19).

5.3.4.2 Conscious changes in attitude toward life

The importance of consciously changing one's thinking and attitude to life was discussed by most co-researchers; this led to their coping better with the situation.

The desire to live is so strong... to be able to go on living, and I simply started working on... enjoying life while I have it, and then I will simply face death when it comes. And when you get over it, then... you've conquered death. It's no threat to you any more... It was very important to me to conquer this fear of death. You only do that by loving life (laughs) (George, I,14-15).

George also spoke of the importance of consciously living one day at a time: 'We just live for today, enjoy each day. You don't know how many you have left...and you don't think about it' (II,13). Joan is of the same view:

...I do my best to live exactly now, for today... I'd go mad if I were always thinking of what's in store... because then I would see nothing but the negative things (I,22).
To live this minute and not think ahead... (I,26).

Rachael is grateful that she succeeded in changing her attitude to life, and hopes that she will be able to enjoy it for a while yet:

..not that I'm afraid of dying... I just feel I'm so young that I shouldn't be dying yet... now that I finally have this [positive] attitude to life.. I'm going to die! I find

it so ridiculous (laughs). Why give me this positive attitude to life, and then kill me right away, and I don't get (laughs) to enjoy it? (I,21).

For some co-researchers, part of the changed thinking consists of preparing to go: 'I can go any time and I'm... ready for it' (Tom, I,5). Barbara says her mind 'goes wandering' whilst preparing to leave her life: 'I've started sort of recalling the past... it's good to think back (I,6).

5.3.4.3 Use of humour

Most co-researchers mentioned that humour had helped make them feel better at difficult times: '...because I'm so positive and make fun of things... it cheers people up... And it cheers me up to cheer people up...' (Rachael, II,7).

Some co-researchers used gallows humour, in order to '...try not to break down' (Joan, I,33). But according to co-researchers, gallows humour was of little help at the most difficult times: 'Really, it was fear that made me act that way... It was simply in defence, trying to defend myself, but in the end you couldn't do it any more' (George, II,12). Benjamin used gallows humour a lot for a time:

...It was a sort of humour you used to... cover over the pain... I think it helped... that I didn't take the trauma... too seriously... It helped me to put a good face on it... Then there were times when I was alone with myself and the humour.. I couldn't share it any more... the pain just charged in, and the trauma.. I would cry into my pillow (I,12-13).

5.3.4.4 Finding strength in faith

Eight co-researchers said that in their illness they sought strength in faith; six of them pointed out that they rarely attended church. 'I simply say: '...God... help me through this' or 'can you help me to stop thinking about it?'...[and] then you find you've

stopped thinking about it' (Rachael, I,13). '...every evening I thank God for the day, and ask him for strength tomorrow. And I try to grasp a bit of light.. put it into my heart...' (Forrest, I,8).

George recounted that faith had helped him overcome negativity and depression: 'I often sat... late into the night, and faith sought me out, I was having a private talk with God.. in my state of pain...I came... to the conclusion that he existed' (George, II,11).

Benjamin said he had become more conscious of religious life than before, and he and Rachael said that a 12-step programme, they had attended, had been very beneficial: '...it... raised up your emotional life and everything' (Benjamin, II,28). '...it helped me to deal with myself psychologically' (Rachael, I;25).

Some of the co-researchers said that they had found strength in their belief in life after death. Barbara had seen people who had passed on: '...I know it exists, I have proof,' (I,9) and Rachael and Norman found it helpful to go to a psychic for support: '[I] am absolutely convinced there is a life after death... I've asked... [psychics] twice when I will die (laughs), but they refuse to answer' (Norman, II,6).

5.3.4.5 Denial

Some co-researchers stated that they had denied their illness in order to 'hold on:' '...no-one was allowed to mention me having a disease... it annoyed me... I simply intended to go on as if nothing had happened, and overcome this adversary, but it has gradually been getting the upper hand' (Benjamin, I,2).

'It's all I know how to do,' Joan says of her denial (I,33), adding that her children are also in denial:

...they don't want to acknowledge the illness... I understand them to some extent because really I myself am... running away... But I break down now and then, when everything becomes so clear and obvious, when it reminds me it's there (I,3-4).

Joan's denial is manifested, among other things, in not thinking of the future, e.g. what will become of her children when she is gone; she acts as if she will not die: 'I am in my children's future!' (I,8).

5.4 Positive and negative influences on perceived quality of life

Part of the research aim was to explore positive and negative influences on perceived quality of life. It transpired that both *internal* and *external* factors had an influence on perceived quality of life when living with an incurable, life-threatening disease.

5.4.1 Positive thinking, hope and faith vs. negative thinking, hopelessness and lack of faith

Most co-researchers were in agreement that a positive frame of mind, hope and faith gave them strength and had a positive influence on quality of life, while a negative frame of mind, hopelessness and lack of faith were major obstacles to wellbeing. George was convinced that this initial negativity 'could have led to his death' (I,21). He was also sure that a positive frame of mind works '...enormously against the disease' (I,23). Rachael was of the same opinion: 'If I can be cheerful while I'm alive... then I'm fine...' (I,22), '...hope makes all the difference' (II,18).

Benjamin described the impact of hopelessness, and the importance of positive thinking:

There were times... when I was close to giving up... I became... really without hope... I felt I was... stuck... that I couldn't go on (II,21). Everyone who... finds themselves in a bad situation... really needs that positivity, to conquer the negative... to see things in a positive light... to try to put a good surface on things (I,19).

Faith has a positive influence on the quality of life of all the co-researchers who are believers (see also 5.3.4.4). In Tom's case, for instance, his hope consists in his belief in life after death: '...there is something more, I'm never alone...' (I,7).

Faith having proved so helpful to most of the co-researchers, Irma regrets not having the simple faith she had as a child, and Joan grieves for her lack of faith: 'I have searched, but not found anything, and.. I think that it's simply over... If I had some certainty that there was something good to come, then I think I wouldn't be as frightened...' (I,9).

5.4.2 To have a role and sense of purpose vs. feeling purposeless

Most of the co-researchers talked about the importance of sustaining a personal role and feeling that they mattered as individuals: 'If we forget the cancer... I've never felt [better] in my life... because I always feel I have a purpose' (Forrest, I,16).

Benjamin said it was crucial that 'you don't perceive yourself as some faulty reject,' (I,22), and Barbara, Irma and Susanne all mentioned the importance of retaining one's dignity, by doing as much as possible themselves: 'You mustn't take everything away from people, while they are able to do something' (Barbara, I,4).

Being able to continue working had a very positive influence on quality of life. Forrest had lost his job, and occupational therapy was no longer viable for him: 'Then...I said: 'You've got to find a role for yourself' (I,26). He started doing voluntary work, which was very rewarding, as it gave him a sense of purpose. Norman too said that voluntary work gave him 'such a lot,' to be able to help others, '...I feel that gives me the best nourishment' (II,4).

George and Joan were also keen to find a role: ‘You need some sort of outlet for... your creativity...’ (George, I,17) and Joan put it even more strongly: ‘I’m going crazy, I just sit here and wait for the days to pass. They are... terribly long days, and... evenings, not to mention the nights’ (Joan, I,7). In spite of strong feelings of purposelessness, neither had felt able to take any steps to change the situation.

5.4.3 Support from family and friends vs. lack of support

As stated above (see 5.3.1.1), support of family and friends can be crucial in improving quality of life, while lack of support from them can lead to far poorer quality of life. The vast majority of the co-researchers described enjoying great support and care from their families. Joan was the exception, as mentioned above.

George knows both sides of the issue. He described his great rage, depression and isolation when he was trying to ‘fight alone,’ but after he ‘allowed the family in’ he felt dramatically better: ‘Because if they’re allowed to take part in it with you, they can give you so much... they lighten your burden’ (George,II,13).

5.4.4 Public social intervention vs. lack of public social intervention

The majority of the co-researchers were unhappy with the social-service system. They felt that pursuing their rights was too complicated, and that it was hard, or even impossible, to live on the benefits they received (see also 5.3.2.4). It transpired clearly that it had a severe impact on their quality of life to deal with constant financial worries, and to have to spend their limited energy and time in ‘chasing up’ their entitlements, which should be automatic and easily accessible: ‘Everyone who is healthy believes that when you become ill there is some system that is activated, that there is someone who takes care of things for you... but that is not the way it is’ (Joan, I,18).

‘The struggle with the social security system is... tough... You’re always being refused this, and refused that... You always get so disappointed, upset... Pursuing your rights, it’s just horrific. You have to fight and fight...’ (Forrest, I,12,14). George and Norman have the same experience: ‘It’s a hassle to be ill, and to have to be always dealing with this every day’ (George, II,10), ‘...trying to work out how the system works.. it’s hopeless, really... It’s.. terribly complicated, and awful..’ (Norman, I,12). Joan feels the same:

You have to submit so many documents, and then [it] isn’t enough... You aren’t given information on anything, you have to chase it all up... How are you, when you’re deathly ill... supposed to think about money matters... and make phone calls all over the place? You have to go to the different places... not everybody has someone who can be going all over town sorting things out for them (I,19-20).

The co-researchers mentioned that the assistance they received from social workers had been of little help: ‘...they seem to meet closed doors, too...’ (George, II,10). Norman indicated that they needed a personal ‘...service officer...’ (I,12) within the social-service system, who would both provide information about rights and take care of the various applications for those in need of that.

A co-researcher who is well-known in society was, on the contrary, happy with the social support received; he had never met with a refusal: ‘That’s the way it is, unfortunately... if you have a well-known name, you get the service’ (pause) (NN, II,24). He pointed out that the services were of a great importance for his quality of life.

Some co-researchers mentioned attitudes of public employees being even unhelpful: ‘It’s as if these people... have no intention of providing information... As if... we’re... misusing public services... we have a right to know what we’re entitled to’ (George, II,9-10).

5.4.5 Professionalism vs. lack of professionalism within the healthcare system

Receiving specialised palliative nursing care at home had a positive influence on the quality of life of the co-researchers, and when healthcare personnel behaved in a supportive and personal way this was also beneficial. The co-researchers had a need for ‘human contact’ with health professionals, and thus when health personnel appeared to be uninterested or rushed, this was discouraging. It also had a negative impact on quality of life, leading to a feeling of insecurity, when services which the patients had expected did not meet their expectations, or were not available. The factors within the healthcare system that positively or negatively influence perceived quality of life of co-researchers are presented in table 7.

Professionalism within the healthcare system:	Lack of professionalism within the healthcare system:
<ul style="list-style-type: none"> • Specialised palliative nursing care • Professional and supportive conduct of healthcare personnel • Professional resources and security 	<ul style="list-style-type: none"> • Lack of specialised palliative nursing care • Unprofessional and discouraging conduct of healthcare personnel • Lack of professional resources and security

Table 7 Professionalism vs. lack of professionalism in healthcare

5.4.5.1 Specialised palliative care vs. lack of such care

Six co-researchers, of whom five had cancer, and one COPD, received specialised palliative nursing care in the home.⁸ They were all strikingly in agreement on the very positive influence of this service on their quality of life. The fact that nurses were available 24 hours a day gave the co-researchers a sense of security. Soon after the provision of such service began, symptomatic treatment was generally in good order,

⁸ This is a team of nurses with experience and / or further education within the palliative area, who provide palliative care in the home of the client. The nurses can be called 24 hours a day and are able to contact doctors whenever needed.

and the co-researchers mentioned especially the caring behaviour of the nurses, and their skills in human interaction.

Most had, however, been hesitant to accept this service, which they had seen as an indication of how seriously ill they were. Joan said that it was a great mistake that she was not offered the service earlier; but when it was first offered she was nonetheless very negative: ‘...and quite terrified... I thought it had progressed farther than... [the doctor] was telling me... and that the time had come’ (I,6). She decided, however, to accept the service, and stated that her quality of life improved greatly.

Rachael said that the services had ‘totally’ saved her life and mental health: ‘They know exactly what to do, they are tremendously wise about solutions..., [they know] exactly about all the symptoms... understand us psychologically... and keep a good eye on you’ (II,13). Forrest said that the nurses had given him ‘inestimable support:’ ‘I couldn’t have done it without them, enfolded... in care and affection’ (I,16). He called them his ‘saviours,’ ‘physically and... mentally’ and said that they had always had time for him. George agrees: ‘They... do an absolutely marvellous job, it’s largely thanks to them that I am what I am today’ (I,22). He said they were ‘wonderful people,’ who dealt with things whenever something changed, making it possible for him to spend more time at home, which enhanced ‘quality of life enormously.’

Specialised palliative nursing care enabled Barbara to stay at home instead of entering a nursing home. She had been reluctant to go into a nursing home, being considerably younger than the residents: ‘It would have been ridiculous... simply a violation of human rights...’ (I,2). ‘It’s no solution to put me in a place which torments me’ (I,8).

5.4.5.2 Conduct of healthcare personnel: Professional and supportive vs. unprofessional and discouraging

Co-researchers repeatedly mentioned the importance of healthcare personnel interacting with them in a personal and supportive way, and taking an interest in the patient as a person: 'It's a question of the patient not being just a subject, but... a person' (Benjamin, I,24).

Rachael wished for 'more human' physicians: '...I don't know what's wrong with them... they really need to... understand the patients, like some of the nursing staff do'(I,18). Joan is of the same view:

...I would really like my doctor... to be more sort of human... to try to... get to know me better... You have to get to know the person a bit.. form that bond... but he sort of... (pause) just 'jog-trots' along' (I,25).

And George agrees: '...it's mainly a question of being capable of talking to you like a human being... The doctors... it's as if they seem to be... wary of establishing a relationship with you' (II,4-5).

Forrest and Joan had sought support from psychologists, without finding the 'human understanding' they were looking for : 'I found her too theoretical for me... we spoke different languages,' (Joan, I,27), the psychologists were '...far too theoretical.. rather caught up in their own academic field' (Forrest, I,41).

By the same token, co-researchers were displeased when they felt they were not listened to, and did not receive clear answers: 'I want to know where I stand, and then they talk to me like a baby... I find it offensive' (Irma, I,7).

Some co-researchers mentioned how good it was to feel that healthcare personnel gave themselves time with them: '[She] simply sat with me for a long time... It was so

lovely... she sat with me!’ (Forrest, II,10). On the contrary, when co-researchers repeatedly felt that personnel had no time, it had a discouraging effect: ‘Now they’re... under such a strain, these people... With understaffing, and you get the feeling... that they have no time... it has a bad effect...’ (Benjamin, I,24).

Joan, who was repeatedly admitted to the same ward, was distressed and it added to her feeling of aloneness when she recurrently sensed the nurses’ reserved demeanour: ‘...I never see the nurses except when I get the medicine... sometimes I wonder whether this is because they know that I can’t be cured.. or why?’ (Joan, I,35).

5.4.5.3 Professional resources and security vs. lack of these

The co-researchers made it clear that it was important for them to receive a prompt and reliable response to their symptoms and complaints, and that professional resources for the problem be available. Cutbacks in the health service were ‘annoying,’ ‘... the scope of the work is always being reduced...’ (Forrest, I,10).

The co-researcher who had MND mentioned the importance of receiving assistance in ‘...staying one step ahead of the degeneration in all preparation... a patient with MND requires a certain ‘down-stepping’...’(NN, I,6), such as learning how to use aids. This specialised service is lacking. The main campaigning issue of MND patients is to have the choice of going onto a ventilator when the diaphragm stops functioning, and to have all the home services relating to that.⁹ Today the only choice is to go onto a ventilator in an intensive care unit, and ‘take the family there as hostages, or else to die... The time is coming when I’ll have to decide... To live or die? I’m not ready to say goodbye...’ (NN, from a diary). Meeting with paternalism from others related to this is a source of concern: ‘...doctors are loath to see it positively, they want to play God and decide

⁹ This has been practised in Denmark for instance (Bindsley Film, 2004).

what's a good life for me...' (NN, II,1). His wish is that other people's preconceived ideas about life on a ventilator will not prevent him from having the choice.

Forrest and Joan described a discouraging wait in casualty departments, where they waited nine and eleven hours respectively, without anything to eat, for admission as in-patients. This was devastating for them, as both were very ill. It was also hard for them to share a room with others. 'I'm getting all sorts of bad test results... I don't fit into all that 'small talk'... I need some peace...' (Joan, I,16-17). 'I... got irritated... I would draw all the curtains, to try and get a bit of privacy...' (Forrest, II,15).

Irma receives help at home to take a bath once a week, but '...they complain about having to hurry so much...' (I,5). According to her, the visit takes 10-15 minutes; the nursing assistants dry her back and legs after the shower, then leave.

Joan and George both had the distressing experience of consulting physicians repeatedly due to their symptoms, without result, and this has had a major negative influence on their quality of life:

...I'd been admitted... many times... They knew about the tumour. Why did no-one do anything about examining it further? ... I'm terribly angry... the difference could have been that the tumour was [localised]... It is so terrible to think that perhaps I might never have had to go through any of this (pause) (Joan, I,31-32).

It's obvious that someone who comes back again and again saying he's in pain... there's something wrong (pause). ...the [person] should be sent for a CAT scan... They talk about it being expensive... but it [is also] expensive to let someone get so ill... the healthcare service is stuck with the person, and causes him or her... immeasurable damage (George, II,7).

5.5 Summary

Fatal illness has had deep social, physical and personal effects on co-researchers, who use a variety of strategies to make their lives easier. Increased symptoms often reminds co-researchers of the gravity of their disease and provokes anxiety attacks. Positive frame of mind, hope and faith, as well as the feeling of having a role and a purpose, has positive influences on quality of life, and support of family is also important. Another important factor influencing the quality of life of the co-researchers was whether they received adequate social services or not, but many co-researchers had experienced difficulties with pursuing their rights within the social security system. A professional and supportive approach from healthcare personnel has positive influences on quality of life, as well as finding that the professional resources they had hoped for were available. Conversely, when healthcare services did not meet expectations, and when the co-researchers felt that healthcare professionals lacked time, or even interest, this had a negative impact.

These findings will be discussed in the context of reviewed literature in chapter 6.

Chapter 6

Discussion

6.1 Introduction

The essential structure of the experience of living with an incurable, life-threatening disease, and of positive and negative influences on perceived quality of life under those circumstances was presented in the last chapter.

The findings are aimed at enhancing understanding of this lived experience in order to improve palliative care. They are bound by constraints of time, place and circumstances, and the intention is not to generalise them to a wider population, which is never the aim in phenomenological studies (Lincoln and Guba, 1985; Van der Zalm and Bergum, 2000).

The fundamental aim of the study was to provide palliative healthcare professionals with insight and knowledge that could empower them to contribute to their clients' quality of life. In order to fulfil that aim, I found it valuable to discuss with my co-researchers the lived experience, and then what influenced their perceived quality of life. By first reviewing the lived experience, I sensed the co-researchers as more attuned to discussing what had positive and negative influences on their perceived quality of life. It turned out that these two aspects were intertwined, and looking at both gave a more holistic view of the co-researchers' experiences, expectations and needs.

I will now discuss the findings in the context of the reviewed literature, as well as discuss the strengths and limitations of the study.

6.2 The model: The essential structure of living with an incurable, life-threatening disease

The model that emerged from the study findings (figure 3, p.37) constitutes the framework of the findings and reflects the study's contribution to palliative-care literature. The model could be valuable to use in practice, by reflecting on it with the clients, perhaps making it somewhat easier for them to orient themselves about their particular situation, in the search for creative solutions. In that way, the model can serve as a basis for identifying problem areas, and recognising *inner* and *outer* resources in order to make living, as well as the planning of care, easier. At least some patients could find this helpful. The model is grounded in the experiences of people who have also lived with an incurable, life-threatening disease, which could empower some patients, and perhaps mitigate their feeling of aloneness in their experience towards dying, which is a feeling reported in this study and in a study by Fincham *et al.* (2005).

6.3 The overriding theme: 'Remember that I am still alive'

The overriding theme of the study findings, '*remember that I am still alive*,' epitomises their urgent need to 'stay alive,' with the focus on *life* instead of *death*, as well as their need to be regarded as 'living' within society. Their desire to 'stay alive' was prominent and profound, except in the case of the eldest co-researcher, whose willingness to keep on living was contingent upon not being a burden to her family; this is a common source of anxiety in Western societies (Seale and Addington-Hall, 1994). Despite severe physical complications, the co-researchers all endeavoured to go on living in an optimistic way that minimised the shadow of impending death, and expressed the need to go on living as persons who mattered in human relationships with others: family, friends and healthcare professionals. In retrospect, I believe they would all agree with Johnson and Burgeois (2003), who point out that a dying person is living and involved

in other peoples' living experiences until actual death or, as one co-researcher put it: 'It's not over till it's over!'

6.4 The lived experience of living with incurable, life-threatening disease

The overall findings, presenting the co-researchers' constantly-evolving experience of various feelings, symptoms and conditions from one time to another, were not surprising under the circumstances; some of them correspond with previous study findings within the field (Skilbeck *et al.*, 1998; Benzein *et al.*, 2001; Cohen and Leis, 2002; Horne and Payne, 2004; Kennett and Payne, 2005; Rydahl-Hansen, 2005; Coyle, 2006). The physical burden and deterioration are apparent within the findings, and provide valuable insight into the struggle which can be involved in coping with impending death whilst experiencing physical hardship and knowing that in all probability there is more deterioration to come, or as a co-researcher described it: 'Your life consists of getting bad news.'

In addition to fatigue, pain, various digestive problems and breathlessness, commonly reported within palliative care (Skilbeck *et al.*, 1998; Davidson *et al.*, 2004; Strasser *et al.*, 2005; Pantilat and Steimle, 2006; Peters and Sellick, 2006; Tsai *et al.*, 2006), the co-researchers had also suffered from various other, less frequently reported, complications, such as temporary poor sight, burnt mucous membranes, impotence, paralysis, amputation and even cardiac arrest following medication. Besides giving us insight into the burden on co-researchers, these findings manifest in my view the broad knowledge base needed within palliative care in order to react professionally to clients' various needs, in the endeavour to improve their quality of life. Well-controlled symptoms are likely to enable palliative-care patients to continue engaging in life (Vig and Pearlman, 2003), which was the profound desire of co-researchers.

Although palliative-care patients tend to suffer from sexual dysfunction, and wish to discuss these issues (Ananth *et al.*, 2003; Hordern and Street, 2007), these are too rarely mentioned, according to a recent study which revealed that healthcare professionals found themselves vulnerable towards the matter, and often made stereotypical assumptions about patients' needs, instead of consulting them (Hordern and Street, 2007). It has been reported that healthcare professionals and their clients often expect each other to bring the topic up (Sheldon, 2003), which is underpinned by the fact that one co-researcher put off discussing his total impotence with his physician for *several years*. Although the nature of his disease was such that his physician should have strongly suspected impotence, he never asked.

Despite extensive research and guidelines for treatment of cancer pain, pain is still a profound problem for many individuals with cancer (Engle *et al.*, 1998; Boström *et al.*, 2004; Strasser *et al.*, 2005), as well as for those with other incurable diseases (Skilbeck *et al.*, 1997; Meyer, 1999; Matheny, 2001; Horne and Payne, 2004; Andersen *et al.*, 2005; Formiga *et al.*, 2007). Several co-researchers confirmed this. It turned out that, in at least one case, better information and a more systematic follow-up could have relieved unbearable pain experienced by a co-researcher, who believed it was a normal complication following chemotherapy. An unexpected finding was the fact that people are still being refused adequate analgesia. In this case, the refusal was based upon an assumption that the patient *should not have so much pain*. A parallel to this finding was found in a study by Boström *et al.* (2004). As long ago as 1990, the WHO declared that patients have the right to demand sufficient analgesia and that physicians are obliged to administer it (World Health Organization, 1990). Patients who are perceived as displaying negative attitudes are more often 'labelled' as not having 'real' pain, or being an addict (Nash *et al.*, 1999). This indicates in my view the significance of getting to know the patient, and thereby eliminating preconceived ideas and prejudice in

order to deal with the pain, being prepared to change strategies if needed (Larson *et al.*, 1999), and never giving up.

As co-researchers often perceived changes in physical symptoms as indications of deteriorating condition, it was noticeable that such changes could spontaneously trigger overwhelming anxiety attacks. In my view this is an important finding, which should be borne in mind when planning palliative care. It shows that when symptoms, such as pain for instance, increased, co-researchers suffered not only from that pain, but from anxiety and existential concerns as well, evoked by the pain. Hence it was not only relief of the pain that was needed, but also a response to the existential questions and concerns that the pain might have triggered, thereby providing holistic care. There are indeed similarities between this finding and those of Skilbeck *et al.* (1998), Benzein *et al.* (2001), Daneault *et al.* (2004) and Rydahl-Hansen (2005), who report a relation between severity of symptoms and perceived gravity of illness. This finding could also be likened to the finding of Willems *et al.* (2004), where patients with advanced heart failure only thought about their death when symptoms increased. In view of the fact that the prognosis of incurable, life-threatening diseases is often unpredictable (Hanratty *et al.*, 2002; Curtis *et al.*, 2005; Skilbeck and Payne, 2005; Pantilat and Steimle, 2006), and death can even occur suddenly with little warning, as in the case of patients with heart failure in particular (Hanratty *et al.*, 2002; Oates, 2004), it is understandable that patients are on the alert when symptoms increase, worrying about their future. Taking account of this, a wait of many hours in a casualty department, as experienced by two co-researchers, must be judged especially unfortunate. By the same token, it can be disadvantageous for people with an incurable, life-threatening disease to share a room with others, not least when they receive bad news. Patients' right to privacy is safeguarded by law (Alpingi, 1997), and this should be respected.

Every co-researcher used some sort of resources in order to improve their well-being. One co-researcher gave a valuable insight into how effective a resource humour really can be, but also how ‘interpersonally restricted’ it is; when the co-researcher was alone, and had no one to share the humour with, ‘the pain just charged in.’

The fighting spirit was prominent among co-researchers, based on a profound need to keep on living, and it is noteworthy that co-researchers consciously changed their attitudes in order to get as much as possible from life, one day at a time, trying to live in the present and not to look too much to the future. This is consistent with the findings of Benzein *et al.* (2001), Vig and Pearlman (2003), Rydahl-Hansen (2005) and Johansson *et al.* (2006), where palliative-care patients strove to live in the present, and make the best of it. This could also be likened to focusing on the quality of living rather than on dying (Engle *et al.*, 1998; Carter *et al.*, 2004). Most co-researchers found thinking about and focusing on their future either uncomfortable or overwhelming, and therefore avoided it. Most of them did not by any means bargain for dying in the near future. This could perhaps be related to the denial used by some co-researchers in order to ‘hold on.’ Their *conscious* denial, used as a resource, contrasts with the widely-accepted perception of denial of death as an *unconscious* psychological defence mechanism, of which the patient is not a valid judge, and hence that it is the physician’s authoritative role to ‘label’ patients who resist their terminal diagnosis as ‘in denial’ (Zimmermann, 2004). It has even been suggested that these patients do not belong in hospice care, as they refuse to accept their terminal condition (Zimmermann, 2004). Although some co-researchers used denial, they were still in need of palliative care, so I certainly agree with Zimmerman and Rodin (2004), who point out that palliative care should be for those with life-threatening illness; it should not be a prerequisite that they must accept that they are dying. The co-researchers’ words underpin Holmberg’s (2006) interpretation of denial as a personal choice and a source of hope, and it benefited them as such. It is, therefore, our duty as healthcare professionals to model

our empathetic care upon the fact that denial can be a valuable and consciously chosen resource, which we have to respect, however strong our need to ‘correct’ patients’ denial might be.

The above-mentioned mindset, about not bargaining for dying in near future, gave me the idea that the co-researchers perhaps viewed their illness more as chronic than as ‘incurable and life-threatening.’ I considered whether seeing a disease as chronic could help, and be interpreted as a conscious coping strategy *per se*. When searching the literature for examples of this, I found one research participant who indeed used this as a coping strategy, by systematically likening her / his fatal illness to diabetes, and thereby making its threat less overwhelming (Coyle, 2006). My co-researchers did certainly not put it this way, but it can be inferred from their descriptions.

The remarkable finding, that most co-researchers attained a new view of life and an inner strength through their difficulties, coincides with findings of Benzein *et al.* (2001). It was clear, however, in co-researchers’ words, that this inner peace could not prevent anxiety attacks now and then. This is reflected in the cyclical process illustrating the co-researchers ‘struggle’ to cope, and live as meaningfully as possible, throughout the illness trajectory (figure 2, p.34). The illustration is, naturally, a simplification of their reality. It can be used as a framework or model for practice but people's context and experience should never be simplified. Each individual is unique. However, a model can be used for reflection and deeper understanding if used correctly.

6.5 *Internal factors* influencing perceived quality of life when living with an incurable, life-threatening disease

The dialogues with co-researchers revealed how inner factors, such as thinking positively, keeping hope alive and having faith, improved their quality of life. This manifests in my view the healing power people have within, and which can be

supported and nurtured, in order to improve perceived quality of life. This finding coincides with another study where positive thinking facilitated the participants' situation, whilst thinking negatively served to make them miserable (Johansson *et al.*, 2006).

The co-researchers' faith emerged as inner, spiritual conversations, and as silent conversations with God. The finding of how lack of faith afflicted and frightened one co-researcher may conflict with study findings by McIlmurray *et al.* (2003), who reached the conclusion that 'non-believers' did not have greater needs than 'religious believers,' among other things with respect to hope and fear. Other co-researchers found strength in belief in life after death, which some of them had even witnessed / experienced. Such parapsychological phenomena are relatively common among those who are dying, and the importance of respecting the significance of the experience for that person has been pointed out by Barbato *et al.* (1999). I agree with their view, that this meaning should above all outbalance others' disbelief or need for evidence. Two co-researchers found relief in meeting a psychic. As I did not find a parallel to this in reviewed palliative-care literature, but have on the other hand known people from clinical practice with positive experience of meeting a psychic, I considered whether it could be a relatively common resource in Iceland to seek support from psychics. This consideration provoked the idea that it could be opportune to study resources of palliative-care patients *per se*.

Changes in the self-image of palliative-care patients have been reported as a source of struggle (Murray *et al.*, 2004; Willems *et al.*, 2006). This is probably a manifestation of the importance for the co-researchers' quality of life of sensing that they still matter as persons and sustain a personal role. Analogous to this are the findings by Vig and Pearlman (2003), Mok and Chiu (2004), Murray *et al.* (2004), Low *et al.* (2005) and Johansson *et al.* (2006). Having to give up work increased the co-researchers' sense of

being ‘outsiders in society,’ which gave rise to the idea that the relevance of work is perhaps especially high for Icelanders. This finding could, however, be likened to feelings of uselessness that have been reported in this context (Boyd *et al.*, 2004; Murray *et al.*, 2004). I noticed especially that, although two co-researchers were keen to find a role, they did not manage to take any steps towards doing so, but remained at home, isolated and feeling miserable. This finding emphasizes the importance of discussing this matter with each client in order to find an appropriate solution. The above-mentioned needs of co-researchers, to matter as a person and be useful, could in my view be likened to the reported need for maintaining a sense of normality (Benzein *et al.*, 2001; Vig and Pearlman, 2003; Carter *et al.*, 2004; McClement *et al.*, 2004) and not being stigmatised (Benzein *et al.*, 2001). These needs could even be likened to the simple desire of hospice patients, who wish to be regarded as ‘real people’ and not to be ‘treated as already dead’ (Terry *et al.*, 2006a, p.412). Or, as one co-researcher put it, not perceiving themselves as some ‘faulty reject.’ People have a basic need to be valued, also when they know they do not have long to live (Mok and Chiu, 2004).

6.6 External factors influencing perceived quality of life when living with an incurable, life-threatening disease

The fatal illness had an interesting impact upon the family bonds of most co-researchers, either strengthening them or leading to disunity, which is parallel to findings by Cohen and Leis (2002), and is comprehensible in view of the fact that other family members are also in crisis under the circumstances (Davies *et al.*, 1995; Waldrop *et al.*, 2005). This reaffirms the need for a holistic, personal approach in palliative care, involving the whole family in a systematic and explicit way. Following dialogues with the co-researchers who had divorced during their illness trajectory, I could not help wondering if such holistic care right from the beginning could have changed the situation. Each individual will have unique needs when maintaining relationships (McCormick and Conley, 1995) and bringing closure to relationships, when facing

one's own mortality (Lynch and Abrahm, 2002). Receiving help from a palliative-care team in order to fulfil these needs has been reported as crucial (Holmberg, 2006).

The majority of co-researchers were deeply disappointed with the social-service system. According to their experience it was impossible to make ends meet from the benefits they received, and this had already caused grave financial problems. A financial burden has been reported, and is associated with heightened distress (Kayser-Jones, 2002; Seymour *et al.*, 2003; Vachon, 2005) that affects the quality of life of the whole family (Panke and Ferrel, 2005), as it evidently did in co-researchers' cases. When reading referenced literature I did not, however, find studies where the financial concerns were as prominent as they were for my co-researchers. In addition, co-researchers felt that pursuing their rights was too complicated, and they felt weary of spending their limited time in the 'struggle' with the system. These findings correspond in some aspects to the findings of Skilbeck *et al.* (1998) and McIlfatrick (2006), where the social-service system was described as too complicated. A remarkable point arising from the latter study was that the participants felt that receiving service from a social worker did not even suffice to address their needs, and this corresponds to what my co-researchers said. I find the idea of a personal service officer within the system, as suggested by a co-researcher, noteworthy, and worth serious consideration.

The dying process is one of the most social experiences we have in our life, and the meaning of death is co-created by those who participate in the dying person's experience (Leming and Dickinson, 1998), who in the case of my co-researchers are not only family and friends, but also healthcare professionals. The co-researchers' need for 'human contact' with healthcare professionals was clear in their descriptions. This is consistent with study findings by Taylor *et al.* (2001) and Richardson (2002). In a study by Johnston and Smith (2006), 'connecting' was indeed the key theme for the patients, illustrating the value of the relationship between the nurse and the patient. Such a

therapeutic relationship could be considered as the foundation of palliative care (Mok and Chiu, 2004), since it is, more than any other, care that is given through a human relationship (Barnard, 1995).

It has, on the other hand, been suggested that ‘a meaningful perspective on the very nature of our humanity’ is lacking within modern healthcare systems (Watson, 2003, p.201) and that patients are treated more as objects than as persons (Barnard, 1995). Underpinning this is the wish articulated by some co-researchers for their physicians and psychologists to be ‘more human’ and interested in knowing them as persons and their needs, instead of being too theoretical and wary of establishing a relationship. Supporting this also are the co-researchers’ experiences of reserved demeanour, impersonal service and even paternalism. This may in my view be likened to being treated stereotypically, which can lead to feelings of dehumanisation (Rogers *et al.*, 2000). When the existential changes that have occurred in these patients’ lives are kept in mind, along with the fact that they will probably be reliant upon care from healthcare professionals for the rest of their lives, I sense the above-mentioned needs for more human contact as an entirely understandable and fair request. Palliative-care patients are in a sense inviting healthcare professionals into their lives, and often have to disclose the most private physical, psychological and social aspects of their lives to them. As they, in their vulnerable state of being, rely upon resources from healthcare professionals and have certain expectations when meeting them, it is natural that they are disappointed when perceiving a lack of interest from them.

The co-researchers’ experiences of care from specialised palliative nurses in their homes were strikingly positive; this is seen also in the findings of Corner *et al.* (2003), Vig and Pearlman (2003) and Johanson *et al.* (2006). The nurses were perceived as both caring and competent, which has been, when linked together, defined as professional caring (Halldórsdóttir and Hamrin, 1997). The fact that the nurses could be reached 24

hours a day was important for the co-researchers' quality of life, and this corresponds with the findings of Cohen and Leis (2002), Richardson (2002) and Johanson *et al.* (2006). Also of importance was the fact that the nurses were perceived as always having time, which indicates that their care is first and foremost adjusted to the client's dynamic needs, rather than restricted to a preconcerted formal schedule.

In view of the above-mentioned advantage of being cared for by a specialised palliative team, it is interesting to consider the co-researchers' accounts of being hesitant, or even terrified, when such service was first offered. Such hesitance has been reported (Corner *et al.*, 2003; Seymour *et al.*, 2003; Roscoe and Schonwetter, 2006), as has healthcare professionals' reluctance to offer such services (Roscoe and Schonwetter, 2006). The explanation could perhaps lie in the fact that *palliative* care is often perceived as *terminal* care (McIlfatrick, 2006), and hence receiving the offer of such care leads to great anxiety. This fact, along with anxiety attacks and a high symptom load of co-researchers, as well as the experience of being offered the service too late, as pointed out by a co-researcher and more patients (Fincham *et al.*, 2005), indicates in my view that this prevailing perception of the nature of palliative care needs to be changed, and deliberately expanded to cover an earlier stage in the illness trajectory, as has indeed been pointed out by the WHO (2002), as well as by Meghani (2004) and Andersen *et al.* (2005).

6.7 Limitations and strengths of the study

One of my co-researchers passed away before I was able to seek her verification of the case construction.

In my view, the main strength of the study is that it was carried out with the ill people themselves, as has been strongly recommended if palliative care is to grow as a discipline (Johnston *et al.*, 2005). As I seek knowledge relevant for palliative care in

general, I see it as a strength to involve both male and female co-researchers, of different ages and with various diseases, in an endeavour to reflect the diversity within palliative care.

I believe my clinical experience in palliative care adds to the strength of this study, both because I have experience in having dialogues with people in similar situations, and because I think my experience may have provided me with a sound knowledge base on which to ground my probing. Furthermore, it has been pointed out that a researcher with clinical background can serve as a 'safety factor' in a palliative-care enquiry, being more able to address information concerns of the participants (Barnett, 2001), and it has been suggested that palliative-care professionals conducting studies within the spectrum could probably strengthen the applicability of the findings for practice (Frogatt *et al.*, 2003).

As I am aware that my clinical background could also be seen as a weakness, I endeavoured especially to prevent 'premature closure' (cf. Lincoln and Guba, 1985) on my part during the whole research process.

6.8 Summary

In this chapter the findings of this study have been discussed in the context of reviewed literature, revealing both differences from and similarities with other studies. The limitations and strengths of the study have also been depicted. In the next chapter I will, in consultation with my co-researchers, present ideas about implementation of the findings and future studies.

Chapter 7

Conclusion

7.1 Introduction

In the last chapter the co-researchers' experiences of living with an incurable, life-threatening disease and influences on their perceived quality of life were discussed in the context of the reviewed literature.

In this final chapter I will, in consultation with my co-researchers, present recommendations for future palliative-care practice, as well as suggestions for further research within the area. Finally, I will share some thoughts and concluding comments.

7.2 Implications and recommendations for practice

The method of the Vancouver School of Doing Phenomenology is utilised to gain insight into people's experiences and perception, in order to improve the service provided. In light of that I decided, following upon our dialogues about their lived experience, to consult with my co-researchers on how they saw an ideal healthcare service. Their suggestions are summarised in table 8.

<p>Facilities/services which need to be available</p> <ul style="list-style-type: none"> • More coordinated service, and more collaboration at the diagnostic stage, as needed: 'They mustn't give up on finding out what's wrong' (<i>George</i>). • Good access to the person's physician • Professional team to keep track of the individual's case (especially in the case of rare diseases) • Systematic flow of information and education • Less institutionalisation, greatly increased home services for all • Holistic and professional service • Rehabilitation and occupational therapy available for all • Psychological support and counselling available • Specialised service for MND patients, e.g. systematic 'down-stepping' instead of rehabilitation, and choice of ventilator at home when the diaphragm ceases to function
<p>With respect to social services:</p> <ul style="list-style-type: none"> • People who are so seriously ill should have a personal service officer who is responsible for social services.
<p>We want to work with, and receive service from, healthcare personnel who are:</p> <p>Interested, positive, informative, considerate, honest, personal, sincere, insightful, understanding and pleasant to be with, who listen and take us seriously: 'We're all unique and need different approaches' (<i>Norman</i>), '...I sometimes feel that some people could try to adopt a nicer... or warmer manner' (<i>Susanne</i>).</p>

Table 8

Summary of co-researchers' ideas on ideal healthcare service

Bearing in mind that the co-researchers have all been diagnosed with an incurable, life-threatening disease, it is not unexpected to see their request for more coordinated service, and more collaboration at the diagnostic stage, especially as two of them had consulted physicians repeatedly without being diagnosed. Furthermore, the frustration of these two co-researchers conveys, in my view, the message that people in such a situation may be in need of special care, beyond that of other palliative-care patients, centred upon their anger and frustration.

By recommending holistic service, good access, systematic flow of information and professional team work when needed, co-researchers reveal their request for more

collaboration and continuity, in order to fulfil their need for security and professional resources.

Their wish for greatly increased home services for all, including viable strategies for MND patients, is consistent with their desire to go on living as normally as possible, which is underlined by their request for availability of rehabilitation and occupational therapy for all, manifesting their longing to stay socially active and maintaining or finding new roles. Availability of psychological support and counselling when needed could further support them to engage in life and strengthen relationships within their families. With regard to the above, as well as to the study findings, I recommend that specialised palliative home care should be offered to people with a life-threatening disease earlier in the illness, and that patients' rights to privacy should be safeguarded when hospitalised. Furthermore, I urge the need to prevent long waits for palliative-care patients in casualty departments.

The co-researchers' potent description of their disappointment with the social-service system clearly implies that changes are needed in order to ease their living. A service officer or ombudsman, would not only provide them with information, but would also be able to apply for their entitlements if needed. It would therefore not only be the counsel that is provided, but the transaction as well. The severe and deteriorating physical condition of the co-researchers is a valid rationale for this, along with their psychological burden and existential crisis. Their limited time could then be centred more upon family relations, which in my belief would be positive not only for the respective family, but for society as a whole.

The co-researchers' request for healthcare professionals who are graced with human virtues emerges clearly in their suggestions, and I recommend that we who work within palliative care each search our own heart, and find a way of honouring this request in

clinical practice. This is indeed the least costly request of the co-researchers, but probably not the least effective one. I propose that we really see our palliative-care clients as experts in their lived experience: that we be eager to hear their story and empower their inner healing power.

I recommend that the model of co-researchers' essential structure of living with an incurable, life-threatening disease (figure 3, p.37) be utilised for reflection in clinical practice, as discussed in chapter 6, and that healthcare professionals explore whether the cyclical process illustrating the struggle of the co-researchers to cope and live as meaningfully as possible (figure 2, p.34) applies to their clients. If this is the case, the model indicates also where in the cycle the need is most for care from palliative healthcare professionals, and where it could be safe to withdraw a little and give patients and their families more private space. The cycle also illustrates that palliative nurses should never totally withdraw, but always be prepared to respond to alterations in condition, and preferably to predict changes, in order to react promptly to them. Furthermore, being available 24 hours a day enhances quality of care, as it is uncertain when care will be urgently needed.

Following the dialogues with the co-researchers, I ended by asking them if they had any good advice they would like to share with other people who might be in a similar situation to theirs.¹⁰ Their advice is summarised in table 9; I feel that this list could prove helpful in practice, and could even be used to hand over to those who might be interested.

¹⁰ Two co-researchers told me that they did not feel up to giving advice, as what was helpful was such an individual matter.

Our advice for you who are living with an incurable, life-threatening disease

- Try to accept your situation.
- Take responsibility for yourself. No-one else can do it for you.
- Be frank and candid with your family and friends and with healthcare providers.
- Fight, don't give up. Use all the help available.
- Accept palliative nursing care at home right away.
- Try to maintain a positive attitude, and use humour as much as you need.
- Be active, take part in life, and keep up your "life tempo" as far as possible. Don't sit at the window and wait!
- Seek strength in faith.
- Be stoical. Remember that you can always find new hope.
- Live one day at a time.

Best wishes

Individuals with an incurable, life-threatening disease

Table 9 | **Co-researchers' advices to other people who might be in a similar situation to theirs**

The findings of this study, and the above-mentioned suggestions of the co-researchers, will be used as a model in planning care in a specialised palliative-care unit in Akureyri, Iceland, which I am working to establish with others. The same applies to further planning for existing palliative home care in Akureyri.

I will present and discuss my findings with the co-researchers who are interested in doing so. The findings will also be presented to healthcare professionals verbally and in writing, and to various patients' associations. Furthermore, I will do my duty and present relevant findings to social services authorities, and to the Minister of Welfare in Iceland.¹¹

¹¹ I will, however, not do so until next autumn, because of general elections in Iceland this spring.

7.3 Recommendations for further research

This study has revealed various aspects that might be worthy of further exploration. My recommendations are presented in table 10.

- Phenomenological studies exploring lived experience and positive and negative influences on perceived quality of life of:
 - Individuals living with a life-threatening disease, but not diagnosed as incurable.
 - Individuals living with non-malignant incurable, life-threatening diseases.
 - Individuals living with a chronic disease who are in a need of palliative care.
- A phenomenological study with palliative-care patients about their resources.
- A phenomenological study with palliative-care patients about perceived empowering attitudes within the healthcare and social-service systems.
- A phenomenological study with palliative-care patients, aimed at exploring the lived experience and identifying needs at periods of increasing symptoms.
- An ethnographic study of healthcare professionals' interactions with their clients.
- A survey exploring palliative-care patients' experiences of the social-service system.
- A radical enquiry into the social-service system with regard to the needs and rights of palliative-care patients.

Table 10 Recommendations for further research

7.4 Concluding comments

I found it suitable to use the Vancouver School of Doing Phenomenology, in partnership with my co-researchers, in order to fulfil the aim of providing palliative healthcare professionals with insight and knowledge that could empower them to contribute to their clients' quality of life. It was valuable to discuss their lived experience, and then what influenced their perceived quality of life. It turned out that these two aspects were intertwined, and looking at both gave a more holistic view of the essential needs of the co-researchers.

Despite suffering from diverse physical symptoms, and living a life that 'consists of getting bad news' whilst facing their own mortality, most co-researchers managed to find useful resources that provided temporary solace. The findings express their desire to carry on living as persons who matter in human relationship with others, including

healthcare professionals. Patients within palliative care are known to consider it valuable when their true spirit within the sick body is remembered (Raudonis, 1995). The words of the co-researchers support this. Through reading their rich descriptions of their experience one can truly sense that, living on the brink, they have come to the core of human nature, treasuring humanity and human relations, having no need for grandiloquence or for being 'measured against' theoretical tenets. And when requested humanity and qualities of healthcare professionals are linked to other professional skills as well, this positively influences the patients' perceived quality of life.

The co-researchers expressed their satisfaction with their participation in the study, which I truly hope will encourage enquirers to look at palliative-care patients as valid study participants and go directly to them, instead of consulting others regarding their needs. The words of the co-researchers imply that it is not only endurable to have dialogues about their experience, but can be gratifying. As the study findings reveal the importance to the co-researchers of human contact, I maintain that a qualitative enquiry approach is felicitous and meaningful to them. It is my belief that their voice will be heard more in the future, and that this can only benefit palliative care.

Appendices

Appendix 1	86
Confirmation of approval from the National Bioethics Committee	
- in Icelandic, followed by English translation	
Appendix 2	89
Clearance from the Data Protection Committee	
- in Icelandic, followed by English translation	
Appendix 3	92
Introductory letter	
- in Icelandic, followed by English translation	
Appendix 4	99
Informed consent	
- in Icelandic, followed by English translation	
Appendix 5	102
A letter to those who did not participate in the study	
- in Icelandic, followed by English translation	
Appendix 6	105
Collaboration agreement	
- in Icelandic, followed by English translation	
Appendix 7	108
Certification of translation	

Appendix 1

Confirmation of approval from the National Bioethics Committee

- in Icelandic, followed by English translation



VÍSINDASIÐANEFND

Vegmúla 3, 108 Reykjavík,

Sími: 551 7100, Bréfsími: 551 1444

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Háskólinn á Akureyri, Heilbrigðisdeild
Sigríður Halldórsdóttir, prófessor
Sólborg v/Norðurslóð
Pósthólf 224
602 Akureyri

Reykjavík 13. desember 2005

Tilvísun: VSNb2005120007/03-7 Námsverkefni - nemarannsóknir almennar/BH/-

Varðar: 05-154-afg Reynsla einstaklinga af því að lifa með ólæknandi, lífsógnandi sjúkdóm og upplifun á því hvað hefur jákvæð og neikvæð áhrif á lífsgæði þeirra: Fyrirbærafræðileg rannsókn.

Á fundi sínum 13.12.2005 fjallaði Vísindasíðanefnd um umsókn þína dags. 06.12.2005, vegna ofangreindrar rannsóknaráætlunar. Meðrannsakandi þinn er Kristín Sólveig Bjarnadóttir, en hún er í fjarnámi til meistaraáráðu við Royal College og Nursing Institute for Higher Education/Manchester háskóla og er rannsóknin námsverkefni hennar.

Um er að ræða túlkandi fyrirbærafræðilega rannsókn á þeirri reynslu einstaklinga að lifa með ólæknandi, lífsógnandi sjúkdóm og upplifun af því hvað hefur jákvæð og neikvæð áhrif á lífsgæði þeirra. Þýði rannsóknarinnar verða einstaklingar 18 ára og eldri með ólæknandi, lífsógnandi sjúkdóm og úrtakið verður tilgangsrátt valið með aðstoð hjúkrunarfræðinga sem starfa við líknandi hjúkrun. Tekin verða djúpvíðtöl við 8-11 einstaklinga og þau síðan greind og túlkuð. Í samræðum við einstaklingana verður leitast við að greina þá þætti sem einkenna þessa reynslu. Gert er ráð fyrir að 1-3 samræður eigi sér stað við hvern meðrannsakanda. Úrvinnsla gagna verður ferli ígrundunar og fer fram samkvæmt leiðbeiningum Vancouver skólans.

Eftir að hafa farið yfir umsókn þína og innsend gögn sér Vísindasíðanefnd ekki ástæðu til að gera athugasemdir við fyrirhugaða framkvæmd rannsóknarinnar. Rannsóknaráætlunin er endanlega samþykkt af Vísindasíðanefnd.

Vísindasíðanefnd bendir rannsakendum vinsamlegast á að birta VSN tilvísunarnúmer rannsóknarinnar þar sem vitnað er í leyfi nefndarinnar í birtum greinum um rannsóknina. Jafnframt fer Vísindasíðanefnd fram á að fá send afrit af birtum greinum um rannsóknina. Rannsakendur eru minntir á að tilkynna rannsóknarlok til nefndarinnar.

F.h. Vísindasíðanefndar,
með kveðju,

Björn Guðbjörnsson, formaður



Háskólinn á Akureyri, Heilbrigðisdeild
Sigríður Halldórsdóttir, prófessor
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VÍSINDASÍÐANEFND
National Bioethics Committee

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Reykjavík, May 30, 2006

Ref: VSNb2005120007/03-7 Námsverkefni - nemarannsóknir almennar/BH/--

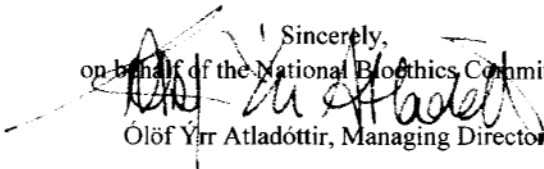
Confirmation of approval : 05-154-afg Positive and negative influences on perceived quality of life of people living with an incurable, life threatening disease: A phenomenological study. Reynsla einstaklinga af því að lifa með ólæknandi, lífsógnandi sjúkdóm og upplifun á því hvað hefur jákvæð og neikvæð áhrif á lífsgæði þeirra: Fyrirbærafræðileg rannsókn.

It is hereby confirmed that at its meeting of December 13th 2005, the National Bioethics Committee discussed your application, dated December 6th 2005, concerning the above-mentioned research project. The project's investigators are yourself as an advisor and Kristín Sólveig Bjarnadóttir, who is currently attending the Royal College of Nursing Institute for Higher Education/Manchester University. Enclosed with your application were copies of the information sheet and consent form for the research participants as well as your CV.

Participants will be approx. 8-11 men and women over 18 years of age selected with assistance from staff nurses. Interviews will be conducted and journal entries analysed. Interpretation of data will follow the Vancouver school of phenomenological studies.

After reviewing your application and all supplementary information the National Bioethics Committee granted the research proposal its full approval.

The National Bioethics Committee kindly requests that researchers include the given referral no. given to their project by the committee in published research papers. The National Bioethics Committee would also like to receive copies of research papers portraying research approved by the committee. Researchers are reminded to notify the committee of the completion of the research project.

Sincerely,
on behalf of the National Bioethics Committee,

Ólöf Yrr Atladóttir, Managing Director

Appendix 2

Clearance from the Data Protection Committee

- in Icelandic, followed by English translation

Sigríður Halldórsdóttir

Steinahlíð 8a
603 Akureyri



Persónuvernd

Rauðarárstíg 10 105 Reykjavík
sími: 510 9600 bréfasími: 510 9606
netfang: postur@personuvernd.is
veffang: personuvernd.is

Reykjavík 21. desember 2005
Tilvísun: S2762/2005/ EB/-

Hér með staðfestist að Persónuvernd hefur móttengið tilkynningu í yðar nafni um vinnslu persónuupplýsinga. Tilkynningin er nr. S2762/2005 og fylgir afrit hennar hjálagt.

Allar tilkynningar sem berast Persónuvernd birtast sjálfkrafa á heimasíðu stofnunarinnar. Tekið skal fram að með móttöku og birtingu tilkynninga hefur engin afstaða verið tekin af hálfu Persónuverndar um efni þeirra.

Virðingarfyllst,


Erla Björgvinsdóttir

Sigríður Halldórsdóttir

Steinahlíð 8a
603 Akureyri

Data Protection Authority

Rauðarárstígur 10 ,105 Reykjavík
Tel: 510 9600 Fax: 510 9606
e-mail: postur@personuvernd.is
website: personuvernd.is

Reykjavík, 21 December 2005

REference: S2762/2005/ EB/-

It is hereby confirmed that the Data Protection Authority has received notification in your name of processing of personal data. The notification has the reference number S2762/2005, and a copy of it is attached.

All notifications sent to the Data Protection Authority automatically appear on the Authority's website. It is pointed out that by receipt and promulgation of the notification, the Authority is not expressing any view on the content.

Sincerely

Erla Björgvinsdóttir

Appendix 3

Introductory letter

- in Icelandic, followed by English translation

Kynningarbréf

Heiti rannsóknar: *Reynsla einstaklinga af því að lifa með ólæknandi, lífsógnandi sjúkdóm og upplifun á því hvað hefur jákvæð og neikvæð áhrif á lífsgæði þeirra:*
Fyrirbærafræðileg rannsókn.

Ábyrgðamaður og leiðbeinandi: Dr. Sigríður Halldórsdóttir, prófessor við Heilbrigðisdeild Háskólans á Akureyri, s. 460-8452.

Rannsakandi: Kristín Sólveig Bjarnadóttir, hjúkrunarfræðingur í Heimahlynningu á Akureyri, s. 896-0412/462-5136.

Fengist hefur leyfi hjá Vísindasiðanefnd til að framkvæma ofangreinda rannsókn og Persónuvernd hefur verið tilkynnt um framkvæmd hennar.

Ég undirrituð, Kristín Sólveig Bjarnadóttir, er hjúkrunarfræðingur og starfa í Heimahlynningu á Akureyri við hjúkrun alvarlegra veikra í heimahúsum. Ég er jafnframt nemandi í meistaranámi sem er samvinnuverkefni Royal College of Nursing/Manchester University og Háskólans á Akureyri.

Lokaverkefnið í námi mínu felst í rannsóknarvinnu og þar sem ætlun mín er að rannsaka reynslu þeirra sem lifa með ólæknandi, lífsógnandi sjúkdóm þá leita ég til þín.

Hjúkrunarfræðingar sem starfa við líknandi hjúkrun aðstoðuðu mig við að finna þig og fleiri í svipuðum sporum. Sá hjúkrunarfræðingur sem þekkir þig hefur væntanlega boðið þér þetta bréf svo þú gætir kynnt þér þær upplýsingar sem hér koma fram um fyrirhugaða rannsókn.

Það hefur lengi verið innan áhugasviðs míns að dýpka skilning minn á því hvernig ég get best stutt við fólk með ólæknandi, lífsógnandi sjúkdóm. Til að afla þeirrar þekkingar, og skilnings og innsæis í reynsluna, finnst mér nauðsynlegt að eiga samræður við einstaklinga sem hafa reynsluna sjálfir, enda lít ég svo á að þeir einir séu sérfróðir um þá upplifun. Þeim fjölgar stöðugt sem lifa lengur með ólæknandi

Introductory letter

Name of study: *Positive and negative influences on perceived quality of life of people living with an incurable, life-threatening disease: a phenomenological study.*

Supervisor: Dr. Sigríður Halldórsdóttir, professor at the Faculty of Health Sciences at the University of Akureyri, tel. 460-8452.

Researcher: Kristín Sólveig Bjarnadóttir, nurse BSc, at the Palliative Home Care Team in Akureyri, tel. 896-0412/462 5136.

I, the undersigned, Kristín Sólveig Bjarnadóttir, am a nurse and work within the Palliative Home Care Team in Akureyri, caring for seriously ill people in their homes. I am also a student for the degree of Master of Nursing at the University of Manchester/Royal College of Nursing/the University of Akureyri. My dissertation involves conducting research and, as it is my intention to investigate the experience of those who live with incurable, life-threatening disease, I am approaching you.

Nurses who work within palliative care assisted me in finding you, and some others in a similar situation. The nurse who knows you has presumably offered you this letter, so you could study this information about the research.

For a long time I have been interested in deepening my understanding of how I can best support people with incurable, life-threatening disease. In order to gain such knowledge and insight into the experience, I find it essential to have dialogues with individuals who themselves have the experience, since I believe they are the true experts in this particular lived experience. The number of those who live longer with

sjúkdóma og mér er mikið í mun að leggja mitt af mörkum til að bæta og efla þjónustu við viðkomandi einstaklinga og fjölskyldur þeirra. Ég óska því hér með eftir þátttöku þinni í rannsókninni ef þú hefur áhuga á að leggja þitt af mörkum til þekkingarþróunar með því að miðla af upplifun þinni og reynslu.

Ég tel að niðurstöður rannsóknarinnar geti nýst heilbrigðisstarfsfólki til að dýpka skilning sinn á hvernig reynsla þetta er og hvernig verður best stutt við þá sem standa í þessum sporum. Rannsóknin gæti einnig gagnast þátttakendum sjálfum, svo og öðrum sem eru með ólæknandi sjúkdóma.

Fyrirhuguð rannsókn mín byggir á aðferðafræði sem nefnist fyrirbærafræði og snýst um að rannsaka mannlega reynslu; í þessu tilviki hvað hafi jákvæð og neikvæð áhrif á lífsgæði þeirra sem lifa með ólæknandi, lífsógnandi sjúkdóma. Gagnasöfnun fer eingöngu fram með samtölum. Ef þú ákveður að taka þátt í rannsókninni mun ég taka eitt til tvö viðtöl við þig sem taka um það bil klukkustund hvort. Ég tek viðtölin upp á segulband og mun síðan vélrita þau orðrétt upp. Ef þörf verður á að fá meiri upplýsingar um lífsreynslu þína þá mun ég biðja þig um eitt viðtal til viðbótar. Ég ein mun hafa aðgang að segulbandsupptökum og vélrituðum gögnum og að rannsókn lokinni mun segulbandsupptökunum verða eytt. Þar sem líklegt er að beinar tilvitnanir í samræðurnar muni birtast í rannsóknarskýrslunni munu þátttakendur fá dulnefni þannig að nafn þeirra komi hvergi fram.

Ég lít svo á að reynsla þín sé dýrmætur hlekkur í þekkingarsköpun á þessu sviði. Það er von mín að þú hafir áhuga á að taka þátt í þessari rannsókn sem vonandi gæti gagnast þér persónulega þar sem samræður sem þessar verða jafnvel til þess að losa um erfiðar tilfinningar. Ef þú ákveður að taka þátt er mikilvægt að þú vitir að þú getur hætt þátttöku hvenær sem er í rannsóknarferlinu án þess að tilgreina ástæðu fyrir því og mun það ekki á nokkurn hátt hafa áhrif á þá meðferð og þjónustu sem þú hlýtur. Einnig getur þú neitað að ræða mál sem eru þér viðkvæm.

an incurable disease increases constantly, and I am eager to contribute to enhancing service for those individuals and their families. If you are interested in contributing to knowledge creation by sharing your lived experience, I invite you hereby to participate in the study.

I believe the research findings could be useful for health care professionals, in order to deepen their understanding of your experience and in providing insight into your needs. The research findings could also be of use for yourself, as well as for others with incurable, life-threatening disease.

My proposed study will be guided by a research approach called phenomenology, which deals with investigating human experience; in this instance the perceived quality of life of people living with an incurable, life-threatening disease. The data will be gathered solely through dialogues. If you decide to participate in the study I will have two one-hour dialogues with you. The dialogues will be audiotaped and then transcribed verbatim. If more information on your experience is required I may ask you for one additional dialogue.

I alone will have access to the research data, and when the study is complete all tapes will be destroyed. As it is likely that direct quotations will emerge in the findings, each participant will be given a pseudonym in order to ensure anonymity.

I see your experience as a valuable link in knowledge creation in this field. I hope you will be interested in participating in this study, which would hopefully be useful for you personally, as dialogues can even ease difficult emotions. If you decide to participate, it is important for you to know that you can withdraw at any time during the study without giving any explanation, and that would under no circumstances affect your treatment or applied service. You can also refuse to discuss any delicate matters.

Það skal tekið fram að ef viðtölin vekja upp óþægilegar tilfinningar hjá þér sem þú hefur þörf fyrir að ræða þá býðst þér að hafa samband við undirritaða til að ræða líðan þína eða að hafa samband við Elísabetu Hjörleifsdóttur, MSc. klínískan sérfræðing í krabbameinshjúkrun sem hefur áralanga reynslu af samræðum við alvarlega veika einstaklinga og fjölskyldur þeirra, s. 862-5369.

Ef þér finnst það gera þér gott að ræða um líðan þína og þú hefur áhuga á að eiga samræður við mig um upplifun þína og koma þannig mikilvægum upplýsingum á framfæri vinsamlegast hafðu þá samband mig (sjá upplýsingar um símanúmer/netfang hér að neðan). Ef þú hefur einhverjar spurningar varðandi hugsanlega þátttöku er þér velkomið að hafa samband við mig og leita frekari upplýsinga.

Ef þú ákveður að taka ekki þátt í rannsókninni þá virði ég þá ákvörðun þína og óska þér velfarnaðar.

Að lokum skal tekið fram að ef fleiri bjóða sig fram til þátttöku en þörf er fyrir, verða þátttakendur í rannsókninni dregnir út af handahófi.

Með fyrirfram þökk og kærri kveðju,

Kristín Sólveig Bjarnadóttir
hjúkrunarfræðingur í Heimahlynningu á Akureyri
Vinnusími/gsm: 896-0412 Heimasími: 462-5136
Netfang: kristinsol@simnet.is

Dr. Sigríður Halldórsdóttir
Vinnusími: 460-8452
Netfang: sigridur@unak.is

Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasiðanefndar, Vegmúla 3, 108 Reykjavík. Sími: 551-7100, fax 551-1444.



I want to point out that if the dialogues evoke uncomfortable feelings which you would like to discuss further, you are invited to contact the undersigned in order to discuss those feelings, or to contact Elísabet Hjörleifsdóttir MSc, a clinical specialist in cancer nursing, who has years of experience of communication with seriously ill people and their families, tel. 862-5369.

If you find it helpful to discuss how you are feeling, and you are interested in conversing with me about your experience and thereby sharing important information, please contact me (see telephone number/e-mail address below). If you have any questions regarding your possible participation, you are welcome to contact me for further information.

If you decide not to participate in the research, I respect your decision and wish you well.

Finally, I specify that if more people than needed offer to participate, the participants in the research will be selected at random.

Kind regards,

Kristín Sólveig Bjarnadóttir

Nurse BSc at the Palliative Home Care Team in Akureyri

Telephone at work/mobile: 896-0412. Telephone at home: 462-5136.

E-mail: kristinsol@simnet.is

Dr. Sigríður Halldórsdóttir

Telephone at work: 460-8452.

E-mail: sigridur@unak.is

If you have questions about your rights as a participant in scientific research or want to withdraw from the research, you can contact the Icelandic National Bioethics Committee, Vegmúli 3, 108 Reykjavík. Telephone: 551-7100, fax 551-1444.

Appendix 4

Informed consent

- in Icelandic, followed by English translation

Upplýst samþykki

Heiti rannsóknar: ***Reynsla einstaklinga af því að lifa með ólæknandi, lífsógnandi sjúkdóm og upplifun af því hvað hefur jákvæð og neikvæð áhrif á lífsgæði þeirra.***

Tilgangur rannsóknarinnar er einkum sá að afla vísindalegrar þekkingar og auka skilning á fyrirbærinu: að lifa með ólæknandi, lífsógnandi sjúkdóm með það að markmiði að auðvelda heilbrigðisstarfsfólki og öðrum að veita faglegri og markvissari líknandi meðferð.

Ég, undirrituð/undirritaður, hef tekið þá ákvörðun að taka þátt í þessari rannsókn sem er hluti af meistaranámi Kristínar Sólveigar Bjarnadóttur.

Tvö viðtöl hennar við mig munu fara fram á þeim stað og á þeirri stundu sem ég vel og munu taka um það bil eina klukkustund. Ef eftir því verður óskað mun ég einnig taka þátt í þriðja viðtali. Viðtölin verða tekin upp á segulband, Kristín mun vélrita þau og enginn annar mun fá aðgang að þeim. Mér er kunnugt um að ég get neitað að ræða mál sem eru mér viðkvæm og ef samræðurnar vekja upp óþægilegar tilfinningar sem ég hef þörf fyrir að ræða frekar get ég haft samband við Kristínu eða Elísabetu Hjörleifsdóttur, klínískan sérfræðing í krabbameinshjúkrun, til að ræða líðan mína. Kristín má nota tilvitnanir mínar í handrit rannsóknarinnar enda verði þær ekki rekjanlegar til mín. Mér hefur verið lofað fyllsta trúnaði og nafn mitt mun hvergi koma fram í vélrituðum samtölum né í handriti rannsóknarinnar. Ef Kristín þarf að ræða niðurstöður rannsóknarinnar við mig er henni velkomið að hafa samband við mig síðar í rannsóknarferlinu. Mér er kunnugt um að hvenær sem er í rannsóknarferlinu get ég neitað frekari þátttöku án þess að tilgreina ástæðu og mun það ekki á nokkurn hátt hafa áhrif á þá meðferð og þjónustu sem ég fæ.

Ég hef kynnt mér ofangreindar upplýsingar og Kristín hefur veitt mér þær útskýringar sem ég hef óskað eftir. Ég tel mig skilja tilgang rannsóknarinnar, auk mögulegs ávinnings og áhættu við hana. Ég veiti þátttöku minni hér upplýst og óþvingað samþykki.

Dagsetning: _____

Nafn þátttakanda: _____

Nafn rannsakanda: _____

Informed consent.

Name of the study: ***Positive and negative influences on perceived quality of life of people living with an incurable, life-threatening disease: a phenomenological study.***

The aim of the study is mainly to create knowledge and gain a deeper understanding of the phenomenon *living with an incurable, life-threatening disease*, with the aim of enabling healthcare professionals and others to provide more professional and more effective palliative care.

I, the undersigned, have made the decision to participate in this study, which is a part of the MSc studies of Kristín Sólveig Bjarnadóttir.

Our two dialogues will occur at a location and a time chosen by me, and will take approximately one hour. I will participate in a third dialogue if asked. The dialogues will be audiotaped, Kristín will transcribe them verbatim, and no one else will have access to them. I know that I can choose not to discuss any delicate matters, and that if the dialogues evoke uncomfortable feelings, which I wish to discuss further, I can contact Kristín, or Elísabet Hjörleifsdóttir, a clinical specialist in cancer nursing, in order to discuss those feelings.

Kristín may quote me in the research report, on condition that the quotations will not be traceable to me. I have been promised complete confidentiality, and my name will not appear in transcribed dialogues, nor in the research report. If Kristín needs to discuss the research findings with me, she is welcome to contact me later in the research process. I know that I can withdraw at any time during the study without giving any explanation, and without affecting my treatment or the service I receive.

I have studied the information above, and Kristín has given me the information I have asked for. I believe I understand the aim of the study and potential advantage and risk related to it. I hereby give my informed and free consent to my participation.

Date: _____

Name of participant: _____

Name of researcher: _____

Appendix 5

A letter to those who did not participate in the study

- in Icelandic, followed by English translation

Akureyri 31. ágúst, 2006.

[Nafn viðtakanda og heimilisfang]

Efni: Vegna rannsóknar Kristínar S. Bjarnadóttur hjúkrunarfræðings á reynslu af því að lifa með ólæknandi, lífsógnandi sjúkdóm.

Kæra / kæri [nafn viðtakanda].

Síðastliðið vor gafst þú hjúkrunarfræðingi þínum leyfi til að gefa mér upp nafn þitt vegna hugsanlegrar þátttöku í ofangreindri rannsókn minni.

Undanfarna mánuði hef ég unnið að gagnasöfnun rannsóknarinnar og nú er komin upp sú staða að ákveðinni mettun hefur verið náð og því mun ekki gerast þörf á að ræða við fleiri viðmælendur.

Ég met hins vegar mikils og þakka þér af heilum hug fyrir að þú skulir hafa gefið kost á þér. Án fólks í þínum sporum væri svona rannsókn svo sannarlega óframkvæmanleg en von mín er sú að niðurstöður rannsóknarinnar veiti okkur heilbrigðisstarfsfólki dýpri innsýn í reynsluheim þeirra sem lifa með lífsógnandi sjúkdóm svo enn frekar megi bæta þá þjónustu sem veitt er.

Ef það er samt sem áður eitthvað sem þig langar til að koma á framfæri eða að ræða þá er þér velkomið að hafa samband við mig.

Ég óska þér og þínum alls hins besta.

Kær kveðja,

Kristín Sólveig Bjarnadóttir

hjúkrunarfræðingur í Heimahlynningu á Akureyri

s. 896-0412 netfang: kristinsol@est.is



Akureyri, 31 August 2006.

[Name and address of recipient]

Re: research project of nurse Kristín S. Bjarnadóttir on positive and negative influences on perceived quality of life of people living with an incurable, life-threatening disease.

Dear [name of recipient].

Last spring you gave your nurse permission to pass on to me your name with respect to possible participation in my research project, specified above. In recent months I have been working on data collection for my study, and now the situation has been reached where a certain saturation has been achieved, and thus I will not need to speak with any more participants.

But I truly appreciate your willingness to participate, and thank you most sincerely. A study of this nature could not be carried out without the contribution of people like you; it is my hope that the findings of the study will give us healthcare professionals deeper insight into the experience of those who are living with life-threatening disease, so that the service provided may be further enhanced.

If you have any points you wish to make or discuss, you are still welcome to contact me.

I wish you and yours all the best.

Sincerely

Kristín Sólveig Bjarnadóttir

Nurse BSc at the Palliative Home Care Team in Akureyri

Tel: 896-0412. E-mail: kristinsol@est.is

Appendix 6

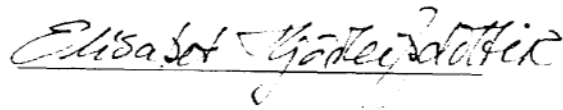
Collaboration agreement

- in Icelandic, followed by English translation

Samstarfsyfirlýsing hjúkrunarfræðings

Vegna rannsóknar Kristínar Sólveigar Bjarnadóttur á reynslu þess að lifa með ólæknandi, lífsógnandi sjúkdóm og upplifun af því hvað hefur jákvæð og neikvæð áhrif á lífsgæðin við þær aðstæður, hef ég undirrituð, Elísabet Hjörleifsdóttir, klínískur sérfræðingur í krabbameinshjúkrun, kt. 170650-4179, heitið að veita þeim meðrannsakendum Kristínar sem eftir því óska, aðstoð meðan á rannsókninni stendur eða eftir að þátttöku er lokið.

Akureyri, 27. október 2006



Nurse's declaration of collaboration

In connection with Kristín Sólveig Bjarnadóttir's study of the lived experience of living with an incurable, life-threatening disease, and the experience of positive and negative influences on perceived quality of life under those circumstances, I the undersigned, Elísabet Hjörleifsdóttir, clinical specialist in cancer nursing, ID no. 170650-4179, undertake to provide assistance to those of Kristín's co-researchers who so request, during the study and after their participation is completed.

Akureyri, 27 October 2006

Appendix 7

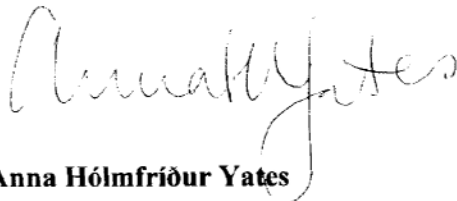
Certification of translation

25 April 2007

Declaration

I hereby confirm that I have translated the appendices to Kristín S. Bjarnadóttir's dissertation on lived experience of living with an incurable, life-threatening disease, and positive and negative influences on perceived quality of life.

Sincerely

A handwritten signature in cursive script, reading "Anna Hólmfríður Yates".

Anna Hólmfríður Yates

Certified translator

Langholtsvegur 172

Reykjavík

Iceland

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