

PhD thesis

Advanced cancer patients as participants in their own lives

A grounded theory study of coping from a patient perspective

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Preface

This PhD thesis focuses on coping in advanced cancer patients seen from a patient-perspective. Data for the study were collected during the period June 2006 to August 2009. As a PhD student I was employed at the *Department of Palliative Medicine, Bispebjerg Hospital* and here I had my daily routine. I wish to thank the department for hosting me during these years.

The idea for the study and the outline of methods came from *Susan Rydahl Hansen*, who wrote the initial study proposal. I am forever grateful to her for appointing me to do the study and offering me the opportunity to become a PhD student with her as my project supervisor. She has taught me so much through discussion and supervision and throughout my time as a PhD student she has been deeply devoted to the project. I further wish to thank *Lis Wagner*, who became my main supervisor. Her unfailing belief in my abilities has been crucial in my endeavours and I deeply appreciate the trust she has shown me.

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And in memory of my father, *Anton*, who will always be in my heart.

Thora Grothe Thomsen
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Original Papers

This thesis is based on the following original papers. In the thesis they will be referred to by their

Roman numerals:

- I Thomsen, T.G., Rydahl-Hansen, S., Wagner, L. (2010). A review of potential factors relevant to coping in advanced cancer patients. *Journal of Clinical Nursing*, **19**, p. 3410-3426

- II Thomsen, T.G., Rydahl-Hansen, S., Wagner, L.(2011). How to be a patient in a palliative life experience? A qualitative study to enhance knowledge about coping abilities in advanced cancer patients *Journal of Psychosocial Oncology*, **29** (3), p. 254

- III Thomsen, T.G., Rydahl-Hansen, S., Wagner, L.: Prioritising, downplaying and self-preservation: processes significant to coping in advanced cancer patients
Manuscript in process, (in you are interested, please contact TGT: t@grotheonline.com)

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APPENDIX

ARTICLES

1 Introduction

This PhD thesis treats the subject of coping in advanced cancer patients. The project is part of a larger framework project studying coping in advanced cancer patients, seen from the respective perspectives of the patient, relatives and professionals. The framework project was initiated by the Research Unit at the Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen. The current research project constitutes the part of the framework project that focuses on coping viewed from the patient perspective. The research project took place in the period 2006 - 2010.

My interest in coping in advanced cancer patients originates in many years' experience as a nurse, both in the hospital and primary care sectors, where patients' handling of serious illness and death was a theme that I found particularly pertinent. Furthermore, I completed my university studies in pedagogy with a master's thesis that dealt with training health professionals in care for the dying. Since then I have had the opportunity to be one of the main players in the development of several palliative modules on a health diploma course, where coping was one of the themes. It was therefore with extensive professional interest that I accepted the challenge to carry out a PhD project, where the central theme would be coping in advanced cancer patients.

1.1 The composition of the thesis

The thesis consists of nine sections, followed by a resume in both Danish and English, a list of references, appendices and the three articles which make up the thesis. Section 1 is a short introduction to the thesis and a clarification of its structure. Section 2 gives an account of the problem, the background to the study and previous research that focused on coping in advanced cancer patients. Section 3 describes the aims and objectives of the study. Section 4

identifies the concept of 'coping'. Section 5 describes how the literature review was undertaken, including review questions, search criteria, inclusion and exclusion criteria, review sources, extraction of data, analysis and synthesis of data and a short description of the results of the review, which are further elaborated in Article I. Section 6 deals with the empirical study. It starts with an account of the overall methodological approach. Then the course of the empirical study is described, hereunder ethical considerations, selection procedure, participants, interviews and the analysis process, together with a short description of significant results from the empirical study. These are further detailed in Articles II and III. Finally, the results from Articles II and III are integrated in a model that illustrate the developed Grounded Theory. Section 7 is a discussion in two parts. The first part discusses the applied method in both the literature review and the empirical study. The second part discusses the connection between conducting a review and the development of a Grounded Theory, together with significant results from the empirical study. Section 8 gives the conclusion to the complete research project. Section 9 puts the significance of the results into perspective, both in relation to the development of clinical practice and in regard to future research.

2 Background

The background is divided into two parts; the first presents the specific research problem and the second presents previous research, which was relevant in elucidating the problem. Finally, a synopsis leads us to the aim of the project.

2.1 The research problem – between the ideal and reality

In WHO's definition of palliative work (World Health Organization 2002), The National Cancer Plan (Sundhedsstyrelsen 2005), The Board of Health's guidelines for palliative work (Sundhedsstyrelsen 1999), The Danish Cancer Society's note on principles (Kræftens Bekæmpelse 1999) and in hospice philosophy (Saunders *et al.* 1995) emphasis is placed on the *ideals* surrounding a dignified death. The ideals are based on, for example, prevention, coping and alleviation of potential and actual suffering, which is linked with physical, psychosocial and existential/spiritual problems (Osse *et al.* 2005, Sand *et al.* 2008, Wilson *et al.* 2007), which patients are confronted with during the course of their illness and lead up to death.

However, several research projects indicated that the *reality* can be very different. Thus, advanced cancer patients experience a marked loss of status, when their condition changes from being a cancer patient in active treatment with a cure in sight to being terminally ill with only a marginal or no prospect of being cured from their illness (Rydahl-Hansen 2005). Their suffering escalates and becomes more diffuse and complex, and at the same time their capacity to express and deal with the suffering deteriorates considerably (Eriksen 1996, Hart *et al.* 1998). Research points further to the fact that health professionals lack knowledge, experience and courage to assist with the prevention and alleviation of the patients' suffering (Hansen 2003). Besides, the

professionals' support can be dominated by a focus on illness, treatment of symptoms and effectiveness (Eriksen 1996, Cassel 1999, Hart *et al.* 1998, Lawton 2000), while the patients to an increasing degree are thought to passively adapt to a context defined by those providing treatment (Clover *et al.* 2004, Hansen 2003). One consequence of the above can be that the patients suppress, conceal, silently bear, deny or displace the suffering, which can be instrumental in becoming anxious, depressive, finding life hopeless or worthless, and in the worst case can lead them to actively seek help to die (Cassel 1982, Chochinov 2004, Kuuppelomäki and Lauri 1998, Morse 2001, Rydahl-Hansen 2005).

The above research throws light on an issue that, despite all the ideals and good intentions, advanced cancer patients and their relatives have to face and manage a reality, which at times can be overwhelming. At the same time professionals are considered to lack knowledge, courage and experience in relation to supporting advanced and incurable ill patients' coping. The issue has led to a study of what past research has shown in relation to coping in advanced cancer patients.

2.2 Research with focus on coping in advanced cancer patients

Previous research points to the fact that advanced and incurable ill cancer patients' opportunities to express and manage their suffering are significantly reduced when there is only a marginal or no prospect of cure from their illness (Eriksen 1996, Hart *et al.* 1998). It is also shown that low mental stress in this group of patients is associated with both high levels of acknowledgement of and positive behaviour in relation to the suffering (Zabalegui 1999). Furthermore, research shows that patients who enjoy a high degree of positive social support report better emotional functioning, fewer serious

stress-related reactions (Ringdal *et al.* 2007) and better mood than patients with a low degree of social support (Koopman *et al.* 1998). Similarly, several research projects show how patients struggle in different ways to reestablish or maintain personal control in relation to specific aspects of their lives (Coyle 2006, Lewis FM *et al.* 1986).

A systematic search in the following databases: Pubmed, Psykinfo and CINAHL covering the period 1996 to 2006 shows how a frequently applied approach to research on coping in advanced and terminally ill cancer patients has centred on specific coping strategies (Blinderman and Cherny 2005, Classen *et al.* 1996, Clayton *et al.* 2005, Costanzo *et al.* 2006, De Faye *et al.* 2006, Kershaw *et al.* 2004, Kuuppelomäki and Lauri 1998, Sharpe *et al.* 2005, Sherman *et al.* 2000, Winterling *et al.* 2004, Zabalegui 1999). According to Lazarus the limitation in this approach can be that coping comes across as a set of specific patterns of behaviour, which does not involve personal factors (e.g. commitments, beliefs and personal control) and situational factors (e.g. uncertainty, novelty and duration), that underlie coping in a given group of persons (Lazarus and Folkman 1984, Lazarus 1999) – in this context advanced and terminal ill cancer patients. Therefore Lazarus recommends that qualitative research should also be carried out that studies the factors, seen from the perspective of the individual, which underlie coping (Lazarus 1999). Furthermore (Folkman and Lazarus 1988) recommend that as many perspectives as possible contribute to elucidating coping in a given group of persons. The systematic search in Pubmed, Psychinfo and CINAHL points to the fact that several studies have been carried out that study the factors that underlie coping in advanced cancer patients (Bolmsjo 2000, Brown *et al.* 2000, Coyle 2006, Fegg *et al.* 2005, Winterling *et al.* 2006, Öhlen *et al.* 2002). However, only few studies have pointed to the *connections* between individual and environmental factors

that underpin coping, as seen from a patient perspective. A study by Davies and Sque (2002) describes how women with terminal breast cancer felt that they were 'outsiders' who looked in on a world that continued without them. In order to be able to enter into that world again it was necessary that the women reconciled themselves to the fact that they had developed a new identity during the course of the illness. In addition, three research projects show how patients with advanced cancer apparently struggle to manage their complex situation by, on the one hand, relating to the illness and on the other hand, fighting to carry on their daily life (Houldin and Lewis 2006, Lethborg *et al.* 2006, Luoma and Hakamies-Blomqvist 2004)

2.3 Summary of previous research

Seen as a whole, previous research on coping in advanced cancer patients points to a multi-faceted process, which partly finds expression as a series of specific coping strategies, and partly involves a range of different factors. At the same time it is clear that there is little research that deals with the connections between individual and environmental factors that characterise coping, as seen from a patient perspective. With a view to increasing the health professional understanding of the complexity of coping, it is therefore necessary to have further research that can help to reveal and describe characteristics and connections to coping in advanced cancer patients. Over time this knowledge can contribute to the development of the clinical care work. Based on the research problem and the knowledge base, aims and objectives of the project were developed.

3 Aims and objectives

The overall aim was to develop a Grounded Theory with focus on the central characteristics in coping in advanced cancer patients, and which, from a patient perspective, are significant to how patients in interaction with their surroundings manage actual problems and emotions.

The objectives were:

- To conduct a literature review which would contribute research-based knowledge around factors relevant for coping in advanced cancer patients from a patient perspective and also could give occasion to clarify and put in perspective analytical reflections in relation to the development of the current Grounded Theory.
- Based on the empirical data, to identify and describe conditions that, from a patient perspective, are significant for coping in advanced cancer patients.
- Based on the empirical data, to identify and describe processes that, from a patient perspective, are significant for coping in advanced cancer patients.

4 ‘Coping’ as a theoretical framework of understanding.

Because ‘coping’ constitutes the research project’s overall theme, it is essential to account for the employed approach to the concept (Olsen 2002). However, within a Grounded Theory research tradition challenges can arise in applying a predefined theoretical framework of understanding, when the focus in the method is to derive an inductive-based theory that ideally emerges from the data (Charmaz 2006, Bryant and Charmaz 2007, Glaser and Strauss 1967). The challenges will be discussed in Section 7.1.3.1. In this section I will start with a short account of the three different theoretical understandings of coping. Then I will describe in more detail the applied approach to coping.

4.1 Coping in a theoretical perspective

Existing research around coping is varied in its understanding of what constitutes ‘coping’. Among first generation coping theorists and researchers (Livneh 2000), however, there is broad agreement that coping embraces actions whose intention is adaption to stressful situations. In addition, coping covers an evaluation of both the internal and external resources available to manage stress-related problems – see for example Lazarus and Folkman (1984), Billings and Moos (1981) and Pearlin and Schooler (1978).

Another approach to coping focuses on personal characteristics that apparently are critical to whether some people are better than others at withstanding harmful effects of stress. Among these personal characteristics are ‘hardiness’ (Kobasa *et al.* 1981), ‘self-efficacy’ (Bandura 1997, Bandura 2006) and ‘sense of coherence’ (Antonovsky 1987). This approach to coping is termed resilience research in some cases (Lazarus 1993, Zand 2007).

Furthermore, there is thought to be a tendency in coping research that apparently has many features in common with resilience research, but which at the same time is particularly

cognisant of how positive feelings can have a protective function in relation to mental and physical health (Folkman and Moskowitz 2000, Folkman 2009, Seligman and Csikszentmihalyi 2000). Coping processes which are associated with positive feelings are, for example, 'Posttraumatic growth' (Tedeschi and Calhoun 2004), self-regulation of goals (Wrosch *et al.* 2003) and meaning-focused coping (Folkman and Moskowitz 2000).

This diversity in the understanding of 'coping' underlines the necessity that, as a researcher, I account for the approach I use in the current project.

4.2 The approach to coping applied in this project

In the project Lazarus and Folkman's theory on the connection between stress, emotions, appraisal and coping is used as the theoretical approach to 'coping' (Lazarus and Folkman 1984, Lazarus 1999). Thereby I have chosen to use an understanding of coping that is inscribed among first generation coping theorists and researchers (Livneh 2000). The choice is founded on the fact that theirs is a well-documented theory which stringently describes the processes involved in coping. Furthermore, the theory lays significant weight on the interplay between the individual and their environment, which is in line with the epistemological approach upon which the empirical study is based – cf. Section 6.1.1.

Lazarus and Folkman define coping as 'constantly cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman 1984, pg. 141, Lazarus 1999, pg. 110) or put more simply, 'coping is the effort to manage psychological stress' (Lazarus 1999, pg. 111). According to Lazarus coping will always be linked to emotions, which can help to tell something about the relation between the person and their environment (Lazarus 1993, Lazarus 1999). Thus, emotions are considered as a conceptual unit, which forms part of the

overall theory's three main processes: the stress process, the appraisal process and the coping process.

'The stress process' refers to the adaptation problems that intrude as a consequence of difficult conditions in life. The theory distinguishes between three different forms of stress: injury/loss, threat and challenge. Each form of stress is activated by different physical, mental and psychosocial situations or actions, which are also referred to as stressors (Lazarus 1999, pg. 32-33).

'The appraisal process' refers to a person's evaluation of a stressful meeting between the individual and their surroundings. The appraisal process can be either conscious or unconscious. There is a distinction between two forms of appraisal: primary and secondary appraisal. Primary appraisal deals with an evaluation of what the situation means for the individual, while secondary appraisal deals with an evaluation of the opportunities the individual has to act in relation to the experience imbalance (pg.75-80). Relational meaning is an essential part of the appraisal process, which refers to a constant interaction between personal and environmental factors. An essential point is, however, that even though there is talk of interaction between the person and their environments, it is the person themselves who in the end judges what the situation means for her/him (pg. 60).

'The coping process' consists of two main functions: a problem-focused function and an emotion-focused function. The problem-focused capacity is based on the search for information and support that contributes to the choice of specific actions, which can change the problematic person-surroundings relationship. The emotion-focused capacity is directed towards expressing, controlling and reviewing the emotions linked to the stressful situation, and reconciling oneself to the basic circumstances that cannot be changed in the situation. Both main functions may be divided into several coping factors (which elsewhere

are also described as ‘families of coping’ – see Skinner *et al.* (2003), which again can be classified as specific coping strategies (pg. 110-117).

In the current research project the chosen coping theory is applied to a range of specific contexts, e.g. in connection with a requisite categorisation of data in the literature review – cf. Section 5.3.6, and in connection with the design of the interview guide, which was used in the empirical study – cf. Section 6.2.5. In Section 7.2.5 it is discussed how the results of the research project are thought to prepare the way for future research around coping in advanced cancer patients to adopt a more nuanced understanding of coping than is used in the current project.

5 Literature review process

Seen in relation to the project's overall aim, cf. Section 3, the intention of the literature review was two-pronged. The results of the review should both contribute research-based knowledge on factors relevant of coping in advanced cancer patients and allow for more detailed and analytical reflections in relation to the development of a Grounded Theory. In order to fulfil both intentions the review was conducted at the same time as the first interviews and analyses in the empirical study. The strengths and challenges linked to conducting the review side by side with the empirical study are discussed in Section 7.2.1.

In the presentation of the review below I state the aim of the review as it is described in Article I, the theoretical framework used, the methodological approach and the analysis process. In conclusion, the significant results are mentioned; these are further described in Article I.

5.1 The aim of the review

The aim, as described in Article I, was to identify characteristics that are considered to describe coping in advanced cancer patients, as seen from a patient perspective. Based on the identified characteristics the second aim was to identify potential factors which are relevant to coping in advanced cancer patients.

5.2 Theoretical framework of understanding

In recognition of the diversity of approaches to the field of coping, I chose, as described in Section 4.2, to apply Lazarus and Folkman's theory on the connections between stress, appraisal, coping and emotions as the theoretical framework of understanding in

the review. A particular strength of using Lazarus and Folkman's theory was that it underpinned the opportunities for methodological stringency and transparency (Olsen 2002). The theoretical frame of reference was thus drawn upon at many stages of the review process, e.g. in connection with determining the search strategy; in evaluating to what extent the results from potentially relevant articles were relevant for coping in advanced cancer patients; as a categorisation tool in the first part of the analysis and synthesis process and in the discussion section.

5.3 Methodological approach

In order to get as detailed a picture as possible of the characteristics of coping in advanced cancer patients, and also because research in coping in advanced cancer patients has shown to be characterised by wide methodological diversity, it was necessary to formulate a review that would include both qualitative and quantitative studies. It transpired that the guidelines from the Centre for Review and Dissemination (2001) could be used in carrying out a systematic and stringent literature review which would fulfil the aim. The chosen method is discussed in Section 7.1.1. Based on the chosen methodological approach the review was conducted in eight phases: Review questions, Search strategy, Inclusion/exclusion criteria, Review sources, Quality assessment, Extraction of data, Analysis and Synthesis, and Conclusion. The eight phases are also used as the framework for the description of the review below.

5.3.1 Review questions

From the aim of the review two review questions were prepared, which were significant in relation to the formulation of the analysis process, cf. Section 5.3.6.

- Which characteristics describe advanced cancer patients' coping, as seen from a patient perspective?
- On the basis of the characteristics brought to light, which potential factors are thought to be relevant to coping in advanced cancer?

5.3.2 Search criteria

With a focus on the period between January 1996 and June 2007 searches of the following databases were conducted: Pubmed, Psychinfo and CINAHL. Based on the research questions, the following search criteria were used: coping, advanced cancer and incurable cancer. These were combined with: factors, coping strategies, coping mechanisms, coping capacity, palliation, stress, stress management, distress and appraisal – cf. Appendix I.

5.3.3 Inclusion and exclusion criteria

Articles were included in the review if they met the following criteria:

- Published in a peer-reviewed journal
- Explicit research methods were described
- Objectives and results from the study were directly relevant to coping in advanced and incurable cancer
- Took a patient perspective

Articles were excluded from the review if they were:

- Not written in the English language
- Not focused on patients with advanced or incurable cancer
- Not focused on the diversity of problems experienced by advanced cancer patients

(World Health Organization 2002)

5.3.4 Review sources

In all, 30 out of 746 articles were included - see Table 1 in Article I, pg. 4. 716 articles were excluded because:

- 461 articles did not focus on the diversity of problems experienced by advanced cancer patients (World Health Organization 2002), but instead on isolated issues, such as, for example, pure biomedicine, pain or religion
- 240 articles did not focus on patients with an advanced or incurable cancer disease
- 5 articles were not published in peer-reviewed journals
- 10 articles appeared to be duplicates of other articles already included

5.3.5 Assessment of articles and extraction of data

In advance of the extraction of relevant data, I undertook a systematic assessment of each article with a view to ensuring that the inclusion criteria were respected. The assessment was based on recognised quality assessment tools (Public Health Resource Unit 2007, Malterud 2008, Malterud 1993) and on a matrix that was developed ahead of the assessment process, and which was partly based on Lazarus and Folkman's understanding of coping (Lazarus and Folkman 1984, Lazarus 1999). The latter helped to create clarity regarding relevant 'coping characteristics' – cf. Appendix II. In situations where there could be doubt about the extent to which results were relevant or not, the assessment process was discussed with another

researcher. Following the assessment I extracted relevant data from the 30 included articles. The relevant data were inserted into a matrix consisting of six columns, where the fifth column shows the extracted coping characteristics – cf. Table 2 in Article I, pg. 5-9.

5.3.6 Analysis and synthesis of relevant data

The analysis and synthesis process was in two parts. The first part referred to the first research question, which dealt with which characteristics that describe coping in advanced cancer patients see from a patient perspective. In this part of the analysis the extracted results were systematised and thereafter categorised into three categories, on inspiration from Whitemore and Knafl (2005), each of which was based on Lazarus and Folkman's understanding of coping (Lazarus and Folkman 1984, Lazarus 1999):

- Category A: Characteristics primarily reflect *stressors*
- Category B: Characteristics primarily reflect *factors relevant to the patients' appraisal* of their combined illness and life situation
- Category C: Characteristics primarily reflect *coping strategies* used.

This breakdown was necessary because early in the analysis process it became clear that the results that treated coping strategies could not immediately be compared, for among other reasons because they were based on different measurements and questionnaires.

As a researcher I therefore was faced with several well-known methodological challenges in coping research – see e.g. Somerfield and McCrae (2000) and Folkman and Moskowitz (2004). In order to meet the challenge I developed – inspired by Livneh (2000) and De Faye *et al.* (2006), a hierarchical coping system – cf. Table 3 in Article I, pg 10. Before placing the individual coping strategies in the hierarchical coping system, it was necessary to conduct a careful comparison of the extracted coping strategies,

whereby the relation between the individual coping strategies became more obvious. In addition, in my endeavour to classify the extracted coping strategies I used a combined ‘top-down’ and ‘bottom-up’ approach (Skinner *et al.* 2003), which was found to be both complex and time-consuming, albeit relevant, because in the end it meant that in the second part of the analysis and synthesis process I was in a position to undertake a systematic analysis of the extracted coping characteristics – including coping strategies.

The second part of the analysis and synthesis process refers to the second research question, which treated the different potential factors that are thought to be relevant to coping with an advanced cancer. This part of the analysis and synthesis process was inspired by inductive content analysis (Elo and Kyngas 2008), where the categories are derived from data.

The analysis material consisted of the 160 coping characteristics that were extracted from the included articles. The analysis and synthesis process was carried out in two phases. In the first phase all the coping characteristics were collected in a matrix to make clear what each individual characteristic covered. The collected matrix was read through several times while headings and notes were written in the margin, which described different aspects of the content. In the second phase all the headings and notes were compared, organised and grouped, whereby it was possible to divide the extracted coping characteristics into seven meaningful categories, which were based on the empirical material and which represented potential factors significant to coping in advanced cancer patients. The seven factors can be seen in Table 4 in Article I, pg. 11.

5.3.7 Seven potential factors – results from review (Article I)

The results brought to light seven potential factors significant to coping in advanced cancer patients: ‘Creating meaning’, ‘Support systems’, ‘Minimising the impact of cancer’, ‘Bodily and mental functioning’, ‘Control’, ‘Uncertainty’ and ‘Emotions’. The results indicate that emotion-focused coping may be used more often by advanced cancer patients than problem-focused coping. However, it cannot be ruled out that this finding relates to a nomenclature of coping function that is too limited. Furthermore, the results indicate that the seven potential factors may be related to both the appraisal process and the coping process. The results of the literature review are further detailed in Article I.

6 The empirical study

The overall aim of the project was to develop a Grounded Theory with focus on the central characteristics in coping in advanced cancer patients, and which, from a patient perspective, are significant to how patients in interaction with their surroundings manage actual problems and emotions. The term Grounded Theory can refer both to the *method* that is used in the research process and to the result of the research process, i.e. a Grounded '*Theory*'. According to Bryant and Charmaz a Grounded Theory deals precisely with 'A Theory that has resulted from the use of the Grounded Theory Method. In common parlance, however, the term refers to the method itself (Bryant and Charmaz 2007, pg. 3). In order to achieve the greatest possible clarity, I have chosen to explicate in several places reference to either the theory: Grounded Theory (GT) and to the method: Grounded Theory (GTM). A GT can be both *formal* and *substantive* (Glaser and Strauss 1967, pg. 32). In this context I am interested in the development of a substantive theory – i.e. a theory that is concerned with an independent, empirical area (in this connection coping in advanced cancer patients from a patient perspective).

As the basis for the development of the substantive GT a qualitative interview study was conducted that gave the opportunity to generate data based on the patients' experiences and appraisal of the problems and emotions they related to their specific situation (Kvale and Brinkmann 2009). The description of the work towards the development of a GT is in two parts. First I describe the overall methodological approach from an epistemological and a methodological perspective, respectively. Then I describe the course of the empirical study – hereunder inclusion considerations, interviews and analysis process. In conclusion the important results from the empirical study are mentioned, and which are further detailed in Articles II and III.

6.1 The overall methodological approach of the study

I chose to base the overall methodological approach on a Strauss and Corbin-inspired approach to the GTM (Corbin and Strauss 2008, Strauss and Corbin 1998). The reason for the choice is that the method Grounded Theory allows for an uncovering and description of central characteristics in coping in advanced cancer patients, which have significance for how the patients deal with actual problems and emotions in interaction with their surroundings, in that the method places particular focus on actions and interactions in and between individuals (Charmaz 2006, Corbin and Strauss 2008, Glaser and Strauss 1967, Strauss and Corbin 1998). Furthermore, a particular coding layer in a Strauss and Corbin-inspired methodological approach called 'axial coding' (which is further described in Section 6.1.2 and Section 6.2.7.2) allows for intense coding around significant categories, whereby it is thought to be possible to uncover and describe conditions and processes significant to coping (Corbin and Strauss 2008, Strauss and Corbin 1998)- cf. the objectives of the research project in Section 3. As the chosen Strauss and Corbin approach is often referred to as 'Straussian Grounded Theory' - see for example Kelle (2007) - I have chosen to use the term where I considered it relevant, since it maintains a necessary distinction between several different GTM approaches (Morse *et al.* 2009).

6.1.1 Straussian GTM from an epistemological perspective

Straussian GTM takes as its starting point the philosophy of pragmatism and the tradition of Chicago interactionism (Corbin and Strauss 2008). To show the epistemological roots Corbin and Strauss put forward a series of 'assumptions', which are specific extracts from Dewey's (Dewey 2009) and Mead's and Blumer's work

(Blumer 1998). The authors consider the series of assumptions as '*working axioms that lie quite specifically behind our conception of methodology*' (Corbin and Strauss 2008, pg. 6). These assumptions make it clear that Blumer's understanding of symbolic interactionism Blumer (1998) has had particular influence on Straussian GTM. On this background I have chosen to emphasise three foundational premises for symbolic interactionism, each of which underpins the method (Blumer 1998):

1. Human beings act towards things on the basis of the meanings that the things have for them.
2. The meaning of these things arises out of the social interaction between people.
3. These meanings are handled in, and modified, through an interpretive process used by the person in which he by communicating with himself deals with the things he encounters.

The three premises show how human actions are dependent on meaning, which occurs in the interaction between people. Furthermore it becomes obvious how human actions are considered as being firmly rooted in people's coping with the world and are not seen as a product of factors, each of which constitutes action. On the contrary, human actions constitute a social product that occurs through a process of self-interaction. Thus there is thought to be broad agreement between the understanding of the relation between the individual and their surroundings, which is expressed in as well the chosen method's epistemological foundation and as in the chosen approach to coping – cf. Section 4.2.

Apart from the fact that Straussian GTM has roots in pragmatism and Chicago interactionism, Corbin (2009) acknowledges that she has over time become influenced by a constructivist-inspired approach to GTM (Charmaz 2006), in that she is of the opinion '*that concepts and theories are constructed (they don't emerge) by researchers.*

Out of these multiple constructions, analysts build something that they call knowledge' (Corbin 2009, pg. 39). Thus, Corbin breaks with a central criticism of the classical GTM (Glaser and Strauss 1967), whose pivot point has been the extent to which it is possible for a theory to 'emerge from data' – cf. e.g. Kelle (2006).

6.1.2 Straussian GTM in a methodological perspective

In line with other GTM approaches, a very central element of Straussian GTM is that *categories* are developed or constructed from the data, i.e. groups of concepts that represent relevant phenomena, and which allow the researcher to reduce and combine data (Corbin and Strauss, pg. 159). This happens without it being necessary for the researcher to force data in a certain direction (Strauss and Corbin 1998, Corbin and Strauss 2008). Also in line with the other GTM approaches it is required that the researcher shows *sensitivity* during the entire analysis process, i.e. the capacity to detect relevant themes, problems, relations and occurrences in the data, by using, among other things the experience and theoretical insight researchers carry around (Corbin and Strauss 2008, pg. 32-33).

A particular characteristic of Straussian GTM is the use of a 'new' coding step called 'axial coding', which from an analytical perspective fits between the classical coding steps open coding and selective coding (Corbin and Strauss 2008, Strauss and Corbin 1998) – cf. Section 6.2.7.2. The strength in using axial coding is that it allows the researcher to undertake intense analyses around a category, which at the given moment represents an axle in the ongoing theory construction, and thereby *apparently* holds a special position in the further theory development process (Strauss and Corbin 1998 pg. 123). A second characteristic of Straussian GTM is the recommendation that

the researcher makes use of both a series of specific questions – the coding paradigm – as an actual tool, called 'the Conditional/Consequential Matrix' or 'the Matrix'. Both the coding paradigm and the Matrix are based on a pragmatic and symbolic interactionist frame of reference and can help the researcher in different ways to discover contextual relations between the developed categories (Strauss and Corbin 1998, Corbin and Straus 2008). A third characteristic of Straussian GTM is that the method lays the ground for the researcher – apart from coding for properties, i.e. '*characteristics that define and describe concepts*' (Corbin and Strauss 2008, pg. 159), which are also coded for in other GTM approaches – also to be able to code for dimensions – i.e. '*variations within properties that give specificity and range to concepts*' (pg. 159). Strengths and challenges in relation to the specific use of Straussian GTM are discussed in Section 7.1.2.

6.2 The empirical study process

The empirical study encompassed several phases: planning, inclusion of patients, interviews and analysis. The different phases merged with each other, which was a condition of the overall methodological approach, because the analysis was started as early as the first interview and the inclusion phase continued until theoretical saturation was achieved (Corbin and Strauss 2008). For the sake of clarity, I have however chosen to describe the study as a linear process and therefore begin the presentation with the ethical considerations which were made in connection with the planning of the study. I will finish with a short presentation of the results of the study. In addition I have chosen to draw upon different experiences, reflections and choices which I as a researcher have been through in connection with the accomplishment of the empirical study (Corbin and

Strauss 2008, Kvale 1997). The communicative validity and workmanship of the study is discussed in Section 7 and also the study's pragmatic validity is described in Section 9 (Corbin and Strauss 2008, Kvale 1997, Kvale and Brinkmann 2009, Olsen 2002).

6.2.1 Ethical considerations

Research around advanced and incurable ill cancer patients can bring up pertinent ethical issues. One of the issues is the extent to which it is an unnecessary burden for patients to participate in a project, where on the one hand they contribute with worthwhile knowledge, and on the other hand can be brought into a situation where emotional reactions can arise (Davies *et al.* 1998, Wilkie 1997). Research shows, however, that the strain advanced and incurable ill cancer patients can experience in connection with participating in research-based interviews is often counterbalanced by the opportunity to tell someone – who is willing to take the time to listen and will keep their confidence unless they wish their story to be told – about situations that concern them most at the time (Barnett 2001, la Cour 2008, Hansen 2003). In this study interviewees were asked how they experienced being interviewed. All patients described the positives in having the opportunity to talk about the things that were on their minds in their specific situation without being put under time pressure, and even though they were emotionally affected by the situation during the interview. Furthermore, all patients were informed that if they felt they needed further support, they would be given guidance about how to get help from the existing support organisations for cancer patients.

A second issue is that, in the interview situation, the researcher enters into a relation with the participant that on the one hand is about winning the participant's

confidence and trust, and on the other hand represents a power to steer the conversation in a direction that the participant can experience as crossing a boundary (Kvale 1997). In order to handle this duality, I assured myself in advance of every interview that the patient was both informed about the intention of the interview and about their role in the interview, including that there were no correct or incorrect answers to my questions. The patients were likewise informed that they could at any time break off the interview without any consequences for their treatment. Furthermore, I ensured that my professional status and attitudes would not be expressed in front of the patients and that I pointed out to them that my role as a researcher was entirely independent of the patients' and the professionals' other relationships. In order to ensure that all participants knew their rights, it was ascertained both verbally and in writing that they could at any time break off the interview, and that their statements would be treated confidentially and anonymously. Informed consent was obtained from each participant - cf. Appendix III. The study was approved by the local Scientific Committee under no. KF 01297281 and was accepted by the Danish Data Protection Agency.

6.2.2 Selection procedure

A set of specific inclusion criteria was used in the selection procedures. Patients should be over 18, born in Denmark and speak Danish. Furthermore it should be clear in the patient's journal that continued treatment would be palliative in nature or that at least one course of treatment for relapse did not have a satisfactory effect on the cancer illness. Furthermore, the patients should have a life expectancy of at least three months, based on professional assessment. Finally, before each interview the patients should score 24 points or more in Folstein's "Mini-Mental State Examination" (MMSE), which

is established as a screening test in relation to cognitive function in cancer patients (Folstein *et al.* 1984). Patients who scored less than 24 points would be excluded from the study, which however did not occur in this project. Before using the MMSE I explained to each patient that the questionnaire was to ensure that patients would not be involved in the research project if it was demonstrated that their capacity to express themselves clearly was affected by, e.g. tiredness or the effects of medication. This would pose the risk that patients would make statements that they later perhaps would not stand over. There were no comments from patients about the use of MMSE.

Based on the requirement of the overall method that data generation and analysis should occur simultaneously and not be treated separately (Glaser and Strauss 1967, Strauss and Corbin 1998), the inclusion criteria were supplemented with four selection principles (Morse 2007). One of the principles was *availability*, which meant that the first patients were chosen consecutively as they were identified by the departments involved. A second principle was *variation*, both in cancer types and socio-demographically. The two principles informed the initial strategic sampling, which made possible the development of a grounded theory, which goes beyond certain illness groups, gender and social groupings. A third principle was *development over time*, which allowed for time-related variation in coping to be studied, as the patients were interviewed three times at approximately one month's interval, on condition that they had enough energy and their illness allowed it. A fourth principle was *theoretical sampling* (Corbin and Strauss 2008, Morse 2007, Strauss and Corbin 1998) where patients were chosen according to the descriptive needs of the emerging categories and theory. By using the principle 'theoretical sampling' it was possible to study specific aspects of the developed categories. Thus 'theoretical sampling' underpinned the

assessment of when new data no longer led to new theoretical insights or no longer disclosed new properties in relation to the theoretical categories – i.e. the point when 'theoretical saturation' was achieved (Strauss and Corbin 1998, pg. 143).

The clinical inclusion process was shown to be linked to several 'inclusion challenges'. One such challenge related to identifying where exactly the patients were. Potential participants at the general medical and surgical units – the nominated inclusion sites – were often too ill to fulfil the inclusion criterion of a life expectancy of at least three months. It was therefore necessary to include two large oncological units, to which patients were attached while under treatment and from which they were moved only when assessed as being in the terminal phase.

A second challenge was linked to my access to the patients. From the start I chose to include health professionals in the selection process – for example by in some situations allowing a person known to the patient to contact the patient in the first instance. The reason was that I could thereby avoid putting particularly vulnerable people under the strain that can be linked to the choice to decline participation. I experienced, however, that health professionals in many instances acted as 'gatekeepers' – i.e. that they declined on the patients' behalf without consulting with them first – cf. e.g. Preston *et al.* (2009). This experience meant that, over time, I more and more often personally sought out the patients to ask if they wished to participate in the project. These two inclusion challenges can help explain why the principle *theoretical sampling* was shown to be difficult to conduct with this group of patients – cf. e.g. the discussion in Section 7.1.3.2.

6.2.3 Participants

In the period June 2006 – March 2009, 23 patients, admitted to seven selected oncological, medical and surgical departments in the Capital Region of Denmark were invited to participate in the study. Of these, 11 patients did not wish to participate: seven because of tiredness, one due to breathlessness, one considered that it disturbed her control over her situation, two preferred to use their strengths on other activities, one died before the first interview, and one patient was excluded because of confusion. All together 10 patients consented to participate in the study. Subsequently, theoretical saturation was judged to have been achieved. Socio-demographic information on the 10 patients can be seen in Table 1.

No .	Gender	Age	Type of Cancer	Length of time since diagnosis	Marital Status	Children < 18 år	Social Group
1	f	65	pulmonalis	3 months	married	0	IV
2	m	49	lymphoma	8 months	divorced	0	V
3	f	80	coli	2 years	married	0	III
4	f	43	pancreas	15 months	divorced	1	III
5	f	47	rectum	3 years	married	2	II
6	m	80	prostate	2 years	married	0	I
7	m	72	pulmonalis	1½ years	divorced	0	IV
8	m	43	cardia/ ventriculi	10 months	married	2	I
9	m	59	coli	3½ years	divorced	0	IV
10	m	72	coli	1 month	married	0	II

Table 1: Socio-demographic information about the included patients. The final column, 'Social Group' refers to a Danish developed measure of social status in relation to placement in 'higher' or 'lower' social strata (Hansen 1984). 'I' represents the highest social strata.

6.2.4 The interviews

A total of 18 interviews were carried out. Interviews lasted between 45 minutes and two hours (mean 75 minutes). All interviews were recorded on a minidisc and later transcribed verbatim. I transcribed the first eight interviews. The transcription process

gave great insight into nuances in the individual interviews, including how patients reacted to specific questions, together with pauses and tone. The remaining ten interviews were transcribed by another person, who had been given transcription instructions. As researcher I subsequently assessed the quality of the transcriptions by comparing them to the sound files. The interviews were carried out where the patient was accommodated at that time; either in hospital, at home or in a hospice – cf. Table 2.

Patients	Gender	Number of interviews	Reason for cessation of participation	Period between last interview and death	Venue for interview
1	Female	1	Tiredness	3 weeks	Hospital
2	Male	1	Cognitive Impairment	2 months	Hospital
3	Female	3	Design	3 months	Home
4	Female	2	Death	3 weeks	Hospital/ Hospice
5	Female	3	Design	7 months	Home
6	Male	1	Death	1 week	Hospital
7	Male	1	Cognitive Impairment	3 months	Hospital
8	Male	1	Death	3 weeks	Hospital
9	Male	2	Tiredness	8 weeks	Home/ Hospice
10	Male	3	Design	4 weeks	Home

Table 2: Interview characteristics

6.2.5 Interview guide

I was the interviewer for all the interviews, which gave a good sense of connection between the interviews, and allowed for follow-up of specific themes, in the cases where the patient was interviewed on more than one occasion. By including questions from a semi-structured interview guide in the conversation I ensured that relevant knowledge was obtained around relations significant to coping in advanced cancer

patients (Corbin and Strauss 2008, pg. 152, Charmaz 2006, pg. 29). The semi-structured interview guide was inspired by Lazarus and Folkman's understanding of the connection between emotions, problems, appraisal and coping (Lazarus 1999, Lazarus and Folkman 1984) and the following themes were included in the questions: Actual problems and emotions, appraisal of limitations and resources, specific handling of the problems, knowledge and experience, prevention and hope– cf. Appendix IV. With reference to the literature around methodology, the semi-structured interview guide was over time nuanced and changed in places that made it possible to construct and validate the categories and connections between categories that came to light in the analysis process (Charmaz 2006, pg. 29-32).

6.2.6 Interview situation

As interviewer, I was careful to ask open questions that encouraged the patients to elaborate the themes introduced in the interview guide, in such a way that they could in their own words describe their experiences of evaluating and coping with specific issues and feelings. Thus, I endeavoured to give space to the patients to tell their own stories based on the framework of the interview guide (Charmaz 2006, Corbin and Strauss 2008). I was also careful to check agreement between what was said and my own understanding of the words, especially when implicit or unclear descriptions came up. This was done by e.g. requesting the patients to clarify their descriptions, for example by using questions such as 'It is correct that you ...' (Kvale and Brinkmann 2009). Furthermore, silence was actively employed in the interviews. Based on the methodology literature I took silence as an opportunity to leave space for the patient to make associations and reflections (Charmaz 2006, Kvale and Brinkmann 2009). My

premise in doing so was underpinned in specific interview situations, in that, after a short or long pause the patients came up with new themes that were of uttermost relevance, but which demanded both trust and a lead-in to delve into.

In addition, I was aware of the emotional and physical signals from patients and made continuous assessment of how I as an interviewer should react to the signals (Corbin and Strauss 2008, Fog 2007). In several situations I found it therefore necessary to break off the interview and only continue recording when the patient said they were ready. Similarly in two situations I judged that the patient was so tired that it was not appropriate to continue the interview.

6.2.7 Analysis process

The analysis process was based on 'Straussian GTM' – cf. Sections 6.1.1 and 6.1.2, which recommends that the analytical process is carried out in three steps: *open, axial and selective coding*. The three analysis steps are detailed below, together with a description of how the specific analysis was addressed.

6.2.7.1 Open coding

According to Corbin and Strauss 'open coding' can be defined as: '*Breaking data apart and delineating concepts to stand for blocks of raw data. At the same time, one is qualifying those concepts in terms of their properties and dimensions*' (Corbin and Strauss 2008, pg. 195). In this way open coding allows for an 'opening' of the text by dividing it into smaller units which are then studied in detail and compared, in order to discover similarities and differences (pg. 102).

In the current study open coding was initiated immediately after completion of the first interview. The whole text (interview) was read through to get an overview over what the text was about (Corbin and Strauss 2008, pg. 163). Then the text was divided into smaller meaning units, which consisted of short sections or individual sentences, each of which represented themes, actions and interaction significant to coping in advanced cancer patients. Each unit was allocated its own code, e.g. 2.2.56, which related to patient number (2), interview number (2) and unit number in the respective interview (56). This made it possible always to trace a meaning unit back to its original context. By posing questions to each meaning unit (Strauss and Corbin 1998, pg. 74) it was possible to specify what the unit was about, which was immediately noted in relation to the meaning unit. Furthermore, I employed constant comparison between meaning units (Strauss and Corbin 1998, pg.78), by which I discovered significant similarities and differences between the contents of the units. Thereby I could gradually identify preliminary concepts, which with Strauss and Corbin represented the building blocks of the theory (Strauss and Corbin 1998, pg. 101). As the analyses took shape, the concepts were concentrated more and more on the most functional and stable concepts, which over time accumulated to 'higher levels concepts', which according to Corbin and Strauss is the same as categories (Corbin and Strauss 2008, pg. 159). Appendix V shows an example of open coding. To support the open coding I wrote memos whenever I found it relevant - i.e. written notes that made it possible to maintain and systematise ideas and analytical insights around relations, processes and theoretical abstractions, which over time could gain significance for the development of the substantive GT (Corbin and Strauss 2008, Lempert 2007, Strauss and Corbin 1998).

The constant comparisons between meaning units, concepts and categories, that constituted a main feature in the open coding and continued throughout the analysis process, presented a potential danger that I would lose the overview over which meaning units constituted the individual categories. Therefore I developed a matrix that made it possible to maintain the connection between meaning unit and categories. Furthermore the matrix was used to pinpoint the properties and dimensions of the category, cf. Appendix VI. Moreover, I created set of computer-folders that were named after the developed categories. Meaning units that constituted the individual categories were hereafter saved in the respective folder – cf. Appendix VII. By using these two tools I was in a position to maintain stringency and transparency despite the, at times, rather complex coding phase.

6.2.7.2 Axial coding

Strauss and Corbin define axial coding as: *'The process of relating categories to their subcategories, termed 'axial' because coding occurs around the axis of a category, linking categories at the level of properties and dimensions'* (Strauss and Corbin 1998, p. 124). Although the intentions of axial and open coding were different, it was never a case of sequential steps but on the contrary two analysis steps that constantly meshed with each other, in that during the open coding there was often a feeling of how the categories related to each other. Corbin and Strauss (2008) recommend that in this coding phase the analytic focus be placed on both *context* (which is also termed 'structural context' or 'structure' – see for example Strauss and Corbin (1998, pg. 192) and Strauss and Corbin (1998, pg. 123) - and *process*. Context is defined as *'structural conditions that shape the nature of situations, circumstances, or problems to which*

individuals respond by means of action/interaction/emotions (Corbin and Strauss 2008, pg. 87). Process is defined as: *The flow of actions/interaction/emotions that occur in response to events, situations, or problems. A change in structural conditions may call for adjustments in activities, interactions, and emotional responses....*' (pg. 87). Context and process can on the one hand be considered as two directions of analysis that both require different analytical tools and are in a position to demonstrate different theoretical dimensions in the analysis material just like '*a snapshot and a moving picture*' (Strauss and Corbin 1998, pg. 179). On the other hand the two analysis dimensions are very dependent on each which is showed in the final model of the developed GT – cf. Section 6.3.3.

In my efforts to code for context, I endeavoured to follow Corbin and Strauss's recommendations about including 'the Matrix' – cf. Section 6.1.2, which gives rise to both micro relations (those that are closest to the individual) and macro relations (those that are more at a distance to the individual, e.g. social and institutional relations) (Corbin and Strauss, pg. 91). It transpired however, that a specific use of the Matrix did not work properly for me, as the matrix appeared to be too rigid in its construction. I chose instead to design a 'coding tree' – cf. Appendix VIII - that offered the possibility of maintaining analytical focus on both the micro and macro relations in relation to coping in advanced cancer patients in a more flexible way. The coding tree was created manually by making notes about the relevant micro and macro relations in the tree, with a view to typing up the coding tree at regular intervals and saving it in a special computer-folder.

The methodological recommendations in relation to coding for process appeared not to be so specific, which is in part substantiated by the fact that '*process is*

an elusive term. It is as difficult to explain as it is to capture in data' (Corbin and Strauss, pg. 95). Nevertheless the process coding represents an essential part of the total analysis work, in that it represents *'sequences of actions/interactions/emotions changing in response to a set of circumstances, events or situations'* (pg. 98). Corbin and Strauss mention several advantages of analysing data for process. Partly it allows us to inject a kind of 'life' or movement into the relations between categories. Furthermore, process coding encourages the researcher to incorporate variation in the findings, which makes the researcher look for new patterns. Thus the process coding becomes an essential link in the development towards a substantive GT (pg. 100). My approach to coding for process was inspired by Corbin and Strauss to ask questions, e.g. 'What is happening here?', and 'What conditions and activities link a series of incidents with another series of incidents?' (pg. 100). Process coding was most clearly seen in specific memos which made it possible to describe the processes that cropped up, e.g. by posing the above-stated questions. In order to, among other things, maintain stringency and transparency in the process coding, I decided to create a form of overview which gave rise to a systematisation of relevant memos in relation to the developed categories. The overview was saved in a special computer-folder. I read the overview very regularly, and this helped to give me a clear picture of the processes which came into sight during the analysis process. At the same time the overview supported the documentation for the process coding.

6.2.7.3 Selective coding

According to Strauss and Corbin selective coding (which is also termed *integration* (Corbin and Strauss 2008, pg. 263)) can be defined as *'the final step in analysis – the*

integration of concepts [category] around a core category and filling in of categories in need of further development and refinement (Strauss and Corbin, pg. 236-237). In the same way that open and axial coding do not represent sequential analysis steps, neither is selective coding an isolated analysis step. On the contrary it is located parallel to the axial codings.

In the current study the selective coding led to me achieve over time sufficient theoretical insights to be able to pinpoint the category 'Doing things oneself' as the core category – i.e. the category that represented the main theme (Strauss and Corbin, 1998, pg. 146) or central tendency (my term) in the developed GT. The insight came partly as a consequence of the fact that the category emerged frequently in the data. Furthermore, I noticed over time that the other categories repeatedly related to 'Doing things oneself'. After the category was pinpointed as the core category, I chose to rename it 'Struggling to be a participant in one's own life', since I judged that this description more pertinently describes the very central theme in the developed substantive GT. The selective coding further gave me the opportunity to limit, nuance and refine the relations between sub-categories and the core category, which for example directed my attention to more remote connections between the core category and the sub-category 'alleviation from a life-threatening illness' (cf. Figure 1 in Section 6.3.3). It was therefore necessary both to go back in the analysis material and carry out yet another interview, which led to continuing the analysis work until the connection between the core category and the sub-category was completely clear.

As part of the selective coding I used the two analysis tools: memowriting and integrative diagrams. Memowriting made it possible to maintain 'the analytical story' (Strauss and Corbin 1998, pg. 148) that gradually came to the fore in the course of the

analyses. The integrative diagrams – i.e. abstract representations of data (Strauss and Corbin 1998 p. 153) – helped me from a visual perspective to focus on a logical integration between the core category and sub-categories. At the same time the integrative diagrams made it clear where the connections between the categories were insufficient or forced. The selective coding stopped when the analyses no longer led to important new properties, dimensions and connections in relation to the identified categories. Thus from a GTM perspective theoretical saturation were achieved (Strauss and Corbin 1998, pg. 143).

6.3 Results of the empirical study

The results of the empirical study are presented in two articles, *How to be apatient in a palliative life experience? A qualitative study to enhance knowledge about coping abilities in advanced cancer patients* (Article II) and *'Prioritising, downplaying and self-preservation: processes significant to coping in advanced cancer patients'* (Article III). In the two following sections the results from the two articles are outlined in summarised form. From the results detailed in Articles II and III I have developed a model that gives an overall picture of the developed GT. The model is presented in Section 6.3.3.

6.3.1 Four significant life conditions – results of the empirical study (Article II)

The aim of the article I was to identify and describe conditions that, from a patient perspective, are significant for coping in advanced cancer patients – cf. the objective of the project in Section 3. The results, which are further elucidated in the article, show how a central tendency in coping in advanced cancer patients was to struggle to be a participant in one's own life. This central tendency involved four significant life

conditions: Alleviation from a life-threatening illness, Carry on a normal life, Live with powerlessness and Find courage and strength. Each of the four life conditions was characterized by as well coping limitations as coping resources, which shows how coping was played out in a constant interaction between the patients and theirsourroundings. The relations between the central tendency and the four life conditions are depicted in Figure 1.

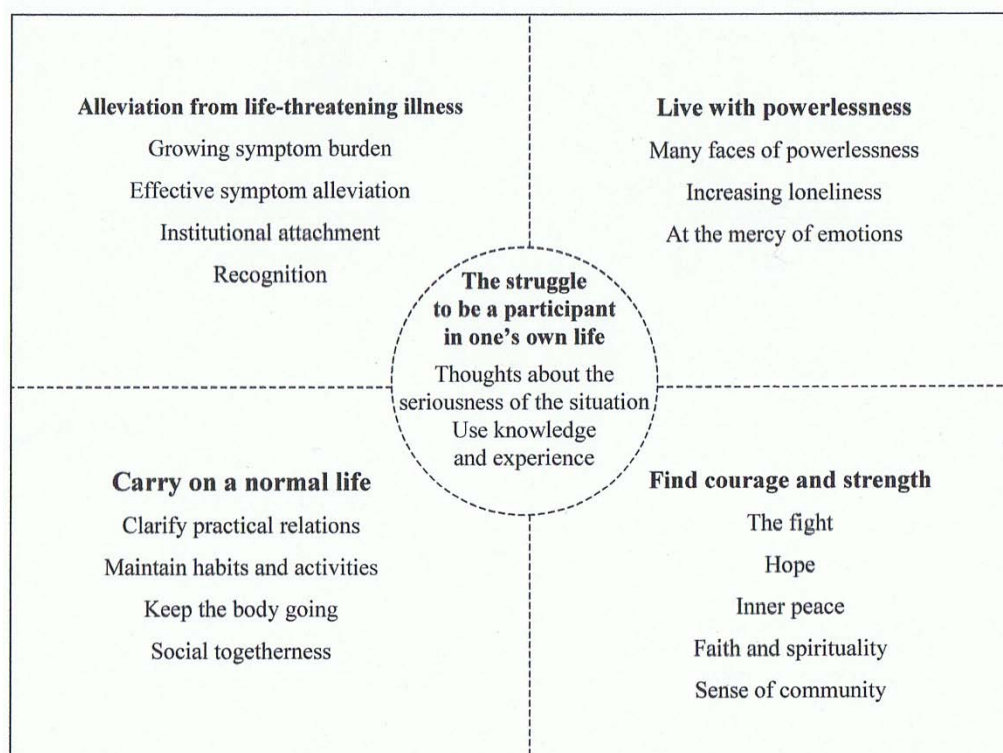


Figure 1: Model to illustrate the four significant life conditions each of which is characterised by as well coping limitations as coping resources. Furthermore, the model shows the connections between the central tendency in coping with advanced cancer and the four life conditions.

The results also showed how previously gained knowledge and experience was an essential resource for coping, which however, was clearly challenged as the situation the patients were in was unprecedented and therefore only a few patients had experienced anything similar before. The discussion made it clear that the central tendency

'struggling to be a participant in one's own life' could be considered as the way in which patients fought to maintain a certain control over life, despite their continually failing powers and the prospect that life would go on without them. Furthermore, social support from both relatives and professionals was thought to be crucial for patients to be able to maintain or re-establish the feeling of being a participant in their own lives.

6.3.2 Three processes – results of the empirical study (Article III)

The aim of Article III was to identify and describe processes that are significant to coping from a patient perspective – cf. the objective of the project in Section 3. The results, and in line with Article II, show how the central tendency of coping in advanced cancer patients was 'the struggle to be a participant in one's own life'. The results also showed how the central tendency involved three processes: the 'process of prioritising', the 'process of playing down' and the 'process of self-preservation' each of which emphasised coping as a constantly changing and dynamic process – cf. Figure 2. 'Prioritising' was shown to be a process where patients were active participants in relation to evaluating, prioritising and finally deciding which actions and interactions they considered appropriate coping efforts in their situation. 'Downplaying' showed how patients fought to play down the invasive influence of the illness on the lives they had built up over many years together with their relatives. 'Self-preservation' pointed to how patients set coping efforts in motion that made it possible for them to find the courage and strength necessary to live with the powerlessness that an acknowledgement of imminent death inherently brought to bear. The discussion indicated that the three processes allowed the patients to make use of meaning-based coping efforts which increased their experience of being a participant in their own lives.

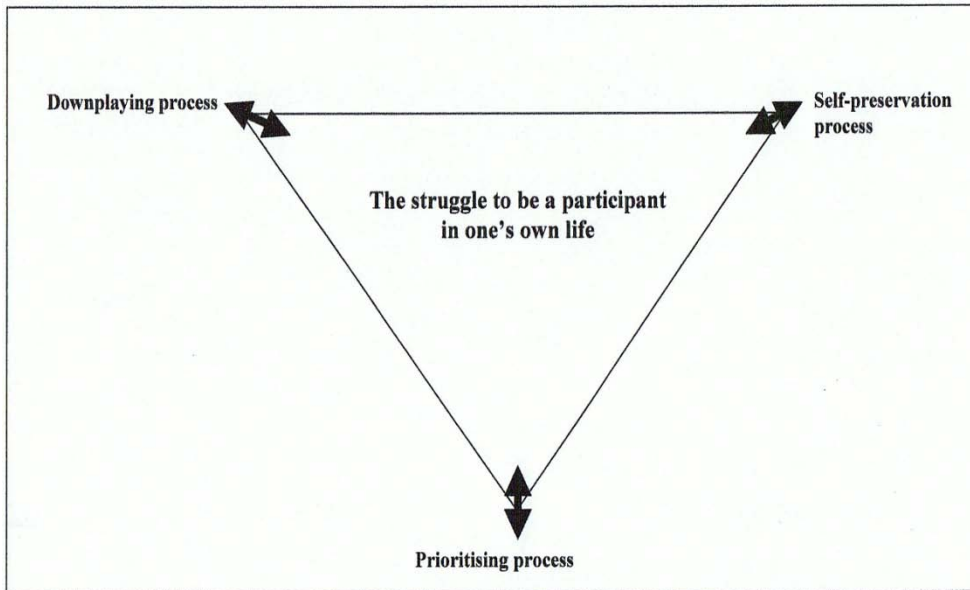
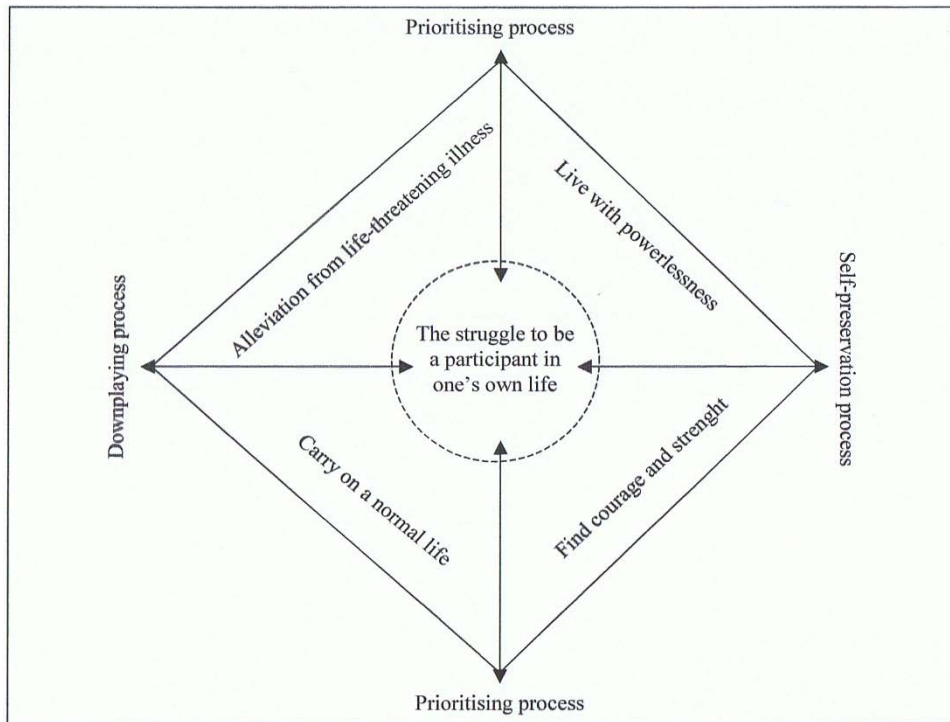


Figure 2: *Model to illustrate the pattern surrounding the central tendency in coping in advanced cancer which involves three significant processes.*

6.3.3 Model of the substantive theory developed from data

Based on the results of Articles II and III it was possible to construct a model that would illustrate the developed substantive GT - cf. Figure 3, pg.45. The model makes it clear how the central tendency, 'struggling to be a participant in one's own life', both involves four significant life conditions and three processes that, from a patient perspective, were significant to how patients with an advanced cancer illness cope with actual problems and emotions - cf. the overall aim of the project Section 3. The model furthermore illustrates how life conditions and processes on the one hand can be considered as characteristics of coping, each of which relates to the central tendency. On the other hand life conditions and processes are inextricably linked, which is illustrated in the model in the way the life conditions 'Alleviate life-threatening illness' and 'Carry on a normal life' underpin the process 'downplaying'. In the same way 'self-

preservation' is underpinned by both the life condition 'Living with powerlessness' and 'Find courage and strength', while the prioritising process is supported by all four life conditions. Thereby the model shows the complex coping-pattern developed from data.



Figur 3: Model to illustrate the connection between the central characteristics in coping in advanced cancer patients which constitute the constructed GT. Thereby the model points out the complex coping-pattern developed from data.

7 Discussion

This section is divided in two parts. In the first part the overall methodological approach employed in the literature review and empirical study is discussed. In the second part the most important results from the review and empirical study are discussed.

7.1 Discussion of method

The methods employed in the literature review and the empirical study are discussed, based on the aims and objectives of the research project - cf. Section 3. The method used in the empirical study is further discussed from a set of evaluation criteria, which is set out in Section 7.1.3.

7.1.1 Method employed in the literature review

The aim of conducting a literature review was two-pronged, in that the review was partly intended to contribute research-based knowledge around factors relevant of coping in advanced cancer patients from a patient perspective, and partly intended to allow me to detail and put into perspective analytical reflections in connection with the development of the current Grounded Theory. To fulfil the first part of the aim, I decided to base the review on guidelines from the Centre for Review and Dissemination (2001). The strength in this approach lies particularly in the fact that the method has a clear and well-described structure, which is immediately usable. In addition the method allows us to combine different forms of methodology in one review, which was considered necessary, since research that focuses on coping in advanced cancer patients involves both qualitative and quantitative studies. The weakness in the method is that the actual data synthesis phase in relation to reviews, which draws upon both qualitative

and quantitative methodologies, is only briefly described. It was therefore necessary to look to other review methods for further inspiration for this phase. Whitemore and Knafl (2005) description of the integrative review, which similarly allows for a combination of different methodologies, describes the analysis and synthesis phase in a more comprehensive way. The method description for example made it clear how it was essential to categorise and organise data before undertaking an actual data reduction or data synthesis, which would lead to identification of factors significant to coping. However, this method, too, left some analytical vagueness, and a usable synthesis method only came to light when I turned for inspiration to inductive content analysis (Elo and Kyngäs 2007), that rigorously describe an actual analysis process – cf. Section 5.3.6. Despite all my endeavours to maintain methodological stringency (Morse *et al.* 2002) and transparency (Olsen 2002), I must however conclude that – partly due to the methodological difficulties linked with compiling data emerging from the use of different methodologies (Folkman and Moskowitz 2004) – further research in the area would be needed before the seven identified factors could be considered to be validated and generalisable (Guba and Lincoln 2005). With this in mind, I chose to denote the identified factors as ‘potential factors’. The links between the results of the review and the development of the GT are discussed in Section 7.2.1.

7.1.2 Method employed in the empirical study

The overall aim of the empirical study was to develop a GT that would focus on the central characteristics in coping in advanced cancer patients and which, viewed from a patient perspective, are significant to how patients in interaction with their surroundings handle actual problems and emotions.

To achieve the aim I employed a Strauss and Corbin-inspired approach to the method Grounded Theory (Corbin and Strauss 2008, Strauss and Corbin 1998). The strength of the method was that, based on the empirical data, it allowed me to point to a series of different characteristics of coping – among which were significant life conditions, processes and a range of coping resources and coping limitations. The method also allowed for the identification of the connection between the different characteristics, whereby the complexity of coping in advanced cancer patients became clear. Thus it can be evaluated that the method made it possible to achieve the aim of the empirical study.

According to Kendall, one challenge in employing Straussian GTM can be that, particularly in relation to the intense codings in the axial coding process, such a large amount of analysis material is generated that the researcher can become distracted from engaging in a higher level of abstract thinking required in grounded theory analysis (Kendall 1999). In the current study I had to acknowledge many times during the analysis phase that, because of the large amount of analysis material, I found it difficult to carry out the abstractions necessary in the development of a GT. By focusing on memo-writing and integrative diagrams (Corbin and Strauss 1998, pg. 218), it became possible over time, however, to carry out the abstractions and thereby the creativity (Corbin and Strauss 2008, Strauss and Corbin 1998) and abductive reasoning (Charmaz 2006, Reichertz 2007, Strübing 2007), which are essential in the development of a GT.

One limitation of the method has been that, because the method is founded on a requirement of 'theoretical saturation' (Strauss and Corbin 1998, pg. 158) rather than on generalisability or transferability (Kvale 1997, Malterud 2008), it will be necessary for further research to be conducted in the field, as long as the results of the study can be

transferred to other substantive areas (Strauss and Corbin 1998). There is a further limitation of this method. Because the aim of the method is to develop a GT based on categories that are constructed from the data related to all the interviews, the GT does not state anything about coping patterns in the individual patient. Neither does it say anything about differences in coping patterns in men and women respectively or in patients who live at home, in the hospital or at a hospice. The theory can further be considered as both geographically and culturally restricted.

7.1.3 Criteria for assessment of the empirical study

According to Corbin and Strauss (2008) 'validity' and 'quality' are closely linked concepts in relation to evaluating qualitative research. However, because quality to a greater extent than validity is thought to express the innovative, well-considered and creative research components, which are used in Straussian GTM, Corbin and Strauss prefer 'quality' (pg. 305). Corbin and Strauss (2008) recommend that the assessment of quality is undertaken based on nine method-specific criteria: fit, applicability, contextualisation of concepts, logic, depth, variation, creativity, sensitivity and evidence of memos (pg. 305-307). According to Corbin and Strauss the nine assessment criteria are to be understood as guidelines, since conditions can arise that demand the inclusion of other assessment criteria. In the current empirical study I have chosen to undertake an assessment of both quality and validity, that involves both method-specific criteria and criteria taken from a more general approach to assessment of qualitative research, e.g. the criteria 'methodological consistency' (Morse *et al.* 2002), which is further discussed in Section 7.1.3.4. The reason for this choice is that I would like to give the reader a greater opportunity to judge the methodological transparency of the study

(Morse *et al.* 2002, Olsen 2002, Sandelowski *et al.* 1997) than isolated use of the method-specific assessment criteria seem to do. As the overall assessment framework I have used Kvale's understanding of validity in qualitative research (Kvale 1996, Kvale and Brinkmann 2009, Olsen 2002). According to Kvale, validity encompasses validity as quality of craftsmanship, communicative validity and pragmatic validity. Quality of craftsmanship deals with the extent to which a study looks at and describes the phenomena intended to be studied in relation to the project's aim and themes. This demands a constant balancing between methodological awareness, self-criticism and openness. Communicative validity encompasses both the validity of the interviewed person's meaning of what was said, and the question about the extent to which the research process and results can be communicated, so others can follow the whole research process. Finally there is pragmatic validity, which focuses on the extent to which the results of the research are relevant to practice and can be used to bring about changes in practice (Kvale 1996, Kvale 1997, Kvale and Brinkmann 2009). In the following sections the quality of craftsmanship is discussed in relation to the themes 'Employment of a theoretical frame of reference', 'Selection procedure' and 'Analysis process'. Furthermore, the study's communicative validity is discussed in relation to the theme 'The researcher as interviewer' and 'Presentation of findings'. The pragmatic validity of the study is described in Section 9.

7.1.3.1 Employment of a theoretical frame of understanding

As is made clear in Section 4.2, I chose in the current research project to include a predefined theoretical frame of understanding (Lazarus and Folkman 1984, Lazarus 1999). According to Olsen (2002) a clear decision about the research project's

theoretical frame of understanding increases the capacity to maintain methodological stringency and transparency between the project's themes, interviews and analysis.

Within a GT research tradition there is, however, discussion around the extent to which it is methodologically appropriate to use a predefined approach to a certain concept, when the focus in the method is to derive an inductive-based theory, which ideally emerges from the data (Bryant and Charmaz 2007, Charmaz 2006, Glaser and Strauss 1967). Even though Corbin and Strauss prefer that research in which Straussian GTM is used begins without a predefined theoretical frame of understanding, they acknowledge that there can be situations where the predefined frame of understanding would be appropriate (Corbin and Strauss 2008, pg. 39). However, the most crucial thing is that the researcher is mindful not to 'bend' the results, so that they fit into the predefined theory (pg. 40). In the specific context of the study I judged it to be appropriate to use the predefined theoretical frame of understanding, partly because the coping field, as shown in Section 4.1, is characterised by wide conceptual diversity. Furthermore, the chosen approach to coping has been significant in choosing the overall methodological approach, since the method was chosen, among other reasons because, in line with the theoretical framework, it emphasises the interaction between the individual and their surroundings – cf. Section 6.1.1. In order to avoid bending the results in a certain direction, throughout the whole analysis process, and inspired by (Blumer 1998), I have been mindful to draw upon the theoretical frame of reference as a sort of guideline in relation to discovering my own analytical routes through an otherwise unknown terrain. In this way the theoretical frame of reference has been used as a '*sensitizing concept*' and not as a '*definitive concept*' (pg. 147-149). On these grounds I assert that the use of a predefined theoretical frame of reference has been justified.

7.1.3.2 Selection procedure

With a view to developing a varied and detailed substantive GT about coping from a patient perspective, and at the same time meet the demand for theoretical saturation (Corbin and Strauss 2008, pg. 143), in addition to using the series of fixed inclusion criteria, I decided also to make use of four selection principles: Availability, variation, development over time and theoretical sampling – cf. Section 6.2.2. The strength in using fixed inclusion criteria was that they systematically and stringently defined the population that established the foundation for the development of a substantive GT. The strength in using the four selection principles was that I could include the patients at the start who immediately met the inclusion criteria, and at the same time I was in a position, as the analyses were underway, to include patients who were thought to be able to contribute data that could both bring variation and refinement to the conceptualisation process and also lead to theoretical saturation (Corbin and Strauss 2008, Morse 2007, Strauss and Corbin 1998).

The use of the four selection principles led to, among other things, the challenge that ahead of inclusion of each individual patient I had to carefully consider the objective of including that particular patient. In some cases it could become necessary to deselect a certain patient which meant that in some periods the inclusion process was prolonged. In addition, I had to further acknowledge that in the light of the difficulties in finding the desired group of patients, cf. Section 6.2.2, it was more challenging to use the selection principle 'theoretical sampling' (Corbin and Strauss 2008, pg. 143) than I had expected. Prompted by Corbin and Strauss (2008, pg. 145-157) I therefore chose in certain situations to take a fresh look at the data material and study it for further aspects that could clarify and validate the developed categories and links between categories.

7.1.3.3 The researcher as interviewer

As interviewer I was constantly aware of my own reactions and how these influenced the situation (Corbin and Strauss 2008). In certain situations I was clearly challenged by emotional engagement in the patient's situation. This happened for example in an interview, where the patient expressed being severely let down and the subsequent feeling of powerlessness. My emotional engagement prompted the need to use leading questions, which among others referred back to themes which the patient had mentioned in an earlier interview. In that way I created space to separate my own and the patient's feelings and thereby re-establish the appropriate relationship with the interviewee (Fog 2007, pg. 84).

In other situation I experienced as interviewer that my experiences as a health professional were brought into play, in that I began to answer specific questions posed by the patient. In that situation I registered that the contact between patient and interviewer had changed and therefore suggested that the patient asked me the question again after the interview (Corbin and Strauss 2008). After this it was possible to return to questions that dealt with themes in the semi-structured interview guide.

The above examples bring to light how I, as interviewer, continuously reflected on the required balance between objectivity and sensitivity (Corbin and Strauss 2008, Kvale and Brinkmann 2009). In reading the interview scripts it appeared that neither 'researcher over-involvement' nor systematic use of leading questions occurred in any of the interviews (Fog 2007).

7.1.3.4 Analysis process

In the analysis process I made ongoing use of the analytical tools 'asking questions' and 'making theoretical comparisons' (Strauss and Corbin 1998, pg. 73). These two tools helped me to include both micro and macro perspectives in the analysis, move forward in the analysis process without making leaps of realisation between the three analysis steps and constantly check and recheck the developed categories. Thus, the tools underpinned the maintenance of 'methodological consistency' throughout the entire analysis (Morse *et al.* 2002), plus they functioned as essential validation tools (Kvale 1997, Morse *et al.* 2002).

One challenge in using the axial coding, according to Charmaz (2006), can be that the researcher is encouraged to set a given analytical framework over the data instead of remaining open to new integrative connections emerging from the data, which is considered crucial in the development of a grounded theory (Charmaz 2006, Glaser and Strauss 1967, Strauss and Corbin 1998). In order to avoid this pitfall, I endeavoured throughout the entire analysis process to remain open to new, different and challenging characteristics, aspects and links which could be significant to coping in advanced cancer patients. I did this for example, based on the data and inspired by Strauss and Corbin (1998, pg. 193), by choosing to include other theoretical frameworks, among others an existential philosophical theory (Yalom 1998, Yalom 2008), which gave rise to the study of links between humanistic themes such as meaning, sorrow and despair. In addition I wrote memos on an ongoing basis, which helped me to keep hold of incipient ideas and important reflections and thus remain open to the process.

7.1.3.5 Presentation of findings

The writing process of the research project showed how there can be several challenges linked to 'translating' the analytical material, developed through the analysis process, and which comes to expression through memos and integrative diagrams, into a clear written production that others can enjoy reading. The challenges related to deciding what kind of 'theoretical story' should be told and in structuring the theoretical story in the form of articles, which was a predefined condition in relation to the current research project. Inspired by Strauss and Corbin (1998), who emphasise the possibility of presenting different aspects of the theoretical story in different contexts, assuming that it is pointed out that it is not the whole story that is being told (pg. 249), I chose to divide the theoretical story over two articles. The articles respectively described the link between the central tendency and four significant life conditions, hereunder the coping-related resources and limitations that characterized each of the four life conditions (Article II), and the link between the central tendency and the three significant processes (Article III). The danger in this division can be that significant life conditions and significant processes appear as two independent result dimensions, which is far from the case – cf. Section 6.2.7.2. To avoid this pitfall I therefore chose in the thesis to present a model of the developed GT which clarifies how the four life conditions and processes, on the one hand, represent two analytical dimensions and on the other hand are mutually interdependent – cf. Section 6.3.3.

7.2 Discussion of results

By way of introduction the link between the process of conducting the literature review and the development of a GT will be discussed. Then the developed GT is discussed in relation to three themes: Complexity of coping in advanced cancer patients, the central tendency in the

developed theory and Social relations as a characteristic of coping. Finally, the approach to coping that was employed will be discussed and clarified.

7.2.1 The link between conducting the literature review and the development of a GT

Besides contributing with research-based knowledge around characteristics of coping in advanced cancer patients, the aim of the literature review was to use the developed knowledge to clarify and put in perspective analytical reflections in connection with the development of the current Grounded Theory. In order to fulfil the last aspect of the aim I chose to conduct the review side by side with starting the empirical study. In GT contexts, however, the appropriate time in a research process to conduct a literature review has been keenly discussed, because the intention of the research is to develop a theoretical framework which ideally emerge from the data (Charmaz 2006, Glaser and Strauss 1967, Strauss and Corbin 1998). From a classic GT approach it is recommended that the researcher postpones the review until the analysis is completed, as both the review and other relevant literature can come to function as a 'lens' of earlier ideas, that impact on the researcher's openness to the analysis process (Glaser and Strauss 1967). Several more recent approaches to GT (Charmaz 2006, Dey 2007, Strauss and Corbin 1998) however suggest that, even though the classic approach makes an important point, that the point is overstated, partly because it is necessary to distinguish between 'an open mind and an empty head' (Dey 2007, pg. 176). Thus, it is possible to conduct a literature review earlier in the research process on the assumption that the results of the review are for example used to bring clarity to one's own ideas, make it possible to draw interesting comparisons and show how and where one's own work fits with or clarifies relevant literature (Charmaz 2006, pg. 167). In the current research project the potential factor 'Minimising the impact of cancer', which was detected in the review, caused

me to investigate in the empirical study how patients assessed the link between the life conditions 'Alleviation from a life-threatening illness' and 'Carry on a normal life', which finally was the inspiration behind the establishment of 'The downplaying process'. Similarly the potential factor 'Creating meaning' supported my awareness in the empirical study of the more existential aspects around coping in advanced cancer patients. In that way I drew upon results from the review to bring clarity to my own ideas. In the same time the results contributed as a foundation for analytical reflection in connection with the development of the current substantive GT. The results of the review made it similarly possible to compare a systematic synthesis of relevant results from earlier research with results from the empirical study, which is detailed below.

7.2.2 Complexity of coping in advanced cancer patients

The results of the review pointed to seven potential factors, each of which was thought to be relevant for coping. It was however not possible to detect connections between the potential factors (Article I). The results of the empirical study showed how the central tendency was 'The struggle to be a participant in one's own life'. The results further showed how the central tendency involved a pattern consisting of four life conditions, each of which was characterised by a series of coping limitations and coping resources (Article II) and three processes (Article III), additionally.

A comparison of results of the review and of the empirical study indicates that the potential factors from the review apparently support aspects around the four life conditions and three processes, which were seen to constitute the substantial character of coping. Thus the aspects from the potential factor 'Control' are thought to underpin the central theme in the developed GT, while the potential factor 'Uncertainty' appears to

underpin aspects of the life condition 'Living with powerlessness'. The potential factor 'Support systems' is thought to underpin both different aspects around social relations which come to light in the four life conditions, and aspects of the life condition 'Find courage and strength', while the potential factor 'Bodily and mental functioning' in particular underpins the life condition 'Alleviation from a life-threatening illness'. Finally the potential factors 'Minimising the impact of cancer', 'Creating meaning' and 'Emotions' appear to underpin important aspects around the two processes 'Downplaying of illness' and 'Self preservation'. Thus, on the one hand it seems as though there is a certain concordance between the results of earlier research and the results of the empirical study, which underlines the relevance of the centrale tendency, the four life conditions and three processes that were developed and described in the empirical study. On the other hand the comparison of results throws light on how the empirical study also imparts new knowledge which is centred around the detection of a *complex pattern* of coping-relevant actions, limitations, resources, life conditions and processes, which in a coping theoretical perspective can be juxtaposed with the development of a 'Structure of coping' (Skinner *et al.* 2003).

7.2.3 The central tendency in the developed theory

'The struggle to be a participant in one's own life', which constituted the central tendency in the developed GT, was characterised by, among other things, the fact that the patients put a lot of energy and effort into maintaining or re-establishing the feeling of having influence over their own life, which can be explained as a constant fight to maintain personal control (Coyle 2006, Rydahl-Hansen 2005, Lewis FM *et al.* 1986, Luoma and Hakamies-Blomqvist 2004, Volker *et al.* 2004) and thereby maintain or re-

establish authenticity, understood as daring to be oneself (Arman and Rehnsfeldt 2002) and autonomy, understood as upholding one's own limits without others defining them on one's behalf (Street and Kissane 2001). 'The struggle to be a participant in one's own life' is further thought to a certain extent to be juxtaposable with end-of-life dignity (Chochinov *et al.* 2005, Street and Kissane 2001). Thus, based on a discourse analysis of the findings on dignity from studies around end-of-life care, along with an analysis of diverse professional and lay literature, Street and Kissane (2001) show how end-of-life dignity involves autonomy, self worth, body awareness and inter-subjective relations. By relating the central tendency of the developed theory to the maintenance and re-establishment of personal control, autonomy, authenticity and end-of-life dignity, it becomes clear how coping in advanced cancer patients is necessarily to be understood as a process that requires that the individual patient is involved to the extent that their failing strength allows.

7.2.4 Social relations as a characteristic of coping

A common feature of the four life conditions which were involved in the pattern around the developed GT was that they each involved aspects around social relations between patients and their environment: Recognition, Social togetherness, Sense of community and Increasing loneliness – cf. Figure 1, section 6.3.1. Thus, social relations are thought to be understood as a conceptual unit that enter as a significant characteristic of coping in advanced cancer patients, which is underpinned by a host of earlier studies – see for example Arman and Rehnsfeldt (2002), Prince-Paul (2008). The detection of the four different aspects, however, implies that the patients apparently had need of different social relationships in different situations. Thus it was thought that health professionals

occupy a special role in relation to alleviation of symptoms, while significant social networks were of great significance in relation to carrying on a normal life.

Furthermore, it was thought that it was especially people who were held in one's confidence that were involved in relation to the patient's managing of more personal life themes, such as living with powerlessness, and finding courage and strength – cf. the results section in Article II. As far as it is possible to validate this observation through future research, it may be significant in organising future palliative care, because it paves the way for a professional discussion focusing on which individuals – from the patient perspective – are best placed and prepared to enter into the many different social support functions that combine to constitute palliative care.

7.2.5 The results of the study from a coping theoretical perspective

Both the results of the review and those of the empirical study point in the direction that it is not enough to explain coping as an individual's efforts to adapt to stressful situations (Lazarus and Folkman 1984, Lazarus 1999) – assuming it is possible to capture the complexity of coping in advanced cancer patients. It is also necessary to understand coping as a process where the patients act with the intention of reassessing their situation, and thereby achieve a better connection between their view of the world and the actual situation, which can help to increase their positive feelings in the middle of otherwise very difficult circumstances (Folkman 2009, Park and Folkman 1997, Seligman and Csikszentmihalyi 2000).

If the abovementioned clarification in the understanding of coping in advanced cancer patients is to be included in the planning of future palliative services, it is also considered crucial to challenge a generally employed approach of health professionals towards patients,

i.e. the problem-oriented approach that is primarily rooted in finding out, understanding and solving the many different problems that arise as a consequence of the illness, see for example WHO's description of palliative care (World Health Organization 2002). As the results of the study indicate, it is thus thought to be necessary for health professionals to also be capable of taking an approach to patients that aims to support the individual to find and manage the values and resources, which from the patient's perspective increase positive feelings, and perhaps give just a glimpse of a feeling of being a participant in the autumn of one's life. Such an approach to patients-demands may be both time-consuming and personally challenging for the health professionals because it among other things requires a change of role from primary being acting and dynamic to being also exploring, self-reflective and listening (Jensen and Johnsen 2001). Nevertheless, a change of roles seems necessary if the health professionals wish to contribute to support the complex coping-pattern which is pointed out in the developed GT.

8 Conclusions

The overall aim of the research project was to develop a Grounded Theory to focus on the core characteristic of coping in advanced cancer patients that, from a patient perspective is significant for how patients with a serious cancer handle problems and feelings in interaction with their environment.

Based on the overall aim a substantive theory of coping in advanced cancer patients was developed, which added new knowledge to that which exists by pointing to the links between central limitations, resources, life conditions and processes that, from a patient perspective, characterise coping with actual problems and feelings. The following conclusions can be drawn from the research project and from the developed substantive theory:

- The central tendency in coping in advanced cancer patients is the patient's struggle to be a participant in their own life.
- 'The struggle to be a participant in one's own life' involves four significant life conditions: 'Alleviation from a life-threatening illness', 'Carry on a normal life', 'Live with powerlessness' and 'Find courage and strength'. Each of the four life conditions is characterised by a series of coping limitations and coping resources, which throw light on how coping happens in a constant interplay between the patient and their environment.
- 'The struggle to be a participant in one's own life' further involves three processes: 'The prioritisation process', 'The downplaying process' and 'The self-preservation process', each of which pointed to coping as a constantly changing and dynamic process.
- Several of the central characteristics of coping that are found in the empirical study are underpinned by seven potential factors, each of which represents a

synthesis of previous research results, respectively: 'Creating meaning', 'Support systems', 'Minimising the impact of cancer', 'Bodily and mental functioning', 'Control', 'Uncertainty' and 'Emotions'.

- 'Social relations' appears to be of great significance in relation to coping in advanced cancer patients. The results also indicate that patients involve different people in different situations.
- The results of the research project indicate that coping cannot be explained only as the individual's efforts to adapt to stressful situations. Coping must also be understood as a process where the patient acts with the intention of reassessing their situation and thereby achieving a better connection between their view of the world and the actual situation, which can increase the experience of positive feelings in otherwise very difficult circumstances.

9 Perspectives

The results of the research project contribute to development and change in clinical practice by entering into the current national and international debate around palliative care. A central theme in the debate is how future palliative care should be organised, so that patients – and their relatives – achieve the best possible quality of life (Bom 2010, Olson and Cristian 2005, Kræftens Bekæmpelse 2010). The results of the research project can, for example, feature in debates around how patients can be supported optimally to prioritise the activities on which they should spend their remaining strengths. This could include choosing tools considered appropriate by the patient to pinpoint and express the goals they see as meaningful – see for example Wrosch *et al.* (2003), Zoffmann (2004). The results can furthermore lead to discussions about the knowledge and information that seriously ill cancer patients need, but especially how that knowledge and information is conveyed to the patient, so that they feel they get the knowledge they require and avoid the feeling of being encumbered with knowledge that can worsen the feeling of anxiety or insecurity (Thomsen *et al.* 2010). An awareness of this problem may open a discussion of the way for health professionals to become trained to listen to the patient and their relatives and on this basis be in a position to deduce what knowledge and information should be included in the actual situation and to decide how and by whom the knowledge and information is most appropriately passed on. Furthermore, it is thought to be necessary to discuss how palliative care can be organised so that the situation is avoided where the patient (or the relative) is the co-ordinating person between different health professional authorities.

9.1 The significance of the results for future research

The developed substantive GT should lead to further research that investigates coping in advanced cancer patients from other perspectives, for example from the relatives' and health professionals' perspectives. By juxtaposing the results from such studies a detailed and multi-faceted picture of coping can be delineated, which through further theory generation can lead to a formal theory – i.e. a theory which is less specific to a group and place, and in such, apply to a wider range of disciplinary concerns and problems (Strauss and Corbin 1998, pg. 23).

By throwing light on constant movements between alleviating illness and carrying on a normal life, the results offer further inspiration to investigate coping from other methodological approaches, for example from a lifestyle perspective, which would study the significance of the phenomenon from a first person perspective in relation to how coping is integrated in, and takes its place in the individual's daily lifestyle practice (Ryle 2010, p. 34). In that way it would be possible to investigate how coping plays out in both different contexts and in different people. In addition, the results can bring about the instigation of, for example, action research projects that would investigate which specific initiatives can help to develop and change a given aspect of palliative care, for example in order to discover an appropriate organisation of care that leads to greater life quality in patients and relatives or with the intention of developing specific tools that can promote communication between patients, relatives and professionals – cf. e.g. (White 2008, Benzein and Saveman 2008).

10 Summary

10.1 Dansk resumé

Tidligere forskning viser, at patienter med alvorlig eller uhelbredelig kræft ofte udtrykker behov for professionel hjælp til at håndtere komplekse problemstillinger. Samtidig peger forskning på, at støtte fra sundhedsprofessionelle kan være domineret af symptombehandling, samt at sundhedsprofessionelle ofte mangler viden og mod til at støtte patienterne og deres pårørende. Dermed synliggøres behovet for at øge sundhedsprofessionelles indsigt i coping hos alvorligt kræftsyge patienter og skabe grundlag for, at der over tid udvikles konkrete redskaber, som kan indgå i udvikling af den basale palliative indsats.

Undersøgelsens formål var at udvikle en Grounded Theory med fokus på centrale kendetegn, der set fra et patientperspektiv, har betydning for, hvordan patienterne med en alvorlig kræftsygdom i samspil med deres omgivelser håndterer aktuelle problemer og følelser. Undersøgelsen involverede både udarbejdelsen af et litteratur review og en empirisk undersøgelse i form af en kvalitativ interviewundersøgelse. I reviewet blev der gennem en systematisk litteratursøgning identificeret 30 relevante artikler. En stringent analyseproces identificerede syv potentielle faktorer med betydning for coping: 'Skabe mening', 'Støtte systemer', 'Minimere kræftens betydning', 'Kropslig og mental funktion', 'Kontrol', 'Usikkerhed' and 'Følelser'. Resultaterne gav anledning til analytiske refleksioner i forbindelse med udviklingen af den aktuelle Grounded Theory.

Den kvalitative interviewundersøgelse inkluderede 10 patienter i alderen 43-80 år, som blev interviewet 1 til tre gange. Der blev i alt gennemført 18 interviews. Metoden "Grounded Theory", som beskrevet af Strauss og Corbin, blev

anvendt som analysestrategi. Resultaterne viste, hvordan 'At kæmpe for at være medspiller i eget liv' fremstod som en central tendens, som involverede fire livsvilkår: 'Lindre livstruende sygdom', 'Udfolde opbygget liv', 'Leve med afmagt' og 'Finde mod og styrke'. Hvert livsvilkår var kendetegnet ved en række begrænsninger og ressourcer, som synliggjorde, hvordan coping foregik i et konstant samspil mellem patienterne og deres omgivelser. Mønsteret omkring den centrale tendens involverede endvidere tre processer: 'Prioritering', 'Nedtoning' og 'Selvopholdelse', der hver for sig pegede på coping som en konstant foranderlig og dynamisk proces.

På baggrund af undersøgelsens resultater konkluderes, at coping hos alvorligt kræft sygepatienter er centeret omkring at bevare eller genoprette oplevelsen af at være medspiller i eget liv. Mønsteret omkring den centrale tendens involverer både betydningsfulde livsvilkår og processer. Endvidere konkluderes, at coping hos alvorligt kræftsyrge patienter ikke alene kan forklares som en persons bestræbelser på tilpasning til stressfyldte situationer. Coping må ligeledes forstås som en proces, hvor patienterne handler med henblik på at genvurdere situationen og dermed opnå en bedre sammenhæng mellem deres syn på verden og den konkrete situation, hvilket kan øge oplevelsen af positive følelser midt i en ellers meget svær situation.

Undersøgelsens resultater bidrager til forandring og udvikling af klinisk praksis ved at indskrive sig i en aktuel debat omkring organiseringen af fremtidig palliativ indsats, som bl.a. har sigte på, hvordan palliative patienter og deres pårørende opnår den bedst mulige livskvalitet. Endvidere giver resultaterne bl.a. anledning til yderligere forskning, der har fokus på udviklingen af konkrete værktøjer, som kan være med til at fremme kommunikationen mellem patienter, pårørende og professionelle.

10.2 English summary

Previous research shows that patients with advanced or incurable cancer often express the need for professional help to manage complex issues. At the same time research points to the fact that support from health professionals can be dominated by symptom treatment, and that health professionals often lack knowledge and courage to support patients and their relatives. Thus, the need for health professionals to gain insight into coping in advanced cancer patients is clear, together with the need to create a foundation for the development of specific tools that can figure in the development of basic palliative care.

The overall aim was to develop a Grounded Theory with focus on the central characteristics in coping in advanced cancer patients, and which, from a patient perspective, are significant to how patients in interaction with their surroundings manage actual problems and emotions. The study involved both a literature review and an empirical study in the form of a qualitative interview study. In the review 30 relevant articles were identified from a systematic literature search. A stringent analysis process identified seven potential factors significant to coping: 'Creating meaning', 'Support systems', 'Minimising the impact of cancer', 'Bodily and mental functioning', 'Control', 'Uncertainty' and 'Emotions'. The results gave rise to analytical reflections in connection with the development of the actual Grounded Theory.

The qualitative interview study included 10 patients aged between 43 and 80, who were interviewed between one and three times. In all, 18 interviews were conducted. The method, "Grounded Theory", as described by Strauss and Corbin, was employed as the analysis strategy. The results showed how 'Struggling to be a participant in one's own life' emerged as the central tendency, and involved four life

conditions: 'Alleviation from life-threatening illness', 'Carry on a normal life', 'Live with powerlessness' and 'Find courage and strength'. Each life condition was characterised by a series of limitations and resources, which made it clear how coping occurred in constant interaction between the patient and their environment. The pattern around the central tendency further involved three processes: 'Prioritising', 'Downplaying' and 'Self-preservation', each of which pointed to coping as a constantly changing and dynamic process.

Based on the results of the study, it can be concluded that coping in advanced cancer patients is centred around maintaining or re-establishing the feeling of being a participant in one's own life. The pattern around the central tendency involved both significant life conditions and processes. Furthermore, it can be concluded that coping cannot be explained only as a person's efforts to adapt to stressful situations. Coping must also be understood as a process where the patient acts with the intention of reassessing their situation and thereby achieving a better connection between their view of the world and the actual situation, which can increase positive feelings in the middle of an otherwise very difficult situation.

The results of the study contribute to change and development in clinical practice by entering into the current debate around the organisation of future palliative care, which aims, among other things, to discover how patients and their relatives can achieve the best possible life quality. Furthermore, the results should give rise to further research that would focus on the development of specific tools that can help to promote communication between patients, relatives and professionals.

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