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**MEANING-MAKING IN INTEGRATIVE HEALTH CARE:
Studies on patients' and practitioners' experiences**

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MEANING-MAKING IN INTEGRATIVE HEALTH CARE: Studies on patients' and practitioners' experiences

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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This thesis is dedicated to my beloved family; my husband Thomas and our children Theo and Elias

ABSTRACT

Background and aim: Patients living with chronic pain often turn both to conventional and complementary health care. Integrative health care combines conventional and complementary therapies in the clinical care of patients. Despite frequent integrative health care services internationally, there are knowledge gaps relating to patients' and practitioners' experiences of integrative health care in different clinical contexts. The overall aim of this thesis was to elucidate patients' and practitioners' meaning-making in integrative health care for persons living with chronic pain, and to develop a first version of a patient instrument measuring existential signs of health and suffering.

Methods: The thesis has a qualitative enquiry design with four studies conducted in two different integrative health care settings; in primary health care (studies I and II), and in anthroposophic integrative health care (studies III and IV). Primary care patients' experiences and perceptions were explored in focus group discussions (n=11) and analysed with latent content analysis (I). The collaborative process of integrative primary care practitioners in patient conferences (n=15) was analysed with discourse analysis (II). Individual interviews (n=15) concerning the meaning of caring were conducted with practitioners of anthroposophic integrative health care and analysed using phenomenological hermeneutics (III). The patient instrument was developed in three phases; first, interview data from patients (n=64) who had received anthroposophic integrative health care were used to develop an item pool, secondly, cognitive patient interviews (n=8) and third, expert consultations (n=5) were used to refine the instrument.

Results: Patients experienced being encountered as whole persons in integrative primary care, a model of care that despite some collaboration and financial challenges was characterised by a valuable combination of bio-medical diagnostics and empowering self-help strategies (I). The shared meaning-making among integrative health care practitioners in primary care was interpreted as a basis for collaboration and caring that enabled a synergetic process contributing to the formation of an enhanced team identity over time (II). Anthroposophic integrative health care practitioners' use of a shared language, including certain concepts, seemed to extend the practitioners' understanding of patients' health, suffering and caring, and their existential dimensions (III). The patient instrument was based on two interrelated dimensions, the existential signs of "Health" and "Suffering", which were characterised by five domains: "Life passion and energy", "Personal freedom", "Presence in life", "Relationships" and "Meaning" (IV).

Conclusion: The findings suggest that patients' and practitioners' meaning-making in integrative health care relates not only to biopsychosocial aspects but also to existential dimensions of health and suffering, which can have implications for caring of persons with pain. Integrative health care practitioners' integrated collaboration and use of shared concepts may contribute to their ability to understand and alleviate pain patients' suffering and to facilitate broader whole person perspectives of care. This understanding, taken together with the developed patient instrument that measure existential signs of health and suffering, can be used to further inform the evaluation and development of interdisciplinary forms of health care.

LIST OF SCIENTIFIC PAPERS

- I. **Andersson (Andermo) S**, Sundberg T, Johansson E, Falkenberg T. (2012) Patients' Experiences and Perceptions of Integrative Care for Back and Neck Pain. *Altern Ther Health Med*. May-Jun; 18(3):25-32.
- II. **Andermo S**, Sundberg T, Forsberg C, Falkenberg T. (2015). Capitalizing on Synergies - A Discourse Analysis of the Process of Collaboration Among Providers of Integrative Health Care. *PLoS ONE*10(3): e0122125.[doi:10.1371/journal.pone.0122125](https://doi.org/10.1371/journal.pone.0122125)
- III. **Andermo S**, Hök J, Sundberg T, Arman M. (2016). Practitioners' Use of Shared Concepts in Anthroposophic Pain Rehabilitation. *Disabil Rehabil*. Oct 14:1-7. doi.org/10.1080/09638288.2016.1231843
- IV. **Andermo S**, Sundberg T, Falkenberg T, Nordberg Hök J, Arman M. Measuring Patients' Health and Suffering– The First Stages of Instrument Development (manuscript)

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1 INTRODUCTION

This thesis focuses on the meaning-making among patients and practitioners in integrative health care. For a long time I have had an interest in the field of health care and models of interdisciplinary collaboration. When I started university I began with studies in social anthropology and continued studying public health. In social anthropology I became increasingly interested in medical anthropology and social and cultural constructions of health and illness in different contexts. Specifically, I focused on the area of traditional medicine. My interest in people's meaning-making in relation to existential aspects of life expanded during anthropological field work among traditional healers in Guatemala. I noticed how persons' perceptions of health and illness as well as of themselves and their world view could influence how they related to health and their health-seeking behaviour. Persons could seek health care from completely different traditions and combine and integrate these forms of care into a whole, which at first appeared confusing to me, but then became clearer during my anthropological studies. When studying public health I grew a strong interest in approaches to improve health in various populations and in different ways of assessing patients' health.

When I was planning my master thesis in public health, I came into contact with the Research Unit for Studies of Integrative Health Care at Karolinska Institutet. During my work on the master thesis I took part in a clinical research project on integrative health care for persons with back and neck pain in primary care. During this period I became fascinated with patients' experiences of living with chronic pain and their search for health and health care. Often persons living with chronic pain described a lonely struggle in their search for care, where they often combined different types of care, and described being stuck between different fields of practice, with caregivers who neither communicated with them nor understood them as a whole person. The lack of understanding between different fields of health care practices became an important issue for me. I have since been working as a university lecturer, teaching courses in public health, caring science and complementary and integrative health care, along with continuing work in the integrative health care research group. The writing of this thesis has provided me with the opportunity to research the meaning-making among practitioners and patients in different integrative health care settings. I hope this work will contribute to the further development and understanding of how to address and assess interdisciplinary qualities in health care.

2 BACKGROUND

In this thesis, patients' and practitioners' meaning-making are studied in relation to their experiences of rehabilitation of chronic pain in two different integrative health care settings. Meaning can be defined in many ways, and the “notion of meaning as central to human life” is a common definition (Park, 2010). Meaning-making is understood as an ongoing process with new negotiations of meaning extending our understanding about our basic ontological values, which are not always conscious (Park & Folkman, 1997). To live with a chronic or prolonged health problem, such as chronic pain, may dominate a person's whole existence, affecting their perception of the meaning attached to the basis of life (Ojala et al., 2014; Ojala, Hakkinen, et al., 2015; Park & Folkman, 1997). Patients living with chronic pain often use a combination of conventional and complementary health care practices to form an integrative health care (Barnes, Bloom, & Nahin, 2008; Bucker, Groenewold, Schoefer, & Schafer, 2008; Eklöf & Tegern, 2001; Su & Li, 2011). The theoretical foundation of caring science is used to further the understanding of patients' and practitioners' meaning-making in integrative health care in relation to caring, health and suffering. Integrative health care and caring science share common ontological understandings of the meaning of caring and view of the whole person as an integrated entity (Arman & Rehnfeldt, 2011; Eriksson, 2002; Sierpina, 2001; The Swedish society of nursing, 2016). In integrative health care, interdisciplinary collaboration and integration between practitioners is understood as the basis for caring for the whole person (Boon, Verhoef, O'Hara, & Findlay, 2004). Therefore, practitioners' meaning-making in relation to caring as well as their interaction and collaboration is explored. Patients' experiences of health and suffering in the context of integrative health care, together with the theoretical foundation of caring science, are combined to direct the development of a first version of an instrument measuring existential signs of patients' experiences of health and suffering.

2.1 THEORETICAL FOUNDATIONS OF CARING SCIENCE

The theoretical foundation of this thesis is the Nordic tradition of caring sciences, specifically departing from the theory of caritative caring, and focusing on the human being as an entity and health and suffering as interrelated to human life (Arman, Ranheim, Rydenlund, Rytterstrom, & Rehnfeldt, 2015; Eriksson, 2002; Lindström, 2014; Rehnfeldt, Arman, & Lindström, 2016). Caring science is an autonomous human science focusing on the core of caring. As such, caring science is independent of professional belonging, whereas nursing science refers to knowledge specifically necessary for the practice of nursing (Arman, Dahlberg, & Ekebergh, 2015). The notion of the human as an entity with a body, soul and spirit is central both in theories of caring science, including the theory of caritative caring (Eriksson, 2002, 2007; Lindström, 2014) and in integrative health care (Roberti, Alivia, & Guadagni, 2012; Sierpina, 2001). The Swedish society of nursing (2016) states that the

human being is a “unity consisting of body, soul and spirit, with health as the totality of the human being’s experiences and values.” As such, caring for the whole person, as an integrated human being, is based on ontological questions concerning the view of the human and of the practitioner’s ability to attend to the patient’s world (Arman, 2015a, 2015b; The Swedish society of nursing, 2016). Within the caritative caring approach there is an emphasis on human beings’ dignity and ethical values in caring (Lindström, 2014; The Swedish society of nursing, 2016).

2.1.1 The patients’ world of health and suffering

In this thesis, health and suffering are viewed as interrelated aspects of human life, in line with a caring science perspective (Arman, Ranheim, et al., 2015; Eriksson, 1984, 2001). From the humanistic perspective of caring science, health is understood in relation to a person’s life and whole life situation. More, specifically, health is perceived as existential experiences that are multi-dimensional and subjective in nature. Thus, there is a wider perspective than the absence of disease (Nyström, 2014; Wärnå-Furu, 2012). There are several definitions of health. The World Health Organization (1946) has defined health as “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Although the definition addresses more aspects of health than the absence of disease, it encompasses a utopian definition of health. A person does not need to be healthy in all those areas to experience health. There are also several models of health. Medin & Axelanderson (2000) describe three main models for the relation between health and disease, consisting of (1) health as an absence of disease, (2) health and disease as opposites on a continuum and, (3) health and disease as different dimensions where a person can have a disease and experience health at the same time, as well as experience ill-health even when not diagnosed with a disease. However, in caring science, a dualistic view of health and disease is insufficient to understand the lived experience of health. Erikson (1984) developed a model, ‘the health cross’, described as the third model in Medin and Alexanderson’s (2000) categorization. The model has been widely used to understand the relation between subjective experiences of health and ill health in relation to the physical observed health status. However, although the model addresses two dimensions of health, the subjective and observed (objective) on a continuum, the model does not fully capture the lived experience of health as an existential experience.

As such, a patient’s world includes both biological and existential perspectives at the same time, in each caring encounter (Dahlberg & Segesten, 2010). The existential concerns are about our basis in life. Arlebrink (2012) describe a person’s search for meaning as the most profound existential matter. A person’s perception of the meaning, for example in terms of beliefs and valued goals, which Park and Folkman (1997) refer to as our ‘global meaning’ might be affected when someone becomes ill or lives with a chronic health problem. To find meaning in one life situation makes us live and not just exist (Arlebrink, 2012). In the

ontological health model, developed by Eriksson et al. (Eriksson, Bondas-Salonen, Herberts, Lindholm, & Matilainen, 1995), existential qualities of health and suffering are further elaborated upon. In the model, health is described as a movement where the human moves in between the dimensions of doing, being and becoming in an effort to become an integrated whole person consisting of body, spirit and soul (Eriksson et al., 1995; Nyström, 2014). Nyström (2014) describes becoming as a growth towards an increased understanding about oneself and towards becoming the person one is destined to be. This is described as an intense process in which the person becomes reconciled with circumstances in life. In becoming, a person's suffering becomes an integrated part of life. Being is described as a rest in the search for well-being and balance. Being is also described as relational, where one finds balance and harmony and acceptance of oneself in relation to others. It is in relation to others that people are able to show themselves as they are. The dimensions of being and becoming are described as a movement between activity and stillness. Doing involves healthy behaviours that need to be connected to being and becoming in order to be meaningful. If doing only involves aspects of health that is a norm or behavioural aspects not integrated into the person's own understanding, it becomes empty. Thus, the healthy behaviour needs to be in relation to a person's own desire in the context of their life and existence in order to be meaningful (Nyström, 2014).

In this thesis, the concept "patient" is mostly used to describe persons seeking help in different health care settings. To use the word "person" instead of "patient" was considered, since the concept "person" is often used to describe the person as a participant in caring, whereas the concept of "patient" is considered a clinical concept. However, as Dahlberg and Segesten (2010) points out, the concept of "patient" within caring science differs from a medical or administrative concept, since the patient within caring science is viewed in relation to the whole person and his/her life. Eriksson (2001) states that the concept of "patient" means "a suffering person". Eriksson (1984, 2001) discusses health in relation to suffering, instead of just relating health to disease. Patients' multi-dimensional and subjective experiences of suffering have been described in relation to their illness, to the care given, and to life (Eriksson, 2001). Furthermore, suffering is described as a movement between unbearable and bearable suffering (Eriksson, 2001). Nyström (2014) argues that health and suffering are connected to life, as companions in each person's life. As Gadamer (1996) points out, health is often taken for granted: when someone encounters illness, the awareness of health appears. In this sense, health and suffering are understood in the light of each other, and health may be experienced in its absence. Sveneaus (2014) argues that suffering has implications for a person's entire life, including priorities and goals in life as well as how one acts and communicates with others. In everyday language, suffering may be described with words such as despair, pain, anxiety and loneliness (Arman, 2012; Rehnsfeldt et al., 2016). Although, suffering has been described as a "loss of self" (Charmaz, 1983), the experience of suffering may involve a new look at life and a path to self-discovery (Arman, 2012; Charmaz,

1983). However, as Arlebrink (2012) noted, this is not a common understanding of suffering in contemporary society. Instead, suffering is understood as something that affects us and needs to be avoided. The fact that we are able to cure many diseases has alleviated a lot of suffering related to the biological aspects of disease (Arlebrink, 2012). To just avoid suffering is, however, problematic from an existential perspective. Notably, caring aims to alleviate suffering, promote health, and prevent ill health (Eriksson, 2001, 2007).

2.2 INTEGRATIVE HEALTH CARE

There has been a rising popularity of complementary and integrative health care, where patients' demand for complementary and integrative health care has been referred to as "a patient-led revolution" (Bishop & Lewith, 2010) or a social phenomenon (Gale, 2014). Although patients turn to complementary and integrative health care for various reasons, it has been proposed that the rise of integrative health care to a large extent can be explained by the high levels of chronic and incurable diseases in today's society (Pan & Gao, 2012). From a caring science perspective, this health-seeking behaviour points towards patients' extended need for health care in the search for cures, alleviation of suffering, and promotion of health. Some health problems, such as chronic pain, might have implications for a person's entire life even when they are difficult to diagnose and treat. The patients' search for health care in the area of complementary and integrative health care might also be a reflection of patients searching for something other than what conventional health care has to offer. However, the area of integrative and complementary health care is a diverse field with various definitions.

2.2.1 Definitions of integrative and complementary health care

Integrative health care in general refers to the interdisciplinary integration and collaboration between conventional and complementary health care incorporating both philosophy and practice. Integrative health care has been defined as "A system of healthcare that is patient-centered and collaborative, encompassing a diversity of therapeutic options [including complementary and alternative medicine] that have been found to be safe, effective and informed by available evidence to achieve optimal health and healing (Gaboury, April, & Verhoef, 2012). The four studies included in this thesis were conducted in two different integrative health care settings. The terms *integrative medicine*, *integrative care* and *integrative health care* are used interchangeably in the studies. The reason for this is that *integrative medicine* is the most commonly used and accepted term in the field (Holmberg, Brinkhaus, & Witt, 2012), whereas the terms *integrative care* or *integrative health care* to a greater extent acknowledge the caring aspects within the area (Boon, Verhoef, O'Hara, Findlay, & Majid, 2004; Gaboury et al., 2012) and the role of all health professions. The integrated use of conventional and complementary health care is intended to address the

whole person and not just the physical body symptoms (Maizes, Rakel, & Niemiec, 2009; Sierpina, 2001).

The definition of what constitutes complementary health care may vary. The World Health Organization has defined the area of traditional and complementary health care as “a broad set of health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system” (World Health Organisation, 2015). Coultier and Willis (2004) argue that definitions that only highlight what complementary health care is not are useless, as they do not provide answers to what it is. Building on the World Health Organizations’ definition of traditional and complementary health care, Falkenberg et al. (2012) developed a pragmatic definition of complementary health care adapted to the European context.

“Complementary and alternative medicine (CAM) utilized by European citizens represents a variety of different medical systems and therapies based on the knowledge, skills and practices derived from theories, philosophies and experiences used to maintain and improve health, as well as to prevent, diagnose, relieve or treat physical and mental illnesses. CAM has been mainly used outside conventional health care, but in some countries certain treatments are being adopted or adapted by conventional health care.”

2.2.2 Use and provision of complementary and integrative health care

Although, there has been an increase in the uptake and provision of integrative health care in the world, which can be exemplified by the large number of US university hospitals having integrative health care departments (Academic consortium for integrative medicine and health, 2017), the provision of complementary and integrative health care in Europe can be described as a diverse field with large variations in how it is provided, regulated and understood (Ammon et al., 2012; Falkenberg et al., 2012). What is considered complementary care in one context might be part of conventional health care in another context (Falkenberg et al., 2012; Gaboury et al., 2012). Even though many complementary health care approaches have their origins in traditional medical practices, Adler (2002) argues that the area of complementary health care is “neither a wholly new phenomenon nor has it returned from being away”. Rather, the area has had a persistent presence since persons have used different health care traditions, both complementary and conventional health care, and combined them into what Adler (2001, 2002) refers to as a syncretic whole. In research, there has been a concern about patients’ use of complementary health care, specifically when the field is unregulated and to a large extent used by patients outside the conventional health care system (Zollman & Vickers, 1999). Zollman and Vickers (1999) have addressed patients’ risk of encountering unqualified practitioners, and the risk of missed or delayed diagnoses.

Patients might also experience dangerous adverse side-effects and they might refuse effective conventional treatment (Angell & Kassirer, 1998; Davis et al., 2006; Zollman & Vickers, 1999).

However, in many countries there is a gap between the patients' use of complementary or integrative health care and the availability of the same within public or private health care. In Sweden, complementary health care is mostly practiced outside the conventional health care setting and is to a large extent unregulated (Carlson & Falkenberg, 2007; Wiesener et al., 2012). In Norway, on the other hand, there has been an increase in the provision of complementary health care in conventional care settings, with 50% of the hospitals offering complementary therapies in 2008 (Salomonsen et al., 2011), compared to 25% in 2001 (Salomonsen, Grimsgaard, & Fonnebo, 2003). In the United States, integrative health care is now considered an established part of conventional health care, with integrative health care being practiced in various integrative health care centres across the country (Academic consortium for integrative medicine and health, 2017; Horrigan, Lewis, Abrams, & Pechura, 2012). Although, complementary health care is mostly practiced outside the conventional health care setting in Sweden, various complementary health care approaches are used within conventional care and some established integrative health care units exist. One such example is an integrative care unit at a large university hospital offering tactile massage and healing touch (Airosa, 2015; Airosa, Falkenberg, Öhlén, & Arman, 2013). Another example is a private hospital providing anthroposophic integrative health care (Vidarkliniken, 2016). The latter is a form of integrative health care that combines conventional physician and nursing care with selected anthroposophic therapies such as massage, art and music therapy, and specific nursing techniques (Kienle et al., 2013; Vidarkliniken, 2016).

Previous research has shown that patients turn to complementary and integrative health care mainly in addition to, not instead of, conventional health care. The reasons for searching for complementary and integrative health care approaches include prevention of disease, health promotion, maintenance of health and to get new perspectives on health (D'Crus & Wilkinson, 2005; Hanssen et al., 2005; Thorne, Paterson, Russell, & Schultz, 2002). Other researchers suggest that patients value and integrate complementary care for health problems that may not be successfully treated by conventional care alone (McCaffrey, Pugh, & O'Connor, 2007), or wish to avoid pharmaceutical drugs (Bucker et al., 2008). This is also shown in a systematic review, where dissatisfaction with conventional care was the most common reason for patients to search for complementary care (Eardley et al., 2012). Danell (2015) reported that patients' initial decision to turn to complementary health care may be based on frustration and disappointment with conventional care, although long-term use was motivated by the holistic and individualized characteristics of such care.

Studies on the patients' use of complementary and integrative health care in Sweden shows varying prevalence rates between 5-64 % (Eardley et al., 2012). In a population survey from the year 2000 in Stockholm, Sweden the prevalence of ever use of complementary health care was 49% (Eklöf & Tegern, 2001; Hanssen et al., 2005), and this is similar in other Scandinavian countries with a prevalence of ever use of 34 % in Norway and 45 % in Denmark (Hanssen et al., 2005). Highly educated females use complementary health care more often than other socio-economic groups and more often than men (Bishop & Lewith, 2010; Bucker et al., 2008; Hanssen et al., 2005; Thomas & Coleman, 2004). Notably, musculoskeletal disorders including chronic pain are the most common reasons for patients to turn to complementary or integrative health care (Barnes et al., 2008; Bucker et al., 2008; Eklöf & Tegern, 2001; Su & Li, 2011).

2.3 LIVING WITH CHRONIC PAIN

Chronic pain, commonly referring to pain that has remained for more than three months, is a major health problem with both individual and societal consequences (Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2010). Approximately 18-20 % of the population in Sweden live with chronic pain (Harker et al., 2012; Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2006, 2010). Patients with chronic pain often have complex and other overlapping symptoms such as, depression, anxiety, sleep disturbance, headache and fatigue (Shipley, 2010; Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2006). There are also socio-economic and gender differences related to chronic pain. More women than men live with chronic pain. A similar pattern is seen among low educational groups that have a higher prevalence of chronic pain than those with high education (Backhans, Stjernschantz Forsberg, & Lager, 2015). Furthermore, another study found that about 5 % of the adult population in Stockholm had experienced back and/or neck pain that had affected both their work ability and their ability to perform daily activities for at least two days a week during the previous six months (Backhans et al., 2015). On a societal level, chronic pain contributes to a high socio-economic burden with high care related costs together with other indirect costs such as sick leave and early retirement (Gustavsson et al., 2012). Since chronic pain increase with age, the problem is predicted to grow in the future as the population becomes older (Backhans et al., 2015; Leadley, Armstrong, Lee, Allen, & Kleijnen, 2012).

Research exploring patients' experiences of living with chronic pain have shown that their experiences affect the whole person, leading to psychosocial consequences such as distress and loneliness as well as a low quality of life and a loss of identity (Froud et al., 2014; Ojala, Hakkinen, et al., 2015; Smith & Osborn, 2007; Snelgrove & Lioffi, 2013; Toye et al., 2013). Smith and Osborne (2007) discuss how, for persons living with chronic pain, their life and the meaning it has "can change beyond recognition", including everything from a change in the ability to perform daily activities to changes in self-view. From a phenomenological

perspective, Bullington (2009) addresses the phenomena of chronic pain from the perspective of the lived body. This perspective implies a non-dualistic understanding of the lived body consisting of an intertwined unity of mind, body and world. From this perspective the intense focus on the body in pain intrudes upon a person's whole experience of being in the world, including experiences, perceptions, feelings, thoughts as well as how to act in the world. This means that it is difficult for a person in pain to pay attention to anything other than the painful body. As such, living with chronic pain may involve a loss of self (Osborn & Smith, 2006; Smith & Osborn, 2007) and gradual withdrawal from social life, which can affect relationships and social roles. Previous research has highlighted how relationships get damaged, specifically close relationships (Froud et al., 2014). Froud et al. (2014) describe a paradox of avoiding others and simultaneously expressing a need for support in relationships. Physical limitations from the experience of pain can contribute to low self-esteem, shame and frustration (Snelgrove, Edwards, & Lioffi, 2013). Furthermore, the experience of pain can undermine a person's ability to plan and perform activities they have previously enjoyed (Froud et al., 2014). Thus, the experience of pain may dominate a person's whole existence (Juuso, Skar, Olsson, & Soderberg, 2011; Ojala et al., 2014)

2.3.1 Chronic pain as a health system challenge

The World Health Organisation (2010) have recognised that health systems around the world are becoming fragmented as they struggle to meet patients' increasingly complex health care problems. One such health problem, which is considered to be highly complex in nature, is chronic pain (Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2006, 2010). This can be reflected in the considerable health care usage, with about 30 % of the patients in primary care seeking medical advice for pain-related problems (Hasselstrom, Liu-Palmgren, & Rasjo-Wraak, 2002). Even so, and remarkably, only one out of seven persons receives a biomedical explanation of their pain problem (Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2010). Persons suffering from chronic pain often lack the language to talk about their experiences (Jackson, 1994). This has been further reflected in patients' experiences of caring encounters, and several research reports have addressed how patients with chronic pain, specifically those with no identified pathology, have experiences of not being believed or rejected by health care practitioners in conventional care as well as by the social security system (Juuso et al., 2011; Ojala, Häkkinen, et al., 2015). Juuso et al. (2011) have shown how women with fibromyalgia live with a double burden, including both the aggressive, unpredictable pain as well as the burden of being doubted by others due to the invisibility of their pain. Overall, living with chronic pain may lead to extended suffering; relation to their illness, of the care given, and of life (Eriksson, 2001). Thus, rehabilitation of chronic pain may need to take account of this extended suffering in patients. Interdisciplinary rehabilitation has been suggested as one possible way to address the complexity of problems for chronic pain

sufferers (Foster, 2011; Foster et al., 2003; Gatchel, McGeary, McGeary, & Lippe, 2014; Turk, 1996).

2.4 INTERDISCIPLINARY COLLABORATION TO MEET PATIENTS' NEEDS

Interdisciplinary collaboration was acknowledged already in 1978 by the World Health Organization as essential to ensure the success of primary health care (World Health Organisation, 1978). Furthermore, interdisciplinary collaboration is understood as a key factor in meeting patients' complex health problems, including chronic pain, strengthening the health system, increasing the effectiveness of health care and improving health outcomes (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005; Hall, 2005; World Health Organisation, 2010). The World Health Organisation (2010) states that collaborative practice "happens when multiple health workers from different professional backgrounds work together with patients, families, careers and communities". In a concept analysis, Petri (2010) suggests that the concept of interdisciplinary collaboration involves "a problem-focused process", "sharing", and "working together".

The principles underpinning successful rehabilitation of chronic pain are under constant development (Foster et al., 2003; Waddell & Burton, 2005; Wade & de Jong, 2000). There is now consensus that it is inadequate to use only a biomedical approach; instead, rehabilitation of chronic pain needs to address several elements including biological, psychological and social aspects (Foster, 2011; Foster et al., 2003; Gatchel et al., 2014; Turk, 1996). The biopsychosocial model originally developed by Engels (1977) and further adopted by Loeser (1982) has gained acceptance and is widely used in interdisciplinary pain rehabilitation (Foster, 2011; Foster et al., 2003; Gatchel et al., 2014; Turk, 1996). The biopsychosocial approach acknowledges that pain is a complex interaction between physiological, psychological, and social factors (Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2006). As Waddell & Burton (2005) writes, biopsychosocial problems need biopsychosocial solutions, suggesting that the rehabilitation needs to focus on all of these elements. Multimodal rehabilitation, a form of interdisciplinary rehabilitation, is now commonly recommended for patients with persisting or intermittent pain that has lasted more than three months and have such a dignity and consequences that a person's daily life is affected (Nationella Medicinska indikationer, 2011). Multi modal rehabilitation differs from unimodal (one modality) and intermediary rehabilitation (different modalities without coordinated team work), involving a team consisting of several professions that collaborate in the planning and delivery of rehabilitation within conventional care. Multimodal rehabilitation refers to several professions working in a team towards a common goal that is defined in collaboration with the patient (Nationella Medicinska indikationer, 2011). Gatchel et al. (2014) notes that there is confusion about the differences between the terms "interdisciplinary" and "multidisciplinary". "Multidisciplinary" refers only to different practitioners working with the same patient but with limited integration and communication

between each other. “Interdisciplinary” collaboration implies that the practitioners work at the same location with frequent communication (D'Amour et al., 2005).

Different studies have addressed both possibilities and limitations of the biopsychosocial model (Gatchel et al., 2014; Ghaemi, 2009; Kamper et al., 2015; Quintner, Cohen, Buchanan, Katz, & Williamson, 2008; Waddell & Burton, 2005). In general, the biopsychosocial model has been a valuable response to biomedical reductionism (Gatchel et al., 2014) and there are promising effects of biopsychosocial interdisciplinary rehabilitation for chronic pain (Kamper et al., 2015). In a recent Cochrane systematic review (Kamper et al., 2015), interdisciplinary biopsychosocial rehabilitation for people with chronic low back pain was shown to be more effective than usual care and physical treatments to decrease pain and disability. However, Ghaemi (2009) argues that the biopsychosocial model has contributed to eclecticism, where all approaches are welcome but that the goal of care is missing. In Ghaemi's (2009) words, the focus in the model is put on the ingredients of care rather than the recipe. Other researchers have argued that there is a lack of understanding about and interaction between the different components of the model (Ghaemi, 2009; Harding, Campbell, Parsons, Rahman, & Underwood, 2010; Quintner et al., 2008). In relation to pain rehabilitation, several researchers have suggested that the biopsychosocial may be insufficient in preventing a mind-body dualism in clinical practice. In this sense, it has been argued that there is a need to extend the model to also include existential aspects (Bullington, 2009; Bullington, Nordemar, Nordemar, & Sjöström-Flanagan, 2003; Ghaemi, 2009; Lundberg, Styf, & Bullington, 2007).

2.4.1 Integrative health care as a response to patients' health care needs

The interest in integrative health care, in this thesis, was prompted by patients' common use of complementary and integrative health care, specifically for chronic pain. Integrative health care is a developing form of interdisciplinary collaboration with various degrees of establishment in different countries, health care settings and jurisdictions (Ammon et al., 2012; Wiesener et al., 2012). Hollenberg & Bourgeault (2011) suggests that there are both differences and similarities in interdisciplinary collaboration between conventional and integrative health care. A similarity is the goal to improve patient care and patients' health. The main difference is that integrative health care involves collaboration across different paradigms, whereas inter-professional collaboration in conventional care concerns collaboration within the same paradigm.

The area of integrative health care needs be understood in relation to both history and to context (Gaboury et al., 2012; Gale, 2014). Kaptchuk and Miller (2005) have argued that there is a need to move beyond the distinctions of conventional and complementary health care as models opposite to each other, rather suggesting that a pluralistic health care model would allow different health care professions to coexist and collaborate, recognising and

accepting each other's differences. There are different approaches to interdisciplinary collaboration, including collaboration within integrative health care.

2.4.2 Practitioners' collaboration within integrative health care

In research on integrative health care, the importance of practitioners' collaboration has been emphasised (Boon, Verhoef, O'Hara, & Findlay, 2004; Boon, Verhoef, O'Hara, Findlay, et al., 2004). From a theoretical perspective, Boon et al. (Boon, Verhoef, O'Hara, Findlay, et al., 2004) have developed a theoretical model for integrative health care, including the philosophy/values, structure, process and outcomes in order to guide practitioners and health systems when developing integrative health care. This initial framework was then further developed into seven different models of integrative health care: parallel, consultative, collaborative, coordinated, multidisciplinary, interdisciplinary and integrative (Boon, Verhoef, O'Hara, & Findlay, 2004). The different models are described on a continuum from non-integrative (parallel model) to fully integrative (integrative model) (Boon, Verhoef, O'Hara, & Findlay, 2004). The integrative model refers to an interdisciplinary, non-hierarchical integration of conventional medicine and complementary health care, with an interdisciplinary team approach that involves mutual respect, trust and understanding allowing for each practitioner to contribute to the care with respect to their different skills and knowledge. Creation of a common goal and philosophy of health care and rehabilitation have been highlighted as key ingredients in interdisciplinary collaboration, including integrative health care and chronic pain rehabilitation (Belanger & Rodriguez, 2008; Boon, Verhoef, O'Hara, & Findlay, 2004; Gatchel et al., 2014; Hellman, Jensen, Bergstrom, & Bramberg, 2016). However, in research about integration between conventional and complementary care, there is often a biomedical dominance in the collaboration (Wiese, Oster, & Pincombe, 2010). This dominance is described in terms of a broader political and societal dominance of the biomedical paradigm. A biomedical dominance has also been shown in the discourse between practitioners, with a collaboration characterised by a biomedical language as well as steered by the conventional physicians in the team (Anderson, 1999; Frenkel & Borkan, 2003; Gaboury, Lapierre, Boon, & Moher, 2011; Hollenberg, 2006). Anderson (1999) demonstrate how a test panel of conventional and complementary practitioners used a biomedical language to discuss patients with back and neck pain. In the panel, alternative theories or non-Western theories were expressed, but the theories were not discussed or contested. Thus, even though a theoretical understanding about important aspects of collaboration in integrative health care exists, such collaboration seems difficult to achieve in practice. However there is a lack of studies exploring how the interaction within a team of practitioners working with interdisciplinary integrative health care develops over time.

2.5 UNDERSTANDING AND EVALUATING PATIENTS' EXPERIENCES

2.5.1 Approaches to evaluation

Several researchers have recommended that integrative health care needs to be understood as a complex system of care, or even as a "black box", since it consists of multiple care components that are individually adjusted and directed towards the whole person (Bell & Koithan, 2006; Bell, Koithan, & Pincus, 2012; Walach, Falkenberg, Fonnebo, Lewith, & Jonas, 2006). From this perspective it can be argued that the overall effectiveness of integrative health care can be measured, but that the evaluation of what and how much each care component contributes to the overall effectiveness of integrative health care remains unknown or hidden in the "black box" (Walach et al., 2006). Similarly, Bell et al. (2012) argue that whole system care, such as integrative health care, is non-linear, evolving and dynamic and thus needs to be evaluated with respect to this nature. They conclude that there are no single, easily predefined outcomes in whole system research. This is a question of epistemology, where the question whether or not integrative medicine works has been considered as the "the big question" (Gale, 2014). Walach et al. (2006) question the nature of such a hierarchical model of evidence in healthcare, which is largely limited to investigations of specific efficacy. They argue that a broader circular evidence model may be more appropriate for whole systems research and use the "efficacy paradox" as an example of how non-specific and specific effects may influence statistical significance, and thus show that the hierarchical model in some cases might be misleading for the evaluation of the general effect of complex health care interventions (Walach et al., 2006).

In relation to rehabilitation of chronic pain, it has been argued that the differences in existing interdisciplinary rehabilitation programs for chronic pain do not allow comparisons between the different programs or an understanding about which components in the programs that contribute to the effect (Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2010). Therefore, there is a need to further the understanding about the process of care within different rehabilitation programs including integrative health care and patients' experiences of changes in health.

2.5.2 Understanding patients' experiences of integrative health care

Qualitative research on patients' experiences of integrative health care shows that patients may experience unanticipated changes in health (Arman & Hok, 2016; Cartwright & Torr, 2005; Hsu, Bluespruce, Sherman, & Cherkin, 2010; Hunter, Marshall, Corcoran, Leeder, & Phelps, 2013; Koithan, Verhoef, et al., 2007). One example is that patients who initially turn to complementary health care for treatment or symptom reduction describe a shift in focus towards a wider view of health and wellness (Arman & Hok, 2016; Cartwright & Torr, 2005; Rugg, Paterson, Britten, Bridges, & Griffiths, 2011). Rugg et al. (2011) describe how patients take an active role in their treatment. This has been described as a change in empowerment,

with improved self-care skills, where patients take responsibility for their health (Arman & Hok, 2016; Koithan, Bell, Caspi, Ferro, & Brown, 2007). Research has also shown how participants take control over their health, finding new ways to handle both their health problems and their life better, including dealing with stress, life and illness (Cartwright & Torr, 2005).

Other changes happening to patients can include increased awareness, more energy, and changes in social relations (Cartwright & Torr, 2005; Paterson & Britten, 2003; Rugg et al., 2011). Increased awareness is described in terms of becoming more balanced with oneself, adopting a healthier lifestyle, being aware of one's body and its needs. This may result in a new look at oneself, including one's self-identity and self-worth (Cartwright & Torr, 2005). Patients also describe how they get more physical energy, increasing their experienced ability to do daily activities and exercise (Rugg et al., 2011). Energy is also described in terms of being more alert, with an increased ability to concentrate and solve problems as well as in terms of a 'boost' to total relaxation (Cartwright & Torr, 2005). Cartwright & Torr (2005) have also reported changes in social and professional relationships, including increased acceptance and tolerance of others, being less judgmental and more interested in others' interests.

Unexpected changes in health have also been shown in research about patients receiving integrative health care for chronic pain conditions. Hsu et al. (2010) have explored outcomes experienced as meaningful by patients living with chronic pain after complementary health care. In the study it was shown that patients experienced increased treatment options and hope, increased body awareness and ability to relax, positive emotional changes, as well as changes in thinking, allowing them to cope better with their back pain. However, these changes in health were elucidated with qualitative methods' rather than detected with existing instruments.

2.5.3 Instruments to measure patients' changes in health and suffering

In research as well as in clinical health care practice there has been a long debate about how to best evaluate patients' changes in health, including relevant outcome measures to capture patients' changes in health and suffering after integrative health care. The reason for this discourse is recognition that major components of patients' experiences of changes in health and suffering after complementary and integrative health care have not been captured with existing instruments (Hunter J, 2013 ; Verhoef & Mulkins, 2012). Thus, there is a gap in evidence, where qualitative studies have elucidated patients' experiences and changes in health and alleviation of suffering, although these experiences have not been shown to the same extent in quantitative studies (Paterson & Britten, 2003). It is argued that a range of aspects needs to be further assessed, such as wellness and holistic health (Hunter J, 2013) and the process of personal transformation (Verhoef, Mulkins, & Boon, 2005).

Various instruments have been used to assess health and changes in health in integrative health care. Commonly used generic instruments, such as SF-36 (McHorney, Ware, & Raczek, 1993; Ware & Sherbourne, 1992) and WHOQOL-BREF (Skevington, Lotfy, & O'Connell, 2004; The WHOQOL Group, 1998) have enabled comparisons between different contexts and patient groups. However, such instruments have not been considered to capture the nature of patient experiences and changes in health following integrative health care (Coons, Rao, Keininger, & Hays, 2000; Skevington et al., 2004; The WHOQOL Group, 1998; Ware & Sherbourne, 1992). There are several instruments that assess existential health, such as the spiritual wellbeing scale (Ellison, 1983; Ledbetter, Smith, Fischer, & Vosler-Hunter, 1991), WHOQOL-SRPB (Moreira-Almeida & Koenig, 2006; WHOQOL, 2006) and the purpose in life scale (Crumbaugh & Maholick, 1964). These instruments assess different constructs of existential health, often with a focus on meaning. For example, "The Purpose in Life scale", originally developed by Crumbaugh and Maholick (Crumbaugh & Maholick, 1964) assesses meaning in life. It consists of three dimensions: will to meaning, freedom of will and meaning in life. The WHOQOL-SRPB questionnaire addresses eight areas of existential health including religious aspects and personal beliefs (Melder, 2011). Another instrument, the self-assessment of change (Ritenbaugh et al., 2011; Thompson et al., 2011), has been developed to assess changes in health after integrative health care. However, none of these instruments were perceived to fully capture the range of patients' health changes after receiving the integrative health care reported in qualitative studies (Arman & Hok, 2016; Arman & Rehnsfeldt, 2007; Bell & Koithan, 2006; Cartwright & Torr, 2005; Hsu et al., 2010; Hunter et al., 2013; Koithan, Verhoef, et al., 2007; Mulkins & Verhoef, 2004; Rugg et al., 2011). From a caring science perspective, an extended understanding of patients' experience of the development of health and suffering is not limited to the causal explanations of specific efficacy. Instead, as Eton, Bauer, Sood, Yost, & Sloan (2011) have argued, multiple aspects of patients' health and wellbeing may be affected in integrative health care. These may include existential signs of health and suffering as described in qualitative research. At present, there is a lack of relevant instruments that adequately capture patients' experiences and changes in existential health and suffering.

3 RATIONALE

Musculoskeletal conditions including chronic pain are the most common reasons for patients to turn to complementary and integrative health care. Due to the complexity of chronic pain and the implications for the patients' daily lives, interdisciplinary rehabilitation is now recommended to address patients' needs from a biopsychosocial perspective. Integrative health care is one such form of interdisciplinary approach that provides a whole person perspective of care. Although there are promising results of interdisciplinary rehabilitation, including integrative health care, there are challenges in understanding the processes of such care as well as how to measure and understand patients' changes in health and suffering, including existential dimensions.

From a caring science perspective, health and suffering are understood as involving multidimensional experiences of an existential character. Previous studies investigating patients' experiences of complementary and integrative health care have reported unanticipated and existential changes in health. Few studies have investigated patients' experiences of integrative health care in the setting of comprehensive models or established integrative health care hospitals for pain rehabilitation. Moreover, there is a general gap in knowledge concerning the caring practice in different integrative health care settings. Specifically, there is a lack of research elucidating how practitioners conceptualise care and how collaboration and interaction develop between practitioners in different kinds of integrative health care teams. Available instruments that measure patients' experiences of health and suffering do not specifically capture patients' experiences of changes in health after interdisciplinary integrative health care. To improve patient care it is essential to improve the understanding of the processes of care as well as the outcomes of care in terms of patients' experiences of caring, health and suffering.

4 AIM

The overall aim of this thesis is to elucidate patients' and practitioners' meaning-making in integrative health care by studying their experiences of chronic pain rehabilitation, and to contribute to the development of a patient instrument measuring existential signs of health and suffering.

Specific objectives are:

1. To explore patients' experiences and perceptions when receiving conventional or integrative care in the management of back and neck pain.
2. To explore how the interaction and collaboration developed between integrative health care providers participating in a series of case conferences for consensus-based management of patients with back and neck pain during a pragmatic randomized controlled clinical trial in primary care.
3. To elucidate the meaning of anthroposophic practitioners' conceptualisations of caring for persons living with chronic pain.
4. To develop a first version of an instrument to measure patients' experience of health and suffering, focusing on existential signs.

5 METHODS

5.1 DESIGN AND SETTINGS

The overall thesis design is a qualitative enquiry. The choice of a qualitative approach was based on the overall aim of the study. Research questions concerning meaning-making in relation to caring, health and suffering can be answered best using an inductive perspective, capturing the essence of the meaning-making in the contexts where they are experienced (Patton, 1990). Thus, processes of interaction were studied as they happened and the patients' and practitioners' experiences were captured by listening to and interpreting their own voices and descriptions.

The four studies included in this thesis were conducted in two different integrative health care settings; a model for integrative health care in primary care (studies I and II), and in the setting of a long-term clinically established anthroposophic integrative health care hospital (studies III and IV). Although both settings were integrative health care, with a combination of conventional and complementary health care, the two settings were also different in many aspects. The two different models and settings are described below.

A model of integrative health care for a primary care setting

The first two studies were conducted in the setting of a pragmatic randomised clinical trial in primary care whereby conventional primary care was compared with a model of integrative health care delivering conventional primary care integrated with naprapathy (manual therapy), massage therapy, acupuncture, qigong and shiatsu in the management of patients with back and neck pain. Participating primary care units were located in the suburbs of Stockholm, Sweden.

The integrative health care model in primary care was developed in a research project with the aim of exploring a non-hierarchical, interdisciplinary and patient-centred mix of conventional and complementary health care for patients with back and neck pain. The development and implementation of the integrative primary care model was conducted between the years 2003-2006 and has been described in detail elsewhere (Sundberg, Halpin, Warenmark, & Falkenberg, 2007). In short, the integrated primary care team consisted of eight health care providers representing general practice, Swedish massage therapy, naprapathy (manual therapy), shiatsu, acupuncture, and qigong. Patients were recruited from four primary care units in south suburban Stockholm. Inclusion criteria were males and females, 18 to 65 years old that had non-specific low back pain or neck pain that had lasted for at least two weeks. Exclusion criteria were patients with severe causes of back and neck pain, including specific pathologies such as fractures, infections, disc hernias, cancer, or osteoporosis (Sundberg et al., 2007; Sundberg, Petzold, Wandell, Ryden, & Falkenberg,

2009). Eighty patients were randomised to receive either conventional primary care or the developed integrative health care model. The conventional primary care management of the patients was coordinated by the treating general practitioners and followed standard primary care routines and guidelines such as advice, prescription of analgesics, referral to physiotherapy and sometimes a certificate for sick leave. The primary care patients in the intervention group received conventional primary care management integrated with individualized complementary treatments to form the integrative health care, which was based on consensus group discussions of the integrative health care team. The patients received on average seven integrative health care treatments over a period of ten weeks in addition to the conventional primary care. The comparative effectiveness of the integrative health care model intervention was compared to usual primary care and has been evaluated quantitatively (Sundberg, Hagberg, Zethraeus, Wändell, & Falkenberg, 2014; Sundberg et al., 2007; Sundberg et al., 2009). This thesis contributes with qualitative evaluations based on the developed primary care model of integrative health care (studies I and II).

Anthroposophic integrative health care in a hospital setting

The setting of the third and fourth studies was a long-term established anthroposophic hospital located in the countryside south of Stockholm, Sweden. Anthroposophic medicine was founded by Rudolf Steiner and Ita Weigman in the 1920s and is internationally established in 80 countries worldwide (Kienle et al., 2013). In Sweden, anthroposophic integrative health care has been provided since the 1980s and has been supported by provider agreements with major county councils in Sweden. The hospital design with colouring, material and architecture of the building is understood to give support to the patients' healing process by providing a caring atmosphere (Vidarkliniken, 2016). There are several large gardens around the study hospital and an inner garden in the main building contributing to a calm atmosphere. When entering the hospital, there is a sign requesting visitors to turn off mobile phones, while inside, there are no computers or televisions in sight. There are several wards in the hospital, and patients can gather in common living rooms to socialize.

Anthroposophic care is based on a holistic view of the human as an integrated entity of body, spirit and soul (Kienle et al., 2013). All aspects of the care rest on this view of the human being. The anthroposophic hospital offers rehabilitation for patients with different medical conditions, including chronic pain, stress-related conditions, cancer diagnoses and palliative care. Conventional and anthroposophic therapies such as massage and music therapy, arts and crafts, nursing baths and natural remedies are integrated and provided by a team consisting of licensed physicians and licensed nurses and anthroposophic therapists. In this thesis, practitioners working in a one-year rehabilitation program for patients with chronic pain were included as part of a larger research project, also focusing on patients' experiences of the program. The program has been described by Arman & Hök (2016). The one-year long

rehabilitation program involved 21 days in-patient care followed by two day care periods once a week over two ten-week periods. Patients’ treatment plans were individually adjusted involving care from physicians, nurses and anthroposophic therapists. In addition, some patients received psychotherapy and there were also group handicraft sessions in the program (Vidarkliniken, 2015). Table 1 gives a methodological overview of the four studies in the thesis.

Table 1. Methodological overview of study I-IV.

Study	Context	Sample	Data	Analysis
1	A model of integrative health care within primary care	Patients that had received integrative or conventional health care	11 focus group discussions with 26 participants	Latent content analysis
2		Practitioners working in the integrative health care team	Naturally occurring group discussions (n=15)	Discourse analysis, combining discourse psychology and discourse theory
3	Anthroposophic hospital based integrative care	Practitioners working with hospital pain rehabilitation	Individual interviews (n=15)	Phenomenological hermeneutical method
4		Patients that had received health care in the anthroposophic hospital context Experts	Instrument development: Item pool development through qualitative interviews (n=64), cognitive interviews with patients (n=8) and expert opinions (n=5)	Development of an item pool, refining and further development of items

5.2 DATA COLLECTION

Data for the four studies were collected through group discussions and individual interviews. In the primary care studies (studies I and II), two different types of group discussions were used. Data in study I was collected through focus group discussions exploring patients’ experiences and perceptions of conventional and integrative primary health care, whereas data for study II about providers' collaborative processes were collected during naturally occurring clinical patient conferences in primary care (Barbour, 2007; Kitinger, 2013).

In the hospital care studies (studies III and IV), different interview-based data collection techniques were used. The data for study III, elucidating practitioners’ meaning in relation to caring, used individual interviews with an open dialogue based on semi-structured questions (Kvale, 2009). Dialogue based, semi-structured interviews and cognitive interviews using the think-aloud technique were used in the instrument development process in study IV (Knafl et al., 2007; Sudman, Bradburn, & Schwarz, 1996; Willis, 2005).

5.2.1 Focus group discussions (study I)

All primary care patients that had received conventional or integrative health care in the randomised clinical trial were informed about the study and subsequently invited by telephone to participate in a volunteer focus group discussion. Focus group discussions were used since it was perceived that the interaction in the group of participants would generate a rich discussion (Barbour, 2007; Kitzinger, 2013). Thirty-three percent (26/80) of those initially included in the randomised clinical trial participated in the focus group discussions. In total, 15 informants that had received integrative health care and 11 informants that had received conventional primary care participated in 11 planned focus groups. The focus groups were conducted at one of the participating primary care centres. In some of the focus groups, fewer informants than expected participated, mostly due to late cancellations. In one of the focus groups only one informant participated, and it can therefore be considered as an interview. However, all focus groups and the interview were included as the informants were considered to share and discuss their experiences and perceptions of conventional and integrative health care for back and neck pain. Barbour & Kitzinger (Rosaline Barbour, 1998) suggest that a focus group may be used to explore participants' experiences, opinions, wishes and concerns around a specific topic. A question guide was used to support the discussions around the topic of the study. A moderator guided the focus groups and an observer noted the interactions and asked some clarifying questions.

5.2.2 Group discussions in patient conferences (study II)

The data collection for study II was performed at clinical patient conferences conducted by the integrative health care team in primary care during the randomised clinical trial (Sundberg et al., 2007). There were 26 patient conferences in total over a time period of one year and four months. The time between the conferences was approximately two weeks with breaks over the summer holidays and Christmas. Neither the number of patient conferences nor the exact structure of practitioner interaction and collaboration was decided on the start of the clinical trial. Instead, the patient conferences were an on-going process, which evolved as the patients were included in the trial and the practical process of managing and treating patients started. The main focus of the patient conferences was to decide upon the continued treatment plan for the patients included in the clinical trial. All patient conferences were audio-recorded. In order to analyse how the interaction and collaboration developed, patient conferences from different time points (five at the beginning, five in the middle and five at the end of the clinical trial) were selected for analysis.

5.2.3 Individual interviews (study III)

All physicians, nurses and other practitioners working with rehabilitation of patients with chronic pain at the anthroposophic integrative hospital were invited to participate in interviews. The reason all participants were invited was the researchers' interest in elucidating the meaning of different practitioners' conceptualisations of caring for patients with chronic

pain. A program coordinator assisted in identifying the practitioners in the program, who were contacted personally by the interviewers. To make personal contact was based on advice from the program coordinator, since all of the practitioners did not use mobile phones frequently. This process of identifying and contacting practitioners involved a familiarization with the field, spending time at the ward in order to encounter and inform the practitioners. Field notes were taken during the whole process of data collection. Fifteen practitioners agreed to participate and two declined participation due to time constraints. Twelve of the participants were women and three were men. The mean age was 56 years and the participants had between two months' and 30 years' working experience at the hospital. Although two invited practitioners declined to participate, all occupational groups within the pain rehabilitation program were represented.

Two researchers performed the interviews, doing three and 12 each. Before the start of each interview the interviewer located an available room at the clinic or at the nearby research office. The participants were given the possibility to have the interview at the clinic or in a nearby research office. The interviews were conducted in separate rooms and lasted between 27 and 78 min. The interviews were conducted face to face, using an interview guide with open questions. When needed, the question guide was followed. However, the interviews were approached as a dialogue about the practitioners' lived experience of their own work experiences and reflections on working with patients with chronic pain. In this sense, the practitioners were allowed to define the topic of conversation. In addition, neutral probes described by Bernard (2011) including for example being silent, echoing what was said, and just nodding, saying 'OK' and 'I see' were used to stimulate the practitioners to narrate their experience. Two follow-up interviews were performed to further explore some initial interpretations. A physician and an anthroposophic therapist were asked to participate in those interviews. Interpretations of commonly used concepts were used as a guide. The practitioners were asked to describe their thoughts about the concepts.

5.2.4 Instrument development using a qualitative approach (study IV)

The chosen process of instrument development draws on a methodological principle for instrument development (Clark & Watson, 1995; Wilson, 2005) that involved three iterative phases. In this process, several data sources were used. First, an item pool was developed from previously collected data from patient interviews conducted in the period 2002-2015. The included data consisted of qualitative interviews (n=64) focusing on patients' experiences of health and suffering in the context of anthroposophic integrative health care in Sweden. Data were included from four different studies (data sources 1-4) with different patient groups with diagnoses of chronic pain, burn-out syndrome or cancer.

In the second step, the relevance of the developed items was explored in order to further refine the developed items. In total, eight patients at the anthroposophic hospital participated in two rounds of cognitive interviews, using the technique of thinking aloud as a means to

elicit data on participants' thought processes (Knafl et al., 2007; Sudman et al., 1996; Willis, 2005). All participating patients were females, with a mean age of 54 years and had diagnoses of cancer, chronic pain or stress-related illness. The interview started with training of the thinking aloud technique, where the participants were asked to reflect about one or a few questions. After that the respondent read and reflected (thinking aloud) about each question. Probes concerning comprehension, such as "What does the concept mean to you?" were used when needed.

In the third step, the items were discussed with experts. The selection of experts was based on their perceived ability to contribute to content validation in the instrument development process (American Educational Research Association, 1999; Grant & Davis, 1997). Five experts were selected based on three inclusion criteria, namely their experience and knowledge in (1) the theoretical field of Nordic caring science, (2) instrument development and, (3) relevant clinical health care experience. At least three of the experts covered each of the inclusion criteria. Data were collected through individual meetings with each expert, lasting approximately 45 minutes to three hours. The experts were informed about the instruments, including their conceptual underpinning, definitions and dimensions, as well as the measurement model of the instrument and were then asked to reflect on item content, item style and comprehension (Grant & Davis, 1997). The three phases of instrument development are shown in figure 1.

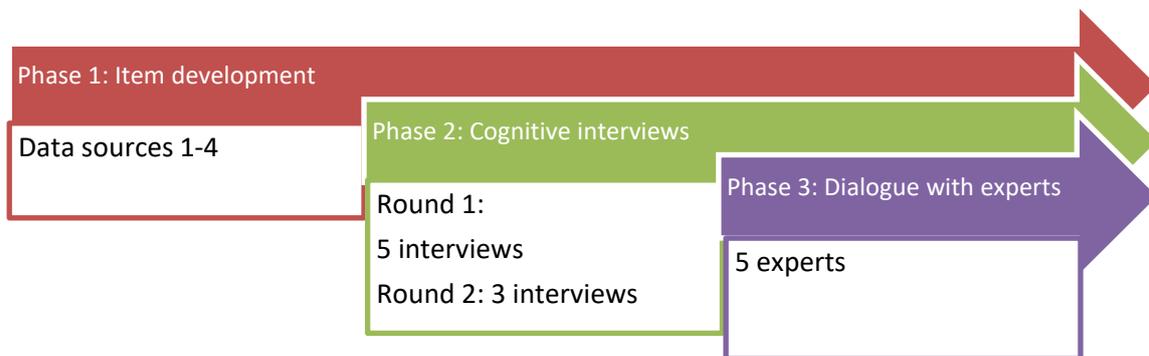


Figure 1. Study IV, three phases of instrument development

5.3 DATA ANALYSIS

The study aims guided the choice of method for analysis in the different studies, described in relation to each study. Focus groups discussions (study I), patient conferences (study II), and interviews with practitioners (study III) and patients (study IV) were audio-recorded. Notes were taken during the experts' meetings in study IV. Collected data were transcribed verbatim for analysis.

5.3.1 Content analysis (study I)

To explore the patients' experiences and perceptions of integrative and conventional health care (study I), the analysis was guided by principles of latent content analysis (Graneheim & Lundman, 2004). Content analysis is used to interpret data in various levels of abstraction. 'Latent content' refers to the implicit, underlying meaning of a text, whereas the visible, explicit, obvious components of a text have been described as the manifest content (Graneheim & Lundman, 2004).

When analysing the interview transcripts, first the research team read all the material to get a sense of the whole. Meaning units, referring to words, sentences or paragraphs in the data that were seen as related to each other in content and/or context were condensed. Condensing a meaning unit is a form of reduction and shortening of a text while preserving the core meaning (Graneheim & Lundman, 2004). The meaning units of the transcripts were digitally marked in the computer program OpenCode and further condensed into codes. Graneheim and Lundman (2004) write that a code is a form of labelling, a tool that enables the data to be used in a new way. The codes were used as a further abstraction of the meaning of the text, enabling further understanding of the latent content in the data. The meaning units and codes were compared and structured into sub-themes, themes and an over-arching theme. A theme refers to a tread of an underlying meaning, the expression of the latent content in the text (Graneheim & Lundman, 2004). The process of analysis was performed inductively; moving in-between text as a whole and its different levels of abstraction.

5.3.2 Discourse analysis (study II)

In order to explore and to gain a better understanding of the process of interaction and collaboration among practitioners in integrative health care (study II) the data was analysed using discourse analysis. There are a variety of different discourse analysis approaches; the analysis in this study was based on discursive psychology (Potter & Wetherell, 1987; Yates, Taylor, & Wetherell, 2001) and influenced by discourse theory (Glynos, 2012; Laclau, 1990; Laclau & Mouffe, 2001; Žižek, 1990). Different approaches of discourse analysis are based on different ontology, focus and purpose (Glynos, Howarth, & Norval, 2009). This can be exemplified in the definitions of discourse; a narrow definition used within discursive psychology is "a textual unit larger than a sentence", whereas discourse is defined as "a wider

set of social practices apart from the spoken and written language” within critical discourse analysis. An even wider definition of discourse is used within discourse theory. From this perspective discourse is understood to “cover all social phenomena” focusing on why and how a particular discourse is formed (Howarth & Torfing, 2004). However, all approaches share a common concern about the question of meaning, focusing on the construction and apprehension of meaning. Discourse analysis departs from a post-modernist view on reality where knowledge is understood to be shaped in interaction between us, thus as a social construction of reality rather than being a reflection of a certain reality (Potter & Wetherell, 1987). Burr (Burr, 2015) describes four characteristics of social constructionism, including (1) to be critical towards ourselves and our understanding about the world, especially the things we take for granted, (2) that the way we understand the world is specific to our cultural and historical time period, (3) that what we know about the world and ourselves is shaped in interaction between people, where language is an important part of the construction of understanding, and that (4) this understanding from a power perspective implicate of actions since some actions are socially accepted.

At first in the analysis, the whole transcripts were read through and coded, focusing on the process of interaction and collaboration as well as the content of the practitioners experiences. The analysis was guided by a discursive psychology which was developed as a reaction of a positivist tradition within psychology. The discursive psychology approach focuses on how people use language in everyday interaction and interpersonal conversations; for example, it can be a way to make things happen or a way to present their view of the world. Analytical questions guided the analysis, focusing on patterns, differences (variability) and consistency of the collaborative process. The concept of subject positions was used to understand how the practitioners positioned themselves in the integrative health care team (Laclau, 1990; Yates et al., 2001; Žižek, 1990). In order to further the understanding of how the practitioners positioned the team in a larger medical discourse, the analysis drew on theories from the discourse theoretical approach (Glynos, 2012; Laclau, 1990; Laclau & Mouffe, 2001; Žižek, 1990). Discourse theory is influenced by post-structuralism, post-Marxism and post-modernity, questioning the notion of truth, essentialism and dominant ideologies and structures (Howarth & Torfing, 2004). Identity is seen to be “shaped in and through its relation to other meanings”.

5.3.3 Phenomenological hermeneutical analysis (study III)

The practitioners' conceptualisations about caring were analysed using a phenomenological hermeneutical method (Lindseth & Norberg, 2004). Within phenomenological hermeneutics, the essential meaning of the lived experience is elucidated in texts and the meaning is interpreted in a circular movement between parts of the text and the whole. In the analysis, the entire text was read to grasp the meaning of the whole body of material. This reading is what Lindseth and Nordberg (2004) refer to as the naïve understanding, when the interpreter become touched and moved by the text. Often the meaning we attach to something is taken

for granted; in phenomenology this is referred to as our *natural attitude*. The naïve understanding was formulated in a phenomenological language that included initial areas of interest as well as a first description of the practitioner's use of shared concepts. The shift between a natural and phenomenological attitude is described as epoché or bracketing of the natural attitude.

In a structural analysis, the researchers strived to adopt a *phenomenological attitude*, where the meaning structure and its typical traits/features appeared. At first meaning units were identified, condensed and sorted into themes. In this process, the meaning units and preliminary themes were reflected upon against the naïve understanding. Lindseth and Norberg (2004) describe the process of reflecting upon the themes in relation to the naïve understanding as a way to validate or invalidate the naïve understanding. Although this step was followed, it was rather a question of a hermeneutical circle with a dialogue between the pre-understanding and the core of the text (Gadamer & Melberg, 1997). In order to further the understanding of the concepts in relation to caring, the structural analysis continued by analysing the essential meaning of the concepts as a reflection of the practitioners' lived experience of caring. The two follow-up interviews were also analysed, with a focus on the practitioners' understanding of the concepts. The themes and concepts that had emerged to underpin the core of each theme were reflected upon in relation to the naïve understanding and the text as a whole, an interpretation that led to a new and comprehensive understanding. In the process of data analysis, all the authors collaborated and discussed the interpretation.

5.3.4 Instrument development (study IV)

The analysis drew on established principles for instrument development (Clark & Watson, 1995; Wilson, 2005). The initial data (sources 1-4) were analysed in an interpretative process in order to elucidate the meaning of health and suffering, with a focus on existential signs, using the patients' words to formulate items. The qualitative analysis was guided by a hermeneutical approach in order to elucidate expressions that carried existential meaning in relation to health and suffering in line with the aim of the study (Gadamer & Melberg, 1997). Meaning units addressing the experience of health and suffering were elucidated and condensed. From the identified meaning units, 153 items were formulated and grouped into domains (Wilson, 2005). The formulated items were reflected upon in relation to theories in caring science in a hermeneutic process to further the understanding of health and suffering as interrelated phenomena (Arman, Ranheim, et al., 2015; Gadamer & Melberg, 1997; Lindström, 2014). The initial item pool was discussed between the participating researchers, who refined and reduced the item pool to form an initial draft of the instrument.

The initial draft of the instrument was used in two rounds of cognitive interviews and in meetings with experts (American Educational Research Association, 1999; Grant & Davis, 1997; Knafl et al., 2007; Sudman et al., 1996; Willis, 2005). After each round of cognitive interviews and after all meetings with experts the transcripts were analysed in order to refine and develop the instrument. In the analysis, problems concerning comprehension, recall, decision and response processes were independently analysed by three or four researchers in each round (Knafl et al., 2007). The identified problems in the analysis were discussed in the research team and problematic items were either revised or deleted. This resulted in three revisions of the instrument to be used in the next round of cognitive interviews and in the meeting with experts. All reasons for elimination and revision were documented and categorized by type of problem. Altogether, both respondents and experts contributed to the development of the construct of the instrument, the domains as well as the items in the instrument.

5.4 ETHICAL CONSIDERATIONS

All included studies in the thesis were approved by the regional ethics committee at Karolinska Institutet (Dnr: 668-03, 650-04, 121-32, 2014/5:2 and 2015/4:3), and followed the guidelines of the Helsinki declaration (World Medical Association, 2013). All participating patients and practitioners received oral and written information about the research projects and all patients and practitioners gave informed consent before participation in the studies. It is possible that participants might agree to participation in research to be cooperative. To avoid this, the researchers emphasised that all participation was voluntary. The participants in the studies were also informed that they could withdraw their participation at any time without further explanation or any negative consequences for their health care. When interviews and group discussions were held, the well-being and dignity of the participants had the highest priority. As such, the researchers were careful not to intrude on a person's integrity. When asked about the experience of participating in the interview or group discussion, the participants described their experiences in positive terms, the possibility to share their experiences was perceived as fruitful. As, such the perceived benefits of the research were understood to be greater than potential harms.

When data was collected, the information about the study was repeated, including information about the study, the data collection procedure and management as well as how the data would be used when reporting the result of the studies. In study II, this information was not repeated in each patient conference, but the researchers repeatedly reminded the participating practitioners about the future analysis of their discussions. The participants were informed that the collected data would be treated with confidentiality by the researchers and that the audio-recorded data would be transcribed and anonymized using coding lists. The anonymized transcripts and coding lists were stored in separate secured and locked locations to which only the researchers had access. During the data analysis and presentation of the

results, the anonymity of the participants was carefully considered and respected. Therefore, only quotations that did not reveal personal information that could be used for identification of patients or practitioners were selected. When presenting participant characteristics the anonymity of the participants was also considered by only reporting data at group level.

6 RESULTS

6.1 PATIENTS' EXPERIENCES AND PERCEPTIONS (STUDY I)

The objective of study I was to explore patients' experiences and perceptions when receiving conventional or integrative health care in the management of back and neck pain. An overarching theme, three themes and eight sub-themes, presented in table 2, addressed the patients' experiences and perceptions of conventional or integrative health care.

Table 2. Overarching theme, themes and sub-theme.

Overarching theme	Integrative care combines valuable conventional medical diagnosis with empowering self-help strategies		
Themes	Management characteristics	Care strengths	Care weaknesses
Sub-themes	Specialist and reductionist management (CC)	Valuable diagnostic support (CC)	Lack of time, accessibility and guidance (CC)
	Health insurance paradox (CC)	Increased treatment response and less need for analgesics (IC)	Financial and collaborative challenges (IC)
	Whole person management (IC)	Individual support, empowerment and self-help strategies (IC)	
CC=conventional care characteristics; IC=integrative care characteristics			

The management characteristics of conventional and integrative health care were contrasted by the patients. Integrative health care was experienced and perceived in terms of a whole person management, including engagements in different aspects of a patient's life. Conventional primary care was described as being both specialized and reductionist. This involved a focus on disease and diagnostic procedures with limited options for care when there was a lack of medical diagnoses. In addition, patients experienced a health insurance paradox, where the public health insurance office could refuse to approve sick leave that the conventional care practitioner had advised.

Both conventional and integrative health care had strengths and weaknesses. The diagnostic support in conventional care was perceived as a valuable strength since it could exclude pathology as the reason for back or neck pain, even though the patients rarely experienced conventional care practitioners providing a biomedical explanation for their back or neck pain. Care weaknesses within conventional care were lack of accessibility, including both difficulties establishing personal contact and time constraints at the actual appointments with

conventional practitioners. When there was no medical diagnosis, patients' experienced limited further rehabilitation options and a lack of guidance.

The individual support in integrative health care was perceived as a valuable strength which seemed to empower patients to take more responsibility for their health. Instead of focusing on pain, patients described how the integrated health care approach helped them to shift their awareness towards increased body awareness and to focus on positive aspects of their life. It could also involve using the body in a more balanced way, which contributed to regaining mobility. Some patients experienced an increased treatment response and a reduced need for analgesics after integrative health care. However, there were also perceived weaknesses with integrative health care, namely financial and collaborative challenges. The collaborative challenges included patients' perceived that conventional and complementary practitioners had not been collaborating or communicating with each other outside of the integrative health care project. Furthermore, patients sometimes perceived conventional practitioners outside of the project to have negative preconceptions about complementary therapies advising against such use. Financial challenges arose when patients could not afford complementary therapies outside the project. Taken together, the patients emphasised the advantage of integrative health care was that it offered a combination of valuable conventional medical diagnosis with empowering self-help strategies.

6.2 PRACTITIONERS' PROCESS OF COLLABORATION (STUDY II)

The objective of study II was to explore how the interaction and collaboration developed between integrative health care providers participating in a series of case conferences for consensus-based management of patients with back and neck pain during a pragmatic randomized controlled clinical trial in primary care. The providers in the study are here referred to as practitioners. The practitioners participated in a series of case conferences for consensus-based management of patients with back and neck pain during a randomised controlled clinical trial in primary care. The results present the discursive constructions of a collaborative process where the practitioners learned to capitalize on the synergies of their collaboration and developed a shared vision of integrative health care. The results present the process of collaboration with an overarching theme and three sub-themes, shown in table 3.

Table 3. Themes and sub-themes.

Patient conferences:	In the beginning (1-5):	In the middle (6-10):	In the last (11-15):
Theme 1: The process of collaboration			
Sub-theme 1.1: Building consensus-based decision-making	A slight biomedical dominance in discourse	Consensus-based integrative decision-making	
Sub-theme 1.2: Building a team	Positioning themselves as individual provider subjects. Emphasizing individual therapies and roles. Learning from each other's methods	Positioning themselves as members of a team— Capitalizing on the knowledge and strength in the integrative health care collaboration. Confirming and contesting each other's informed discussions. Finding their different roles	
Sub-theme 1.3: The evolving role of integrative health care	Searching for a goal for integrative health care.	Emphasizing the importance of complementary therapies	Defining and discussing the goal of integrative health care
	Discussing collaborative shortcomings	Positioning the integrative health care team as an enchanted choice to conventional health care	

The first theme, “Building consensus-based decision-making”, focused on how the decision-making about the patients was structured and negotiated within the integrative health care team. At first, the physician was positioned as an informal leader in the process of decision-making. This was shown by the physician’s use of the pronoun “I” in the decision-making process and by the fact that most decisions about the patients’ treatment were based on the physician’s initial suggestions. At the same time, the complementary therapy practitioners did not make as frequent suggestions about the patients and when they did, these did not have the same impact as the physicians’ suggestions. However, the integrative health care team practitioners’ involvement increased in the middle and at the end of the project. The discourse became more dynamic and the integrative health care team was able to more easily conduct consensus-based decisions about patient's individual treatment plans. This was shown in the discourse as the integrative health care team members both contested and agreed with each other’s treatment suggestions in informed discussions.

The second theme “Building a team”, described the process on how the integrative health care team gradually formed a group identity by moving their subject positions from individual treating subjects to members of a team. At first in the collaboration, the practitioners constructed themselves and the other practitioners as individual treating subjects in the discourse. This was shown when the practitioners explained and emphasised their own

therapies to each other as well as when they tried to understand their own and the others' different roles in the integrative health care team. There was a change in positioning in the collaborative process, where the integrative health care team members moved from a position as individual treatment subjects to a position as members of a team. This process started as they noticed the benefits of the collaboration, such as being able to learn from and share information between each other in the team. Being in a team is not as lonely as being a single practitioner. The practitioners learned about each other's methods and roles in the team and were able to discuss each other's suggestions. At the end of the project the discourse of the conferences shows that the integrative health care team capitalized on the collaboration. The discourse focuses on the importance of the team rather than on each practitioner's individual contribution about the patients' treatment. They also perceived that the power of their collaboration in the team gave the patients confidence in them.

In the third theme, "The evolving role of integrative health care", the practitioners capitalized on the strength of the team, and used the discourse to negotiate the role of the team within a larger medical discourse. At the beginning of the collaboration the integrative health care practitioners searched for a definition of the goal of integrative health care, focusing on what they would be able to contribute, such as a holistic perspective of health care. In the discourse, the practitioners referred to collaborative shortcomings and problematized integrative health care provision. In this sense, they were positioning themselves both as part of the conventional health care and as a marginalized practice. The team negotiated the role of integrative health care provision by suggesting different strategies for strengthening integrative health care within the conventional health care system, including education and policy change. At the end of the project the discourse of the patient conferences showed that the integrative health care team had developed a shared vision of the provision of integrative health care.

6.3 PRACTITIONERS' USE OF SHARED CONCEPTS (STUDY III)

The aim of this study was to elucidate the meaning of anthroposophic practitioners' conceptualisations of caring for persons living with chronic pain. The practitioners' meaning-making was understood as an expression of central underlying caring values expressed in the interviews in the form of shared concepts. Four themes, each of which includes practitioners' use of two or three concepts, are used to illustrate the practitioners' reasoning and approach to patients. Examples of concepts the practitioners used and their conceptual meaning are shown in table 4.

Table 4. Example of concepts that the practitioners use.

Concepts	Conceptual meaning
<i>Trauma</i>	A strong negative experience; A physical and psychological trauma, an abuse or another situation in life that appears as a threat, or shock to the person
<i>Cramp</i>	A tension in the body, the person's energy is stuck in the body A psychological pain that has become physical
<i>Shelter</i>	A person's spiritual shelter between a person and the surroundings A safe and trustful, caring atmosphere
<i>Periphery</i>	Individuals that are more focused on others than themselves
<i>Split</i>	Individuals that are split between their thoughts, what they want, and their feelings
<i>Self</i>	A person's inner self, their essence or being
<i>Process</i>	A person's healthy growth or development in health
<i>Life intention</i>	A person's destiny, their longing in life

In the theme, “The patient as suffering from trauma”, the practitioners emphasised the importance of treating patients respectfully, observing and listening to their lived experience of pain, which was understood as a form of suffering with many dimensions. The concepts *trauma* and *cramp* were used to reflect on patients’ suffering, such as stressful life experiences. In the second theme “Developing a caring shelter”, the concepts *shelter*, *self* and *periphery* were used to address an inherent part of the caring culture with implications for caring. To create a caring *shelter* means assisting the patients to recreate and balance with themselves and others. The practitioners’ caring approach, the environment and different therapies are used to develop a *shelter* in caring culture. In the themes “Pain as an expression of the split self” the concept *split* and *self* was used to understand how the practitioners intended to encourage patients to encounter themselves and explore the meaning of pain in their life, in order to restore the balance between their, body, spirit and soul. The last theme “Engaging in a process to explore life intention”, focused on the concepts of *process* and *life intention* to address the importance of the patients finding their own resources for health. The results showed how practitioners used shared concepts, and how the concepts contributed to shaping a caring culture. The practitioners’ shared concept in this study focused on existential dimensions in relation to pain rehabilitation. From this perspective, the practitioners’ use of shared concepts is understood as an important basis of this kind of interdisciplinary pain rehabilitation.

6.4 MEASURING PATIENTS' HEALTH AND SUFFERING (STUDY IV)

The aim of the study was to develop a first version of an instrument to measure patients' experience of health and suffering, focusing on existential signs. The results present the process of development and revisions of the instrument until the production of the final instrument to be used in further psychometric testing. The patient instrument was based on two interrelated dimensions, the existential signs of "Health" and "Suffering", which were characterised by five domains: "Life passion and energy", "Personal freedom", "Presence in life", "Relationships" and "Meaning".

The format of the questions is grounded in the idea of health and suffering as interrelated and integral parts of human life. The final instrument has 20 items in the format of two concepts or small phrases where the respondents indicate their position on a visual analogue scale between the two concepts or phrases. An example of the instrument is presented in table 5, showing items in the domain "Life passion and energy"

Table 5. Items representing the domain "Life passion and energy"

Lack of energy	—————	Filled with energy
Tired of struggling	—————	Engagement in life
Tired of life	—————	Life passion

The domain "Life passion and energy" encompasses a phenomenon of engagement and life energy, consisting of different aspects of life passion and lack of energy, both physical and existential. The domain "Being present in life", was often experienced in glimpses, and described as an understanding about life in which chaos could be ordered or accepted. Accentuated suffering in this domain was described in terms of chaos and fear, when someone lost their grip on life. "Personal freedom" concerned the perceived ability to listen to oneself and to act in relation to what contributes to health in each person's life. The expression, to "run over" oneself was used to describe accentuated suffering, where one experienced being stuck in negative life patterns, pressured by demands. "Relationships", concerned the experiences of relations to others, ranging between an experience of being lonely to a feeling of having supporting and loving relations. The last domain, "meaning", concerned questions of meaning central to health and integral to a person's life, ranging between a life without meaning to a meaningful life. A meaningful life could involve a feeling of meaning and value, and it could also be described as an awakening, a new beginning with acceptance and reconciliation of suffering. A life without meaning was described as a constant struggle; sometimes one's whole existence was questioned.

During the development process, both experts and patients found the content of the instrument relevant and meaningful. They also gave valuable suggestions that both strengthened the developing construct and contributed to revisions. The first version of the instrument is ready for further psychometric evaluation with a variety of patient groups in different contexts. When fully developed, the instrument is intended to be used to measure existential signs in health and suffering.

7 DISCUSSION

7.1 DISCUSSION OF RESULTS

The results of this thesis show expressions and formation of meaning-making among patients and practitioners in relation to health, suffering and caring in integrative health care, focusing on pain rehabilitation. Specifically, the results of this thesis address patients' meaning-making in relation to experiences of caring (study I) and existential signs of health and suffering (study IV) and practitioners' meaning-making as formed in a collaborative process (study II) and expressed through shared concepts as a base for caring (study III).

7.1.1 Meaning-making in relation to caring

Meaning-making is understood as an ongoing process with new negotiations of meaning extending our understanding as well as our notions about our basic ontological values, which are not always conscious (Park & Folkman, 1997). The results presented in this thesis can be interpreted as meaning-making processes with an existential focus as expressed in patients' and practitioners' use of language. Gadamer (1997) states that there are concepts with a given meaning, while there is also an ongoing development of concepts, contributing to our understanding. Therefore, our understanding about the world we live in is also shaped through the concepts we use (Eriksson, 2012; Gadamer & Melberg, 1997). As such, in this thesis, language and concepts have been considered important in the construction of meaning (Bergbom, 2012; Burr, 2015). In relation to caring, Rehnsfeldt et al. (2016) have used the metaphor of a tree to describe the concept order in caring science; the roots represent the discipline's ethos and its inner values, the core of the tree represents the core concepts, and the branches represent specific praxis concepts related to the act of caring. In their words: "The better the ethos, essential concepts and theories are understood, the better the caring act can be understood" (Rehnsfeldt et al. 2016). From this perspective, it is central to reflect upon and speak about ontological questions in order to connect theoretical and practical understandings in caring.

7.1.2 Patients' and practitioners' meaning-making in integrative health care

The results of this thesis showed that patients with chronic pain in primary care (study I), despite some challenges, experienced being encountered as whole persons in integrative health care. Integrative health care were experienced as a valuable combination of biomedical diagnostics and empowering self-help strategies. In the results of study I, patients contrasted integrative health care and conventional health care in terms of a whole person vs. a reductionist approach. The reductionist approach in conventional health care was described as focusing on disease, with limited options for care when there was a lack of medical diagnoses. Such a reductionist view on health, with its heritage in the Cartesian dualistic split between the body and soul, is stereotypical and has been recognised as insufficient for patients with chronic pain (Gatchel et al., 2014; Swedish Agency for Health Technology

Assessment and Assessment of Social Services, 2010). Since chronic pain is considered to be a complex health problem leading to extended suffering, sometimes to the extent that a person's whole being in the world is affected (Bullington, 2009; Ojala, Hakkinen, et al., 2015a; Smith & Osborn, 2007), there is now a consensus about the need for interdisciplinary rehabilitation (Foster, 2011; Foster et al., 2003; Gatchel et al., 2014; Turk, 1996; World Health Organisation, 2010). Although, interdisciplinary rehabilitation including biological, psychological and social aspects is a valuable response to biomedical reductionism, with promising effects (Gatchel et al., 2014; Kamper et al., 2015), some researchers have pointed out the limitations of the model and emphasised the need also to embrace existential dimensions in the rehabilitation of chronic pain (Bullington, 2009; Ghaemi, 2009; Lundberg et al., 2007).

An initial point of departure in this thesis was patients' common use of complementary and integrative health care in addition to their use of conventional health care, specifically for chronic pain conditions (Barnes et al., 2008; Bucker et al., 2008; Eklöf & Tegern, 2001; Su & Li, 2011). The results of study I suggest that patients experienced and perceived integrative health care to be oriented towards the whole person, with individualized and personal caring encounters that they found to increase treatment response and hence, the level of meaning-making. These findings are in line with previous research concerning the main reasons for patients' use of complementary and integrative health care. This use has been shown to be motivated by the individualized and holistic characteristics of such care, its perceived influence on health, as well as the quality of the relationships with the practitioners (D'Crus & Wilkinson, 2005; Danell, 2015; Hanssen et al., 2005; Thorne et al., 2002). High expectations of being cared for and a positive attitude towards a holistic approach to health, rather than negative experiences of conventional health care have also been reported in relation to anthroposophic integrative health care (Arman, Hammarqvist, & Kullberg, 2011). As a way to further the understanding of caring within integrative health care, meaning-making among practitioners in two different settings was studied.

In this thesis, the practitioners' meaning-making in which the practitioners developed their collaborative practice (study II) and used shared concepts (study III) was understood as the basis of caring for the whole person. The results of this thesis show how practitioners' meaning-making, including a shared understanding and non-dualistic view of the human, was interpreted to extend their abilities to encounter the whole person and not just focus on their physical body and symptoms. The shared concepts used by the practitioners in study III can be understood as praxis concepts based in ontological values in the caring culture (Bergbom, 2012; Rehnsfeldt et al., 2016). Praxis concepts are described to carry the ethos of caring, i.e. the art or spirit of caring, although their meaning is not always explicit (Bergbom, 2012). The Swedish society of nursing (The Swedish society of nursing, 2016) highlights that everyday clinical work needs to be based on "positive concepts and values that characterise our stance and approach". A prerequisite for this is a continuous dialogue about the ontological

foundation of caring (The Swedish society of nursing, 2016). The context of study III was an established hospital that had provided a certain type of integrative health care for more than 30 years. Interestingly, in the context of this study, the practitioners' use of shared concepts did not seem to be dependent on the length of their work experience at the hospital. The practitioners' meaning-making, shown in their shared understanding, were interpreted in study III as an intrinsic part of the caring culture, founded on anthroposophical values. In study II, the process of meaning-making, where the practitioners develop a shared vision and team identity, happened within a randomised controlled trial over a period of one year and four months, during which the practitioners had regular patient conferences. In this context, although it was also an integrative health care model, the model was based on collaboration between practitioners with different paradigms. As such, their process of meaning-making was understood from the perspective of social constructionism, where meaning and knowledge are shaped and negotiated in interaction between people (Burr, 2015).

Understanding the language of suffering

To encounter the whole person as an integrated entity was interpreted to involve not only biopsychosocial aspects but also existential dimensions of health and suffering. For example, the practitioners' (study III) uses of the shared concepts trauma and cramp, was interpreted as praxis concepts that enabled the practitioners to reflect on and to understand patients' experiences of suffering. Koithan, Bell, Caspi, Ferro, & Brown (2007) identified three different states in the process of health change among patients with chronic illnesses after complementary health care. These stages were described as stuckness, unsticking, and unstuckness. The different states were also characterised by the tone and pattern in the patients' use of language, the state of stuckness was similar with few alternative expressions, whereas the state of unstuckness, was characterised by a vivid and dynamic language. The concept of cramp in this thesis is similar to the concept of stuckness, as described by Koithan et al. (2007). Previous research has shown that people living with chronic pain may have trouble communicating their pain and suffering, leading to situations where they do not feel understood in their suffering (Jackson, 1994; Svenaeus, 2014). In Jackson's words (1994) "people with chronic pain report feeling profoundly understood by fellow sufferers and profoundly misunderstood by non-sufferers". Svenaeus (2014) has written about suffering as a mood and a feeling of alienation. As such, every aspect of suffering related to the experience of chronic pain may be difficult to express, since it involves an embodied experience of a whole person's being in the world (Jackson, 1994; Nyström, 2014; Svenaeus, 2014). From a caring science perspective on health and suffering as interrelated aspects of human life, there is a need to acknowledge the patients' suffering in order to alleviate suffering and promote health (Eriksson, 2001, 2007). Even so, suffering is understood as something that affects us and needs to be avoided (Arlebrink, 2012). Arman (2012) discussed the double meaning of suffering, i.e. it includes pain and despair but at the same time it can be understood as a challenge, with a possibility for personal development. The results of this

thesis point to the importance of an extended understanding of the language of suffering including its existential dimensions as a way to alleviate suffering and promote health (Eriksson, 2001, 2007). As such the shared concepts, in study III, were understood to have implications for practitioners and patients to reflect and speak about health and suffering as related to the context of their lives.

Shared understanding in caring

The practitioners' meaning making, shown in their use of shared concepts, was also interpreted as a basis for caring. Bullington (Bullington, 2009) suggested that rehabilitation of chronic pain needs to help patients to open up to the world around them and their sense of self through a process of articulation on all levels since the experience of pain may have centred the patient's focus on the painful body. If a practitioner continues to focus only on bodily aspects it is not helpful for the patients "articulation". Instead, patients need to "articulate" new experiences that involve a new look at themselves (Bullington, 2009). As suggested by Bullington (Bullington, 2009), the practitioners' use of the concept "caring shelter" in study III, was interpreted to invite the patients to experience their own sense of self. In a study conducted in the same context as study III, Ozolins, Horberg, & Dahlberg (2015) used the expression "caring space", to describe patients' experiences of how touch created a "caring space". When touched in a respectful and attentive manner, patients reported feeling protected and sheltered in a vulnerable situation. As such, patients' experiences of touch were perceived to give them an opportunity to face their suffering and sense their own needs (Ozolins et al., 2015). Other studies in the anthroposophic setting have also emphasised the importance of the caring culture and caring relations for the understanding of patients' transformations in health and suffering (Arman & Hok, 2016; Arman, Ranheim, Rehnsfeldt, & Wode, 2008; Arman & Rehnsfeldt, 2007; Esch, Marian, Busato, & Heusser, 2008; Ozolins et al., 2015). Two of these studies have addressed patients' experiences of pain rehabilitation from the same research project and setting as study III (Arman & Hok, 2016; Nordberg, Andermo, & Arman, 2017). The results of those studies (Arman & Hok, 2016; Nordberg et al., 2017) showed that patients in anthroposophic pain rehabilitation experienced that the caring approach, characterised by the practitioners' empathetic and compassionate approach and the included anthroposophic therapies, allowed them to rest in a permissive caring atmosphere. Furthermore, the patients were encouraged to listen to themselves, identify their own needs, and overcome barriers of self-care as well as to renew their sense of a "good life" (Arman & Hok, 2016; Nordberg et al., 2017). However, although previous studies have highlighted the importance of a caring culture and caring relations for the patients' experiences of the caring encounters (Arman & Hok, 2016; Arman et al., 2008; Arman & Rehnsfeldt, 2007; Esch et al., 2008; Ozolins et al., 2015), there is a limited understanding of how such a caring culture and caring relations are created. Research has shown that shared understanding among practitioners in relation to interdisciplinary health care is important (Hellman et al., 2016; O'Connor et al., 2015). However, there is a

lack of studies showing the expressions or language of a shared understanding among practitioners in practice, specifically in the context of integrative health care. The findings of study III show the shared understanding between practitioners in an established integrative health care setting. The shared understandings, reflected in their use share concepts, were understood to have implications for practitioners' ability to encounter the patients as whole persons.

Identity formation and synergies of collaboration

The results in study II show how the practitioners learned to capitalize on their collaborative practice of managing patients living with chronic pain. In the study, the formation of a team identity, where the practitioners gradually moved their subject positions from individual treatment subjects to members of a team was shown in the discourse. An integrative model of collaboration has been suggested to be based on an interdisciplinary, non-hierarchical integration of conventional medicine and complementary health care where the interdisciplinary team collaborates with mutual respect and understanding (Boon, Verhoef, O'Hara, & Findlay, 2004). In study II, the discursive collaboration between practitioners is explored from a longitudinal perspective. The results show how the practitioners developed non-hierarchical, consensus-based decision-making. However, collaboration is more than agreement and communication. Trust, creation of a common goal and a shared identity have also been highlighted as forming the foundation for collaboration (Belanger & Rodriguez, 2008; Boon, Verhoef, O'Hara, & Findlay, 2004; Gatchel et al., 2014; Hellman et al., 2016). In integrative health care, different complementary and conventional approaches, with a wide range of philosophical underpinnings are combined (Eton et al., 2011; Falkenberg et al., 2012). Therefore, arriving at a mutual shared understanding has been considered more complex in integrative health care than within conventional interdisciplinary health care (Eton et al., 2011). The few previous studies focusing on interaction between integrative health care practitioners have shown challenges to collaboration such as power struggles between collaborating practitioners and paradigms (Anderson, 1999; Frenkel & Borkan, 2003; Gaboury et al., 2011; Geist-Martin, Bollinger, Wiechert, Plump, & Sharf, 2016; Hollenberg, 2006). Instead, of collaboration built upon mutual respect and understanding there is often a bio-medical dominance in the collaboration, where integrative practitioners adjust their language to fit a biomedical understanding (Anderson, 1999; Frenkel & Borkan, 2003; Gaboury et al., 2011; Hollenberg, 2006). These patterns of communication have been shown in the discourses between different practitioners in case studies, such as a test panel of integrative health care practitioners (Anderson, 1999). Hall (Hall, 2005) writes that a challenge in inter-professional teamwork is to provide opportunities for team members to understand each other. However, few previous studies have explored discourse and collaboration between practitioners from a longitudinal perspective. In study II, the practitioners' formation of a shared team identity involved a learning process of increased understanding between the practitioners, including a common meaning-making in caring. The

results in study II, highlight the importance to allow time for practitioners in interdisciplinary collaboration to understand each other, this process may be facilitated by scheduled meetings where collaborating practitioners can interact.

Barriers and shortcomings

The results of this thesis address a number of collaborative shortcomings in relation to patients' and practitioners' experiences of collaboration in integrative health care in primary health care (study I and II). The discourse between the practitioners in study II revealed an antagonistic relationship towards a larger medical discourse where the practitioners wished to be part of the conventional health care system, at the same time as they wanted to change the hegemony of a biomedical paradigm to also include their holistic visions. From their perspective, the role of integrative health care needed to be strengthened, and new ideas and ideals accepted and integrated in conventional health if integration was to be the next step. Through a discursive approach, Laclau and Mouffe (2001) have argued that the entire world is an ongoing social construction and negotiation that consists of a constant struggle between antagonism and hegemony. By formulating an emancipatory project, they have argued that there is a need for antagonism in the social world, because if there is no antagonism, every order is hegemonic. This negotiation is what Laclau and Mouffe (2001) refer to as a disarticulation and re-articulation of hegemonic positions that is needed to achieve social change. From this perspective, the practitioners' antagonistic relationship towards a larger medical discourse can be understood as a necessary means to achieve change since integrative health care is not formally part of established or public funded health care in Sweden. From a macrostructural organizational perspective, this antagonistic relationship and the lack of communication and integration may be understood in relation to the provision of health care, where integrative health care to a large extent is provided outside of the conventional health care system. This is also shown in the terminology, where early definitions of "complementary health care" implies that complementary health care practice occurs as a complement outside of the conventional health care (Gaboury et al., 2012). Gale (2014) have suggested that the positioning of a practice as complementary or alternative, imply a social and historical construction reflecting a 'Western' biomedical dominance. Furthermore, Soklaridis, Kelner, Love, & Cassidy (2009) also refer to the denial of public funds as a means by which complementary health care practices are excluded. Although integrative health care implies integration between complementary and conventional practices, there are large differences in integrative health care provision in European countries (Wiesener et al., 2012). In this thesis, the collaborative shortcomings between practitioners also affected patients. The results of study I show that patients had experiences of a lack of guidance and a prejudiced attitude from their conventional practitioners concerning their use of complementary health care. It is in the patients' interest that the different health care practitioners they turn to are able to communicate and collaborate with each other (Frenkel & Borkan, 2003; Salamonsen, 2015). In situations where there is a lack

of collaboration between complementary and conventional health care practitioners, patients might need to bridge the gap by themselves, leading to extended suffering related to care (Arman et al., 2008; Salamonsen, 2015; Sundberg, Hok, et al., 2014). Kaptchuk & Miller (2005) have argued that it is time to overcome an oppositional view of conventional and complementary/integrative health care. The ability of practitioners to have open dialogue, a high degree of professionalism and to work as a team have been considered essential to provide safe and effective health care (Frenkel & Borkan, 2003; Sundberg, Hok, et al., 2014).

Patients' experiences of health and suffering

Patients' experiences of changes in health and suffering in the integrative context were elucidated in the thesis (study I and IV). An extended understanding of patients' experiences of health and suffering, including existential dimensions, may have implications both for caring encounters and for the development of interdisciplinary health care, including integrative health care for persons living with chronic pain. In study I, the results showed that patients felt empowered in integrative health care, which was described as a shift from a negative image towards increased body awareness and positive thinking. Furthermore, integrative health care was perceived to include empowering self-help strategies. Empowerment as a concept is described both as a process and a goal. A definition of empowerment is to "give (someone) the authority or power to do something" and to "make (someone) stronger and more confident, especially in controlling their life and claiming their rights" (Oxford Dictionaries, 2016). In these terms, the process of care, including self-help strategies together with the patients' experiences of health changes, was understood as empowering the patients in their own process towards health. Patients' health changes were also reflected upon by the practitioners in study II, who perceived that the patients benefited from their collaboration, and in study III, where the practitioners described how the patients engaged in a process to find their own resources for health, exploring their life intention. However, the result of the thesis shows how patients (studies I and IV) often described changes in health related to experiences of suffering. In addition, practitioners (study III) emphasised the importance of patients becoming aware of their whole person as a means to restore the balance between their, body, spirit and soul.

In study IV, patients' experiences of health and suffering in the anthroposophic integrative context were used as a basis to develop a new patient instrument to measure existential signs of "Health" and "Suffering". The results show a first version of this instrument, with a construct that is built upon a movement between health and suffering, described in five domains; "Life passion and energy", "Personal freedom", "Presence in life" "Relationships" and "Meaning". The reason to develop the instrument was based on previous, mainly qualitative studies in the integrative health care context showing that patients experienced changes in health of an existential nature (Arman et al., 2013; Arman & Hok, 2016; Arman, Ranheim, et al., 2015; Arman & Rehnsfeldt, 2007; Cartwright & Torr, 2005; Hsu et al., 2010; Koithan, Verhoef, et al., 2007). Integrative health care encompasses multiple components that

are individually adjusted, and it has therefore been considered difficult to evaluate (Bell et al., 2012). An extended ability to measure existential signs of patients' experiences of health and suffering was assumed to further the understanding of caring in integrative health care. The developed instrument, including its domains, is similar, but not identical to other instruments measuring existential health (Crumbaugh & Maholick, 1964; Skevington et al., 2004). When developing the instrument, the item pool was based on patients' contemporary use of language to capture experiences of health and suffering.

From a theoretical perspective in caring science, the developed patient instrument measures health and suffering as interrelated aspects of human life in relation to the ontological health model involving a person's doing, being and becoming in health and suffering (Eriksson et al., 1995; Nyström, 2014). In the process of refining the instrument, the format of two concepts reflecting the phenomena of both health and suffering in each word pair was perceived as relevant and meaningful by patients and experts. From the perspective of the ontological health model, many of the items in the instrument range from the perspective of doing to becoming in each item. Most item ranges towards being or becoming in the healthy end point, but the item "chaos-order", is an example of an item that stretches to "doing" from the theoretical perspective of the ontological health model. The instrument thereby captures both health and suffering, with a focus on being and becoming. Doing, being and becoming in health involve an increased insight into oneself where the human strives to become whole. In becoming, existential questions of desire and meaning are central and the person is reconciled with his/her circumstances in life. In relation to suffering, this process involves having suffering, being in suffering to a becoming in the struggle of suffering. From this perspective; avoidance of suffering may cause more suffering. Facing suffering, on the other hand can alleviate suffering since acceptance and reconciliation to suffering is understood to lead to health (Arman & Rehnsfeldt, 2011; Eriksson, 2001).

From a theoretical caring science perspective, when fully developed the instrument is expected to be valuable for theory development. In relation to both integrative and conventional clinical practice, the instrument is expected to facilitate the assessment of patients' experiences of existential qualities of health and suffering. Such an understanding, which may be relevant to patients, can be used in evaluations and development of clinical practice.

7.2 DISCUSSION OF METHODS

An ontological assumption in qualitative research approaches is that realities are subjective and that the experience differs between different persons and contexts as well as in relation to the specific situation when data is gathered. Evaluating the trustworthiness of qualitative research can be approached from different perspectives and criteria. The methodological discussion about the studies in this thesis includes strengths and weaknesses in relation to the research process and Lincoln and Gubas (1985), proposed criteria for trustworthiness, which include transferability, dependability, confirmability and credibility.

Aims and theoretical framework

The aims of the different studies guided the choice of appropriate methods, including the theoretical underpinnings, in each of the studies in the thesis (Streubert & Carpenter, 2011). The choice of theoretical approaches was based on the aims of the studies in an evolving process during data analysis. The theoretical underpinnings are described in each study. Meaning-making as a process and social construction was most pronounced in study I and II (Burr, 2015), and meaning-making in relation to the theoretical framework of caring science was mostly used in studies III and IV.

Pre-understanding

During the research process, a journal for self-reflection was kept to reflect upon my pre-understanding. In the journal, experiences, assumptions and reactions were noted (Morrow, 2005). This introspection was used, for example, in the process of data analysis to become aware of my own horizon of understanding, including biases and assumptions, in relation to that of the participants when sharing their experiences. In this process, my own pre-understanding was both questioned and used in the interpretation process (Morrow, 2005). In Gadamer's words (1997), the new understanding was understood as "a fusion of horizons" during the research process. As such, my pre-understanding has changed during the work on the thesis. In particular, I have gained access to the participants' experiences. This process has led to an increased interest in and understanding of the theoretical field of caring science, in particular theories on health and suffering. Prior to the work on the thesis, I had an interest in integrative health care in general. I had a broad knowledge about the field, including traditional medicine, from previous academic studies and my work as a university lecturer. My interest was not directed towards any specific field, thus neither the included methods in the integrative health care model in primary care nor the anthroposophic integrative care was my central motivation for the study. Instead, I was interested in understanding more about health and patients' need for health care. As such, my main questions concerned patients' reasons for using different health care approaches and their experiences of changes in health rather than which methods or treatment approaches were most effective. My academic background was theoretical, with no clinical health care training. This can be considered both as a strength and a weakness. The weakness would be a limited pre-understanding of the

clinical field. However, all articles were co-analysed and authored in collaboration with other researchers with relevant clinical health care backgrounds. A strength of a theoretical, non-clinical background is that it can offer the possibility to explore every aspect of the multiple realities in the data, without relying on the clinical pre-understanding.

Data collection and analysis

The quality of data is dependent on the process of data collection. In this thesis, the intention was to collect rich data in relation to the aim of the studies. In the focus group discussions (study I) and patient conferences (study II) the interaction between the participants was expected to generate rich data in relation both to content and the process of interaction (R Barbour, 2014). In studies III and IV, interviews were used to collect data concerning the meaning of caring, health and suffering (Kvale, 2009).

In study I, few persons participated in each focus group; this was because a maximum of six persons could be booked in for each focus group discussion and there were oftentimes some late cancellations. Although the moderator activity encouraged the participants in study I to interact with each other, as suggested by Barbour (2007), it is possible that a larger group would have provided a more dynamic interaction between the participants. Even so, the data were rich in relation to the study. Barbour (2007, 2014) discuss that the use and analysis of focus groups are, like other forms of analysis, built upon ontological and epistemological underpinnings. In focus groups, these underpinnings can be understood as a continuum between a realist and a constructivist approach. The realist approach focus on content and the constructivist approach focus on form and process. In study II, data were collected through group discussions in patient conferences enabling an analysis of the practitioners' interactions. In study II the long period of data collection was perceived to enable the practitioners to interact with each other without too much attention on participating researchers observing the interaction. In this sense, the researchers became a natural part of the field due to the design of the study. Even so, the data was collected within a randomised controlled trial, and this specific situation is not the practitioner's natural environment.

The data collection in study III also involved a long engagement in the field, as time was spent at the clinic in order to engage in conversation and get to know the practitioners. During the data collection in study III an interview guide was used. However, often the practitioners covered most topics in the guide without a need to ask all questions. This happened during one of the follow-up interviews focusing on concepts used in the interview. One question was needed, and after that the practitioners covered each concept one by one without further questions directing the interview. In study IV, a qualitative approach was used to develop an item pool that was further reflected upon in relation to theories in caring science (Arman, Ranheim, et al., 2015; Eriksson et al., 1995; Lindström, 2014). In study IV, most data for the development of the instrument had been collected by a researcher focusing on health and suffering among different patient groups. The choice to use already gathered data was based

on the quality on the data, which was considered to be rich in relation to the aim of the study. In the following cognitive interviews, the method of thinking aloud was useful to express the participants' thoughts about the questions. Furthermore, experts were used in study IV to contribute to the content validity of the developing instrument (American Educational Research Association, 1999; Grant & Davis, 1997). Although the results were empirically derived, it is possible that another theoretical perspective would have highlighted other aspects in the data. The *dependability* of the research findings refers to the consistency of the findings. Could another researcher have collected the same material and come to similar conclusions. The relations that are established during data collection are highly dependent on the researcher's ability to interact with the participating persons in the studies. In this thesis, not all data were collected by the same researcher. For example, two researchers conducted interviews in study III. When analysing the interviews, no researcher-dependent differences were identified. In all studies the analysis was systematically performed in collaboration between several researchers with different backgrounds.

Strengths of the four studies are the systematic qualitative data collection and the analyses, which were well-documented and described, and facilitated by the prolonged engagement in the different settings. Field notes were taken and used to reflect upon pre-understanding during data analysis. The *conformability* of the data refers to the neutrality of the data and the interpretations (Patton, 1990). Empirically grounded citations were used as a mean to ensure that the findings represent the participants voices (Patton, 1990). To focus the interpretation on conceptualisations of the practitioners in study III, was a way of enchanting the voice of the participant, in this case the practitioner's voice. Patton (Patton, 1990) discusses this approach within the artistic and evocative criteria that has been described as the narrative turn emphasising the expressive voice and a dimension of feeling in the data analysis and interpretation. As such, the practitioners' expressions, with focus on particular concepts, are used to express the feeling of caring and the view of the human in their lifeworld. Member checks, researcher triangulation and negative case analysis have been suggested as a means to ensure *credibility* (Patton, 1990). In study III, two follow-up interviews were performed both as a form of limited member check but also to further the understanding of the process of analysis. So-called negative cases were searched for when analysing the data. In study II, the antagonistic relationship towards the larger medical discourse may be understood as a negative case, in terms of questioning the ability to form a team within integrative health care. Although the analysis was based on discursive psychology, the combination with discourse theory contributed to an understanding of "the other" and the relation between antagonism and hegemony in the discourse. In study I, although the included patients had a homogeneous and contrasting view of integrative and conventional health care, they also appreciated the diagnosis support provided in conventional health care. This finding highlighted the multiple realities of the patients' and practitioners' experiences and perceptions. Taken together, the *credibility* of the findings, i.e. the extend how well data and process of analysis address the aim of the study, including rigorous methods, the credibility

of the researcher and the philosophical underpinnings of the study were carefully reflected upon in the research process (Patton, 1990).

To facilitate the reader's decision about the *transferability* of the findings, as clear descriptions as possible were given about the context, selection of participants and their characteristics, as well as the procedures of analysis (Graneheim & Lundman, 2004). However, due to ethical issues and in order to not reveal the participants' identities, their characteristics were given on a group level. Although all qualitative data included in the studies and the presented results of the analysis have been understood as contextually-dependent, the results might be transferable on a more abstract level. For example, the elucidated concepts in study III were identified in relation to the aim of the study and interpreted in relation to the use and meaning in a specific context. Thus, the expression of shared understanding through language and its meaning to caring (study III) may be transferable, although it is likely that the concepts and their meaning would differ in another context. This is similar in study II, where the collaborative process and exchange of knowledge shown in the team may be transferable to another context even though the type of provision of integrative health care varies between different countries regarding its legal and regulative status (Ammon et al., 2012). In this sense, the study shows an example of a professional transformation of a team that can serve as inspiration in another context, specifically, regarding the time and effort needed to develop shared visions and collaboration within a team. In study I, the result of the study is contextually-dependent regarding patients' experiences and perceptions as well as the specific integrative health care model. It is possible that the participants that agreed to participate in the study were more in favour of integrative health care than those who did not participate. However, the intention was not to produce generalizable results, but rather to generate an understanding of the participants' experiences and perceptions of integrative and conventional health care. In study IV, when developing the instrument, data was collected in one context with a specific holistic caring culture, which was considered ideal for studying patients' expressions of existential signs of health and suffering (Kienle et al., 2013). Even so, the development of the items and the refinement with cognitive interviews in the same context may be understood as a limitation of the study. Furthermore, the uneven gender distribution with about 84% women in the initial data for the development of the item pool and the limited number of diagnoses may be a weakness of the study. The developed first version of the instrument will need further psychometric evaluation. The intention was to develop an instrument to be used in different contexts and for different patient groups. The next phase of the project involves further psychometric evaluation, allowing a greater diversity in terms of context and patient characteristics.

8 CONCLUSIONS

This thesis draws on empirical data in two different integrative health care settings, elucidating both patients' and practitioners' meaning-making in relation to their experiences of caring, health and suffering in the rehabilitation of chronic pain. With a foundation in caring science the view of health and suffering as interrelated aspects of human life is used to further the understanding of patients' and practitioners' meaning-making in integrative health care. An overall understanding that emerges in the thesis is the value of an extended existential view of the person suffering from pain, with implications for caring.

In the thesis it is shown that patients living with chronic back and neck pain valued the whole person approach in integrative health care, characterised by a valuable combination of biomedical diagnostics and empowering self-help strategies. The meaning-making among practitioners was interpreted to have implications for the caring encounter, contributing to their ability to meet the whole person. In the thesis, practitioners' existential views of human, health and suffering are shown clinically in their collaborative process and through their use of expressions and concepts. To encounter the whole person in caring means to proceed from an existential view of the human. As such, the focus is on the patients' subjective experience of health and suffering, in addition to the focus on disease and medical diagnoses. Integrative health care practitioners' collaboration and shared understanding were understood to contribute to their ability to understand patients' experiences of suffering, to alleviate suffering, and to promote health. The developed patient instrument was based on two interrelated dimensions, existential signs of "Health" and "Suffering", characterised by five proposed domains: "Life passion and energy", "Personal freedom", "Presence in life", "Relationships" and "Meaning".

The results of this thesis indicate the importance of meaning-making as a basis for caring and acknowledge the importance of addressing not only biopsychosocial aspects but also existential dimensions of patients' experiences of health and suffering in pain rehabilitation. There is a need to focus on health practitioners' possibility to discuss the ontological foundation of caring in relation to their clinical practice. This understanding and the proposed patient instrument, when fully developed, are expected to contribute to the continued development and evaluation of interdisciplinary health care practices and clinical health research, as well as theory development in caring science.

9 FUTURE RESEARCH

In this thesis, patients' and practitioners' meaning-making in relation to caring within integrative health care was investigated in separate studies focusing on either the patients' or the practitioners' experiences in two different settings. Among practitioners, meaning-making was approached from the perspective of the practitioners' conceptualisations and discourse. Further research is needed concerning additional aspects of meaning-making in relation to caring encounters. Perspectives that would provide valuable contributions could be anthropologic or ethnographic studies of the interactions between providers and patients in different interdisciplinary and integrative health care settings and contexts and how those develop over time, possibly in relation to changes of patients' health. The developed patient instrument will need further psychometric evaluation in different cultural contexts, clinical fields and patient groups before implementation in clinical practice. Future research involving the developed patient instrument may also include using it as a basis for interview guides and studies to further explore patients' experiences of health and suffering from existential perspectives.

10 SWEDISH SUMMARY

Bakgrund och syfte: Patienter som lever med kronisk smärta söker sig ofta både till konventionell och komplementär vård. Integrativ vård kombinerar konventionella och komplementära vårdmetoder i det kliniska omhändertagandet av patienter. Även om integrativ vård är utbredd internationellt, så finns kunskapsluckor rörande patienters och vårdgivares erfarenheter av integrativ vård i olika kliniska sammanhang. Det övergripande syftet med den här avhandlingen var att belysa patienters och vårdgivares meningsskapande i integrativ vård för personer som lever med kronisk smärta, och att bidra till att utveckla ett patientinstrument som mäter existentiella aspekter av hälsa och lidande.

Metod: Avhandlingen har en kvalitativ design och inkluderar fyra delarbeten genomförda i två olika integrativa vårdmiljöer; en modell för integrativ vård i primärvården (delarbetena I och II), och i antroposofisk integrativ vård (delarbetena III och IV). Patienters erfarenheter och upplevelser från primärvården undersöktes i fokusgrupper (n=11) och analyserades med latent innehållsanalys (I). Patientkonferenser (n=15) i primärvården analyserades med diskursanalys med fokus på deltagande vårdgivares interaktion och samverkansprocesser (II). Individuella intervjuer (n=15) om vårdande och dess betydelse genomfördes med vårdgivare i antroposofisk integrativ vård och analyserades med fenomenologisk hermeneutik (III). Ett patientinstrument som mäter existentiella tecken på hälsa och lidande utvecklades i tre faser. Med utgångspunkt i kvalitativa intervjudata från patienter (n=64) som erhållit antroposofisk integrativ vård utvecklades en frågepool, vilken reducerades och förfinades med hjälp av kognitiva patientintervjuer (n=8) och expertkonsultationer (n=5).

Resultat: Patienter som erhöll integrativ primärvård upplevde ett vårdbemötande som tog hänsyn till hela personen, detta i en vårdmodell som trots vissa identifierade samarbetsmässiga och finansiella begränsningar kunde beskrivas som en värdefull kombination av biomedicinsk diagnostik och stärkande strategier för egenvård/självhjälp (I). Vårdgivarna i den integrativa primärvårdsmodellen utvecklade över tid ett gemensamt meningsskapande med betydelse för förståelse och lagidentitet vilket stärkte samarbetet och lade grund för vården (II). De antroposofiska vårdgivarna använde ett gemensamt språkbruk med specifika koncept, vilka tycktes öka vårdgivarnas förståelse för patienternas hälsa och lidande samt bidra till ett gemensamt förhållningssätt i vårdandet (III). Det utvecklade patientinstrumentet baserades på två relaterade dimensioner, existentiella tecken av "hälsa" och "lidande", vilka karakteriserades av fem domäner; "Livspassion och energi", "Personlig frihet", "Närvaro i livet", "Relationer" och "Mening" (IV).

Konklusion: Resultaten tyder på att patienters och vårdgivares meningsskapande i integrativ vård inte bara berör biopsykosociala aspekter utan också existentiella dimensioner av hälsa och lidande, vilket kan ha betydelse för vårdandet av personer med smärta. Integrativa vårdgivares samverkansprocesser och användning av gemensamma begrepp kan bidra till deras förmåga att förstå och lindra smärtpatienters lidande och underlätta en helhetssyn på människan som får vård. Denna förståelse, tillsammans med det utvecklade patientinstrument som mäter existentiella tecken på hälsa och lidande, kan användas för att ytterligare informera utvärdering och utveckling av tvärvetenskapliga former av hälso- och sjukvård.

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