



**The person-centred assessment tool Hermes**  
**Development and use in rehabilitation nursing**

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**Thesis for the degree of Philosophiae Doctor**

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**UNIVERSITY OF ICELAND**  
**SCHOOL OF HEALTH SCIENCES**

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FACULTY OF NURSING

**Persónumiðaða matstækið Hermes  
Þróun og notkun í endurhæfingarhjúkrun**

**Kristín Þórarinsdóttir**

**Ritgerð til doktorsgráðu**

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## Ágrip

**Bakgrunnur:** Persónumiðuð nálgun og þátttaka sjúklinga eru grundvallarviðmið í endurhæfingarhjúkrun. Í samræmi við þessi viðmið er mælt með að hjúkrunarfræðilegt heilsufarsmat sé persónumiðað en í slíku mati taka sjúklingar þátt í að meta heilsu sína og væntingar sínar til endurhæfingarinnar. Samt sem áður hefur persónumiðað matstæki í endurhæfingarhjúkrun ekki verið fyrir hendi.

**Markmið:** Meginmarkmið doktorsritgerðarinnar er að lýsa: i) heimspekilegum og fræðilegum hugmyndum og aðferðum sem nýttar voru við þróun persónumiðaðs matstækis í endurhæfingarhjúkrun sem nefnt var Hermes, og ii) innleiðingu og notkun matstækisins í endurhæfingarhjúkrun.

**Aðferðir:** Ritgerðin samanstendur af þremur sjálfstæðum eigindlegum rannsóknum. Í rannsókn I voru 60 eldri eigindlegar rannsóknir samþættar. Í gegnum samþættinguna var gerð gagnrýnin hugtakagreining á persónumiðaðri þátttöku sjúklinga í heilbrigðisþjónustu en rammagreining (*e. framework analysis*) var notuð við gagnagreininguna. Rannsókn II var þátttökurannsókn (*e. action research*) en gegnum hana var matstækið, Hermes, þróað með hjúkrunarfræðingum og innleitt í endurhæfingu með endurteknum ígrundandi hringferlum. Með rannsókninni var kannað hvernig hægt er að þróa matstæki, byggt á fræðilegum og fyrirbærafræðilegum grunni, sem stuðlar að persónumiðaðri þátttöku í heilsufarsmati í endurhæfingarhjúkrun. Þátttendur voru ráðgjafi og 12 hjúkrunarfræðingar í endurhæfingu. Gögnum var safnað með rýnihópa- og einstaklingsviðtölum og endurskoðun á skráningu á Hermes. Gagnagreining var unnin með aðleiðandi innihaldsgreiningu (*e. deductive content analysis*). Rannsókn III var sértæk vettvangsrannsókn (*e. focused ethnography*) þar sem kannað var hvernig notkun Hermes getur mögulega stuðlað að persónumiðaðri þátttöku fólks með langvinna verki í heilsufarsmati í endurhæfingu. Þátttakendur voru 14 sjúklingar með langvinna verki í endurhæfingu og fimm hjúkrunarfræðingar þeirra. Gögnum var safnað með þátttökuathugun og hálf-stöðluðum viðtölum og voru gögnin greind með þemagreiningu.

**Niðurstöður:** Meginniðurstöður rannsóknanna voru þær að Hermes stuðlaði að persónumiðaðri þátttöku sjúklinga í heilsufarsmati í endurhæfingarhjúkrun ásamt því að fyrirbærafræðileg nálgun birtist í matinu.

Rannsókn I sýndi að persónumiðuð þátttaka sjúklinga í heilbrigðisþjónustu er byggð á reynslu sjúklinga, gildum, væntingum og þörfum, og grundvallast á virðingu og jafnræði. Þessi hugtakarammi um persónumiðaða þátttöku sem rannsókn II byggðist á birtist í þremur sambættum stigum. Þau voru: Stig mannglegra tengsla; stig úrvinnslu upplýsinga; og framkvæmdastigið. Í rannsókn II var heilsufarsmatstækið Hermes þróað í gegnum ígrundandi ferli í samstarfi við hjúkrunarfræðinga í endurhæfingu og í framhaldinu var það innleitt í endurhæfinguna. Matstækið var byggt á fræðilegum og fyrirbærafræðilegum grunni. Meginkostur matstækisins var að það stuðlaði að persónumiðaðri þátttöku sjúklinga í heilsufarsmati og sjónarhorn þeirra kom sterkt fram í matinu. Þetta gerði það að verkum að hjúkrunarfræðingar skildu betur ástand og aðstæður sjúklinga. Þá gaf Hermes viðtalinu ramma, stuðlaði að samræðu um heilsufarsvanda og auðveldaði mat á árangri af endurhæfingunni. Einnig samræmdu notkun Hermes ýmsum þáttum í hinum fyrirbærafræðilega bakgrunni. Í rannsókn III kom í ljós gagnsemi Hermes sem matsaðferðar við að meta áhrif langvinnra verkja á sjúklinga. Niðurstöður sýndu hvernig notkun Hermes stuðlaði að styðjandi tengslum og samræðu milli sjúklinga og hjúkrunarfræðinga sem var opin og með túlkandi ívafi. Með þessu móti myndaðist skilningur á veikindunum og aðstæðum sjúklinga sem gat verið hjálplegur við að koma til móts við heilsufarsleg áhyggjuefni. Í heildina stuðlaði Hermes að persónumiðari þátttöku sjúklinga með langvinna verki í heilsufarsmati og nýtingu fyrirbærafræðilegrar heimspeki við heilsufarsmat í hjúkrun.

**Ályktanir:** Þróun og notkun Hermes stuðlaði að persónumiðaðri þátttöku sjúklinga í endurhæfingu. Því er matstækið talið nýtilegt í endurhæfingarhjúkrun. Einnig er mögulegt að matstækið sé gagnlegt á öðrum sviðum heilbrigðisþjónustu. Mikilvægt er að styrkja fræðilegan grunn matstækisins með frekari rannsóknum.

**Lykilorð:**

Persónumiðuð nálgun, þátttaka sjúklinga; heilsufarsmat, hjúkrun, fyrirbærafræði.

## Abstract

**Background:** Person-centredness and patient participation are central ideals in nursing rehabilitation practices. In line with those ideals, a person-centred nursing assessment is advocated: namely, assessment through which patients participate in assessing their health and their preferences for rehabilitation. Yet a person-centred assessment tool for such patient participation has hitherto been lacking in rehabilitation nursing.

Overall aim of the thesis: To describe: i) the philosophical and theoretical background and methods used in the development of a person-centred health assessment, named Hermes, for use in nursing rehabilitation, and ii) the integration and use of the tool in rehabilitation.

**Methods:** This thesis consists of three interdependent conceptual and qualitative studies. Study I constitutes an integrative review of 60 qualitative studies through which an ideal (person-centred) participation in health care is critically analysed via framework analysis. Study II is an action research study, depicting the process through which 12 nurses in rehabilitation and a consultant participated in developing the tool. It explores how a theoretically based assessment tool, underpinned by phenomenology, can be developed for enhancing a person-centred approach to the participation of patients in nursing assessment and care planning in rehabilitation. Data were collected by focus-group and individual interviews and observation of the documentation on the tool. Data were analysed through framework analysis. Study III is a focused ethnographical study. It explores the feasibility of using the assessment tool Hermes, developed in Study II, to enable a person-centred approach to the participation of patients with chronic pain in their health assessment at admission in rehabilitation nursing. Participants were 14 patients with chronic pain and their five nurses. Data were collected by participant observation and semi-structured interviews, and analysed through thematic analysis.

**Results:** The main results of the studies were that Hermes facilitated a person-centred approach to health assessment in nursing rehabilitation and that the philosophy of phenomenology was satisfactorily operationalised in such assessment practice.

Study I illustrated that person-centred participation in health care is based on

patients' experiences, values, preferences and needs, in which respect and equality were central. This concept which informed Study II manifested itself through three intertwined phases: the human connection phase, the phase of information processing and the action phase. In Study II, the trajectory through which the assessment tool Hermes was developed, in collaboration with nurses in rehabilitation and subsequently adopted into practice, emerged. During this process, its theoretical and phenomenological grounding was fine-tuned. The main advantage of the adoption of the tool into practice was that it enhanced the participation of patients in health assessment and their perspectives became salient in the assessment. This in turn promoted nurses' understanding of the patients' situations. Furthermore, Hermes was helpful in structuring the assess interview, discussing health issues of concern and in the evaluating progress. In addition, through the use of the tool, several aspects of its phenomenological grounding were supported. In Study III, the benefits of using Hermes as a method to assess the impact of chronic pain on patients were revealed. The findings demonstrated how the application of Hermes allowed for the development of a supportive connection and dialogue between nurses and patients that was open and interpretive. This generated an understanding of the illness situation and discussions about ways to adjust to health issues of concern. In summary, Hermes facilitated person-centred participation of patients with chronic pain in their health assessment and operationalised a phenomenological philosophy in nursing assessment in rehabilitation.

**Conclusions:** Through the development and use of Hermes, the ideal of person-centred participation in rehabilitation nursing was facilitated. Thus, the tool is regarded as feasible for general use in nursing rehabilitation. Moreover, it could have potential relevance for other health-care settings. Further studies are needed, however, for evaluating its use in alternative settings.

**Keywords:**

Person-centred care, patient participation, health assessment, nursing, phenomenology.

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## **List of abbreviations**

**HCP:** Health care professional

**FHP:** Functional health pattern

**PAR:** Participatory action research

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## List of original papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I-III):

- I. Thórarinsdóttir, K. and Kristjánsson, K. (2014). Patients' perspectives on person-centred participation in healthcare: A framework analysis. *Nursing Ethics*, 21(2), 129-147. doi:10.1177/0969733013490593\*
- II. Thórarinsdóttir, K., Björnsdóttir, K., & Kristjánsson, K. (2017). Development of Hermes, a new person-centered assessment tool in nursing rehabilitation, through action research. *Advances in Nursing Science*, 40(2), 207-221. doi:10.1097/ANS.000000000000132\*\*
- III. Thórarinsdóttir, K., Kristjánsson, K., Gunnarsdóttir, T. J., & Björnsdóttir, K. (2018). Facilitation of a person-centered approach in health assessment of patients with chronic pain: An ethnographic study. *Qualitative Health Research* (in press). doi: 10.1097/ANS.000000000000132\*

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## **Declaration of contribution**

### **Study I**

Thórarinsdóttir and Kristjánsson designed the study. Thórarinsdóttir was responsible for the literature search and analysing the data that were retrieved through the search. Kristjánsson supervised the process and provided important feedback on the initial analysis. Thórarinsdóttir wrote the first draft of the paper with supervision from Kristjánsson. Kristjánsson critically revised the manuscript, edited it and gave approval for the final version of the manuscript to be published.

### **Study II**

Thórarinsdóttir, Kristjánsson and Björnsdóttir designed the study and Thórarinsdóttir and Björnsdóttir were responsible for obtaining ethical approval. Thórarinsdóttir was responsible for collecting and analysing the data through supervision from Björnsdóttir and Kristjánsson. Thórarinsdóttir wrote the first draft of the paper, with supervision from Kristjánsson and Björnsdóttir. Kristjánsson and Björnsdóttir critically revised the manuscript, edited it and gave final approval of the final version of the manuscript to be published.

### **Study III**

Thórarinsdóttir, Kristjánsson and Björnsdóttir designed the study and Thórarinsdóttir and Björnsdóttir were responsible for obtaining ethical approval. Thórarinsdóttir was responsible for collecting and analysing the data through supervision from Björnsdóttir and Kristjánsson and contribution from Gunnarsdóttir. Thórarinsdóttir wrote the first draft of the paper, with supervision from Kristjánsson and Björnsdóttir and contribution of Gunnarsdóttir. Kristjánsson, Björnsdóttir and Gunnarsdóttir critically revised the manuscript, edited it and gave final approval of the final version of the manuscript to be published.





# 1 Introduction

Early nursing theorists already emphasised the need for exploring patients' needs and preferences, which is in accordance with a latter-day person-centred approach, typically highlighted nowadays as central to the quality of care and health-care policies. However, evidence shows that although lip service has been paid for decades to an ideal of person-centredness, often grounded in a Kantian philosophical approach about respect for autonomy, actual patient involvement in nursing assessments still appears to be rare and under-developed (Buus & Hamilton, 2016; Florin et al., 2005; Jones, 2007).

The academic evidence of a shortfall between a theory of person-centredness and its practice concurs with the doctoral candidate's observations in her post as a consultant in nursing documentation at two rehabilitation wards. In spite of an explicit agenda of person-centred approaches to care, the perspective of patients did not reveal itself satisfactorily through the existing nursing assessment at the wards. Driven by the evolving concept of person-centred participation and a phenomenological approach, the doctoral candidate collaborated with nurses in developing a person-centred approach to nursing assessment at the two rehabilitation wards. As a result, the assessment tool Hermes was developed by action research for general use for patients who were admitted to the wards with a variety of medical conditions. For evaluating the feasibility of Hermes for supporting a person-centred approach to the participation of patients with chronic pain in health assessment, an ethnographic study was conducted at one of the wards. As patients with chronic pain were one of the largest patient groups at the ward, those patients were chosen to participate in the study described in this thesis.

This Introduction section will provide relevant background to theoretical, philosophical and practical approaches and methods used in the thesis. It is initiated with an historical perspective on nursing assessment and involvement of patients therein. As the concept of patient participation in health care developed in the first study, as well as underwriting the latter two, the concepts of person-centred care and patient participation will be discussed. Hermes was grounded in existential phenomenology and informed by earlier person-centred assessment methods. Background information will be provided on those two underpinnings. Finally, this section contains a review of rehabilitation and chronic pain.

## **1.1 Nursing assessment and involvement of patients therein**

Nursing assessment is fundamental to all nursing care provided (Berman et al., 2016; Potter, 2017). This centrality of nursing assessment was already emphasised by the first theorist in nursing, Florence Nightingale. She advocated two essential approaches or nursing actions for assessing the patient. The first one centred on involving the patients by asking them what they needed or wanted and finding out what the patients believed to be wrong in terms of practice. While Nightingale warned against asking leading questions, she advocated asking precise questions. If the patient is not eating, for instance, ask when he or she would like to eat and what food is desired. The use of observation was the second area of assessment that Nightingale advocated. She underlined precise observations concerning all aspects of the patients' situations, such as the environment (e.g. light, noise and cleanliness) and its impact on patients (Nightingale, 1859/1992).

The nurse theorist and psychiatric nurse, Peplau, furthered the idea of involving patients in their care (Peplau, 1952/1988). She claimed that nursing is therapeutic because it is a healing art through which an individual who is sick or in need of health care is assisted. She viewed nursing as an interpersonal process between the patient and the nurse, evolving through three phases of a therapeutic relationship (Peplau, 1952/1988). First, the patient and the nurse work together in recognising, clarifying and defining facts related to the patient's expressed need. Subsequently, they identify the patient's problems, set mutual goals and develop a course of action that is accomplished by the patient and/or the nurse and other health providers. She emphasised that the behaviour of the nurse as a person, interacting with the patient as a person, has a significant impact on the quality and outcome of nursing care (Peplau, 1992). Peplau had a major influence on psychiatric nursing as well as on nursing in general.

Victoria Henderson's internationally known human-need theory provided the first structured approach to assessing nursing in which the patient was viewed as a unique individual from a broad holistic perspective, with health considered as having psychological, spiritual and social dimensions (Lobo, 2011). According to Henderson, individuals have 14 basic needs that constitute health in the already outlined dimensions. They may require assistance in activities needed for fulfilling their needs for achieving health and independence. Henderson claimed that the nurse has the responsibility to assess patients' needs and assist them to meet their health needs as well as provide an environment in which the patients can perform activities unaided.

She supported empathic understanding, patient involvement and interdependence, and claimed the nurse must 'get inside the patient's skin and supplement his strength, will or knowledge according to his needs' (Henderson, 1966, p. 63). Henderson proposed 14 respective components of nursing functions in which the basic physical, social and spiritual needs were included. Those provided structure for nursing assessment and included: normal breathing, nutrition, elimination, movements and posture, sleep and rest, dressing and keeping the body clean, protection of the skin, normal temperature, communication and expressing emotions, worshipping, sense of work accomplishment, participation in recreation, and learning. Henderson's theory of human needs which became known and used worldwide is directly linked to the international definition of nursing which Henderson proposed in 1966.

Many structured frameworks for nursing assessment have been developed since the human-needs theory of Henderson. In this thesis the widely known Functional Health Patterns (FHPs)(Gordon, 1994) are of particular relevance. These patterns which are to be used in all nursing settings for a comprehensive assessment of human functioning are depicted in Table 1.

Table 1. Overview of Gordon's Functional Health Patterns (Gordon, 1994).

1. *Health perception - health management* - describes how the individuals perceive their health and well-being the strategies they use to manage their health
2. *Nutrition - metabolic* - describes food and fluid consumptions relative to metabolic needs.
3. *Elimination* - describes patterns of excretory function (bowel, bladder, and skin).
4. *Activity - exercise* - describes exercise pattern, energy and abilities to carry out daily activities, leisure, and recreation.
5. *Sleep - rest* - describes patterns of sleep, rest, and relaxation.
6. *Cognitive - perceptual* - describes sensory-perceptual and cognitive patterns (e.g. vision, hearing, smell, pain, learning style).
7. *Self-perception - self-concept* – describes patterns of general emotions, self-concept, perceptions of self (e.g. anxiety, body comfort, body image).
8. *Role - relationships* - describes patterns of role engagements and relationships.
9. *Sexual – reproductive* - describes patterns of satisfaction with sexuality and reproductive patterns.
10. *Coping –stress - tolerance* - describes a general coping pattern and the effectiveness of strategies used to increase stress tolerance.
11. *Values – beliefs* - describes values and beliefs (including spirituality) and used to guide choices and decisions.

The last half of the 20th century was a fruitful era in theoretical and practical development in nursing. Inherent in this development was the holistic movement that emerged as an organised attempt to move away from the reductionist and dehumanising impact of a bio-medical model that shaped nursing through the medium of medicine (Thorne et al., 1998). The model focuses on the physical or biological aspects of diseases and the diagnosis and treatment of those. It adheres to what many nursing theorists consider an unhelpful dualism (Thorne et al., 1998) where the mind and the body are seen as fundamentally separate and the human body is seen as a material object that is reducible to the collection of its physical parts (Marcum, 2005). Thus, the focus is primarily on the patients' diseases or dysfunctional body parts, without viewing them as whole or in their lived contexts. The patients' conditions are typically framed in terms of diagnostic criteria and of objective observation measurements and physical aspects of illness, couched in fragmented professional language. A paternalistic and distanced stance to the patient, alien to a philosophy of respect, is inherent in the model, with the physician being viewed as an authority figure with the power and expertise to diagnose and treat the patient, but the patient as a passive recipient of care (Marcum, 2005)

The holistic movement outlined above as well humanistic and phenomenological nursing theories contributed to nursing being established as a humanistic discipline (Meleis, 2007). As a humanistic discipline, it focuses on human beings a whole and has as its core an understanding of the individual as a unique focus of respect and care (Meleis, 2007). The term 'holistic nursing' has evolved over the years but according to McEvoy & Duffy, (2008), holistic care embraces an undivided mind-body dyad, supports a therapeutic nurse-patient relationship, is patient-led and focuses on providing individualised care.

In current nursing practice, nursing assessment is typically advocated through a patient-centred interview complemented by clinical observations. A person-centred approach in the interview is regarded an essential medium through which patients' values, expectations, expressed needs and main concerns are continuously elicited through the use of appropriate interview techniques. In the interview, the health history is reviewed, with the intention of providing a holistic view of the patient's health-care experiences and health habits from the following dimensions of health: physical and developmental, emotional, intellectual, social and spiritual (Berman et al., 2016; Potter, 2017).

However, the widely advocated person-centred and holistic approach to nursing assessments often appears to degenerate into little more than fancy rhetoric in practice, according to many studies focusing on such assessments. Talking the talk is not the same as walking the walk in this area. Ethnographic studies, as well as studies where conversation analysis has been conducted, consistently show that the patient's story is often reduced to more or less a fixed set of biomedical categories, and patients are often objectified (Hamilton & Manias, 2006; Latimer, 1998; Middleton & Uys, 2009). Moreover, the assessment interviews tend to be controlled by the nurses, thus inhibiting patients' concerns to be elicited and listened to (Jones, 2007; Middleton & Uys, 2009). Two studies in which nurses' and patients' perceptions of health problems were compared revealed major discrepancies between the two (Adamsen & Tewes, 2000; Florin et al., 2005) as well as in the respective assessment of their severity and importance for receiving treatment (Florin et al., 2005). Furthermore, studies in which documentation of nursing assessments was reviewed demonstrated that such documentation is typically modelled to a large extent on a medical discourse, focusing on the patients' bodies and the provision of physical and medically related care (Buus & Hamilton, 2016). In contrast, psycho-social aspects of care, patients' views and experiences were seldom or rarely documented (Hyde et al., 2005; Irving et al., 2006; Kärkkäinen et al., 2005). One must be cautious in over-generalising here, however. The medical model itself is gradually being modified, and one Finnish study of nursing documentation showed that the views and experiences of patients emerged to some extent (Laitinen et al, 2010). Nevertheless, the broad picture remains of patient-centredness appearing more as a high-minded ideal than actual reality in nursing assessment.

## **1.2 Person-centred-care**

### **1.2.1 Historical development of the concept**

Person-centred care and its near-synonyms, such as patient-, user-, and client-centred care, have been used interchangeably in the health-care literature and refer to certain distinct forms of care. In this thesis, 'person-centred care' or simply 'person-centredness' will be used as an umbrella term to cover all those specific terms. As a form of care, person-centredness is expected to correct tendencies for health care to be on the one hand too disease-centred and focusing narrowly on pathologies. On the other hand, it is intended to counteract the trend of health care to be too staff- or system centred, involving being inappropriately oriented to serve the interests of the health care professionals (HCPs) and organisations and using one-size-

fits-all approaches. The result of both of these two main trends and approaches is, arguably, that insufficient regard is given to patients' subjective illness experiences, preferences and needs (Epstein et al., 2010; Gerteis et al., 2002; WHO, 2007).

More specifically, central aspects of person-centred care involve addressing patients as unique persons from a holistic approach and entering their worlds through understanding their concerns, experiences, needs and preferences (Leplege et al., 2007; Mead & Bower, 2000). Other important attributes of person-centredness are a relationship of a therapeutic nature and the sharing of information and power between patients and HCPs. Person-centred care is presently regarded as the main marker for quality of modern health care, world-wide, as well as constituting an overall principle at the level of legislation and regulation. Accordingly, many distinguished organisations, including the World Health Organization (WHO, 2007), International Alliance of Patient's Organisation (2007), the Health Foundation (2011) and Institute of Medicine (2001) have adopted this form of care as a goal for high-performing health systems.

In addition to its wide-ranging philosophical grounding, the roots of person-centred care can be traced to psychology, in particular to the theory of humanistic client-centred therapy developed by Carl Rogers (1951). The theory relies deeply on the qualities of each individual who is taken to possess considerable resources by him/herself, drawing strength from those. Rogers turns the individual into the subject of his/her own therapy and what is important to him/her. The therapist's role is to accompany the restoration of the patient's health, by adopting a non-judgemental attitude and being attentive, understanding and tolerant. By showing empathy and sensitivity, the therapist will help the person regain full self-confidence (Leplege et al., 2007; Rogers, 1951).

The term patient-centredness in its present incarnation was coined by the psychoanalyst Balint. He claimed that each patient should be seen as a unique human being and be examined as a whole person for forming a more qualified diagnosis by the use of psychoanalytic tools (Balint, 1969). Engel, a psychiatrist who developed Balint's work further, claimed that the dominant model of disease, the biomedical model, had played out its role and proposed a new model, the bio-psychosocial model. In this model, which had a major impact on the development of person-centred care and medicine, disease was attributed to a combination of biological, psychological and social factors (Leplege et al., 2007; Mead & Bower, 2000). Once again, it is instructive to

note how very different theoretical paradigms – in this case humanistic psychology and psychoanalysis – have played causal roles in the development of the ideal of person-centred care.

A pivotal point in the development of person-centred care was the establishment of the first programme based on this form of care, The Picker Commonwealth Patient-Centered Care Program, in 1987 (Gerteis et al., 2002). The programme was based on empirical patient data and comprises seven dimensions that have been used widely since then to evaluate person-centred health care. This programme was the first to note that person-centred care is not only limited to the interpersonal level between HCPs and the patient but involves engagement at an organisational level (Beach et al., 2006).

During the 1990s, Thomas Kitwood (1997) extended the development of person-centred care by his work dedicated to the need for this kind of approach in dementia care. While Kitwood drew on the humanistic ideas of Rogers, his definition of the person was less individualistic. Instead, Kitwood insisted on the interdependent relationality of personhood, which he defined as 'a standing or status that is bestowed upon one human being, in the context of relationship and social being' (Kitwood, 1997).

## **1.2.2 Overview of the attributes of person-centredness**

Since the turn of this century, major contributions have been made to the development of use of the concept of person-centred care, as evidenced by numerous conceptual analyses and literature reviews conducted to clarify what person-centred care represents (e.g. Leplege et al., 2007; Mead & Bower, 2000; Scholl et al, 2014). The identified attributes for person-centred care in conceptual studies will be outlined below.

### ***1.2.2.1 Respect for the patient as a unique person***

Respect for the patient as a unique person is a core attribute, harking back to Kantian philosophy. This highlighted core of person-centredness involves exploring preferences, values, feelings, beliefs, concerns, ideas and expectations of the patient as well as exploring both the patient's disease and illness experiences (Leplege et al., 2007) and their functional impact in the terms of patients' view on how the illness affects their daily life. Exploring those with the patient places importance on developing a clear picture of what patients value about their lives and how they make sense of their situations (Kitson et al., 2013; Leplege et al., 2007; Waters & Buchanan, 2017). The focus is on the experiencing individual but not a disease entity (Mead & Bower, 2000). Acknowledging the person without the impairment of the disease

(Leplege et al., 2007) also involves providing care that is tailored to each particular patient (Sladdin et al., 2017).

### ***1.2.2.2 Addressing the patient from a holistic perspective***

Respecting the patient as a unique individual is intrinsically linked to knowing the person holistically and providing holistic care. This aspect is an important highlight across most conceptual reviews (e.g. Kogan et al., 2016; Mead & Bower, 2000; Morgan & Yoder, 2012; Scholl et al., 2014). This dimension involves understanding the patient's illness within a broad perspective by exploring each patient through her or his unique biological, psychological and social context. This means seeking to understand the whole person involving his or her life history and proximal context such as family and social situation as well as the distant context such as cultural background and community should be taken in consideration (Scholl et al., 2014).

### ***1.2.2.3 Communication and relationships***

Open and humanistic communication is addressed as an essential element of person-centredness in many of the conceptual reviews. Communicational features of HCPs, such as respectfulness, being welcoming, active listening, empathy and encouragement, are often addressed (e.g. Scholl et al., 2014), and in particular the ability of having sympathetic presence and understanding patients from their points of view (McCormack & McCance, 2006). In this respect, a broad range of verbal and non-verbal behaviour to engage in patient-centred communication has been described in recent conceptual papers, e.g. using open-ended questions, summarising important information, making eye contact and nodding (Scholl et al., 2014; Sladdin et al., 2017). Such communication is regarded as a prerequisite for the formation of a continuous relationship. This formation is regarded fundamental to person-centred care, and the building of partnership is particularly addressed (Mead & Bower, 2000; Scholl et al., 2014; Sumsion & Law, 2006). Such reciprocal relationship is characterised by positive rapport building, continuity, trust, connection and sharing of knowledge (Castro et al., 2016; Kitson et al., 2013; Scholl et al., 2014). In the more recent conceptual articles, involvement of the family is regarded as an essential aspect of person-centred care (Kitson et al., 2013; Scholl et al., 2014; Waters & Buchanan, 2017).

### ***1.2.2.4 Sharing of information and provision of education***

Sharing of information between the HCPs and the patients and provision of education (Kitson et al., 2013; Scholl et al., 2014; Sumsion & Law, 2006)

characterised by information flowing freely between the HCPs and patients (Kitson et al., 2013) is an important aspect of person-centred care. In this respect provision of tailored information regarding all aspects of care as well as the elicitation of the patients' needs for information (McCormack & McCance, 2006; Scholl et al., 2014) carry significance. Simultaneously patients should be encouraged to share information in particularly about symptoms and health concerns.

#### ***1.2.2.5 Patient participation, empowerment and strengths***

Participation of patients is emphasised as an attribute in recent conceptual reviews (Castro et al., 2016; Kitson et al., 2013; Waters & Buchanan, 2017) which detail the importance of encouraging patients to participate actively and of engaging them in decision making regarding their own health. That means sharing decision with them, of which a shared care plan is an indicator (Kitson et al., 2013). This signals a stark contrast to most earlier conceptual reviews (Mead & Bower, 2000; Slater, 2006; Sumsion & Law, 2006) which did not address the term 'patient participation' per se.

Focusing on patients' strengths includes emphasising people's strengths and existing abilities, drawing on the early work of Rogers, and is highlighted as an essential component of person-centred care in some conceptual reviews (Slater, 2006; Waters & Buchanan, 2017).

Empowerment is foregrounded in many of the conceptual papers and directly linked to the sharing of power. It involves acknowledging patients' perceived abilities to self-manage important aspects of their illness as well as encouraging them to take responsibility in solving their health-related problems and subsequently take actions to improve their health. By such means, the patients can be activated to become an experts in the management of their health conditions. Other empowering approaches are supporting the patient's autonomy through the offering of educational programmes, patient activation and health promotion interventions (Morgan & Yoder, 2012; Sumsion & Law, 2006; Waters & Buchanan, 2017). However, empowerment is also typically addressed as the result of, rather than an intrinsic component of, person-centred care (Castro et al., 2016).

#### ***1.2.2.6 Provision and the context of care***

Care provision in line with patient's preferences is addressed as an important dimension of person-centred care in many of the conceptual reviews, in particular the recent ones. Emphasis is in particular on emotional support and physical needs (Kitson et al., 2013; Scholl et al., 2014; Sladdin et al., 2017).

Emotional support is provided by responding to emotional issues, by engagement and sympathetic presence (McCormack & McCance, 2006) and by paying attention to patients' anxieties over their health status, treatment and impact of the illness on them or and the family (Kitson et al., 2013; Scholl et al., 2014). The aspect of physical support covers a range of actions that aim at securing the physical comfort of the patient (McCormack & McCance, 2006), including pain management, providing assistance with daily living needs and activities as well as ensuring safe care (Kitson et al., 2013; Kogan et al., 2016; Scholl et al., 2014).

Coordination and continuity of care is addressed in particular as an important aspect of providing person-centred care in four of the most recent conceptual reviews (Kitson et al., 2013; Kogan et al., 2016; Scholl et al., 2014; Waters & Buchanan, 2017) but not addressed in the earlier ones. This aspect includes coordinating and ensuring continuity of care, such as by preparing transitions from inpatient to outpatient and follow-up care and other services after discharge as well. Here, making use of known patient data through the health care system ensures continuity of care.

The context and the environment is addressed as an essential component in many of the conceptual reviews, particularly the recent ones (Kitson et al., 2013; Kogan et al., 2016; Scholl et al., 2014). In their conceptual framework of person-centred nursing, McCormack and McCance (2006) identify the therapeutic environment as one of their main constructs. Yet, they define it as an antecedent of person-centred care but not as an attribute. Such an environment is described as one in which decision making is shared, relationships between staff are collaborative, innovative practices are supported and leadership is transformational. Other reviews (Kitson et al., 2013; Scholl et al., 2014) describe the person-centred environment in a similar way, adding several contextual issues such as access to care, effective teamwork, and a policy-practice continuum (Kitson et al., 2013; Kogan et al., 2016; Scholl et al., 2014). Effective teamwork, as a feature of person-centred care, is characterised by cohesive and co-operative teams of professionals who are skilled in communicating respect and trust among team members as well as sharing of information, mutual goals, values and visions. In such teams, constructive feedback is provided and responsibility equally distributed (Kitson et al., 2013; Scholl et al., 2014). Policy-practice continuum is integral to person-centred care according to Scholl et al. (2014) and entails the effective translation of the policy of person-centred care into care practices.

### **1.2.2.7 Competent HCPs**

The competencies of the HCPs are addressed in Mead and Bower's (2000) seminal conceptual analysis. They proposed that certain personal qualities of the HCPs were integral to person-centred care as the HCPs and patients are influencing each other all the time and cannot be viewed separately. Here relational aspects, in particular self-awareness, are emphasised. Competencies of the HCPs have been scrutinised and stressed further by McCormack & McCance (2006), claiming that for providing person-centred care, the HCPs have to be professionally competent, having developed interpersonal skills and self-knowledge as well as being committed to their work and, being able to clarify their beliefs and values. These required competencies of HCPs are supported by other reviews (Kitson et al., 2013; Scholl et al., 2014) that also address commitment to evidenced practice.

Notice that the attributes described in this section must not be understood as separate pieces making up a jigsaw puzzle of person-centredness but rather as elements that are variously interwoven and interconnected, conceptually and empirically, and different concept analyses individuate and combine them in different ways.

### **1.2.2.8 Benefits and outcomes of person-centred care**

In their conceptual papers on person-centredness, McCormack & McCance (2006) and Morgan & Yoder (2012) emphasise the main benefits in terms of outcomes being increased patient satisfaction and well-being. Accordingly, empirical studies show that the strongest outcome of person-centred care is increased patient satisfaction especially in the context of the communication between HCPs and patients (McMillan et al., 2013; Rathert et al., 2013). There is also a growing evidence for improved emotional well-being as a benefit of person-centred care (Dwamena et al., 2012; McMillan et al., 2013) as well as enhanced self-care abilities (Rathert et al., 2013). Some studies have demonstrated reduced mortality and length of stay (Ekman et al., 2012) as well as reduction in physical symptoms (Rathert et al., 2013) as an outcome of person-centred care. However, these outcomes vary between studies.

### **1.2.2.9 Translating person-centred care into practice**

The process of translating the person-centred approach into clinical practice is complex and challenging as the implementation of research findings in health care overall is (Harvey & Kitson, 2016). The research based framework – The Promoting Action on Research Implementation in Health Services framework (PARIHS) – was developed for the guiding and evaluation of the translation of

knowledge into practice (Kitson et al., 1998). It has been used for this purposes, involving the implementation of person-centred frameworks (e.g. (Hebert et al, 2018; Jangland & Gunningberg, 2017). This framework was originally developed 20 years ago (Kitson et al., 1998), but has been extended by substantial research resulting in the latest version of the framework, i-PARIHS (Harvey & Kitson, 2016; Kitson & Harvey, 2016). In accordance with i-PARIHS, successful implementation of evidence in health care practice is determined by the achievement of agreed implementation goals, the innovation being embedded into health care practice and variations related to context appearing as minor across implementation settings (Harvey & Kitson, 2016; Kitson & Harvey, 2016). According to the framework, the progress of the implementation process is dependent on how the constructs, innovation, recipients, and the context enable or restrict the implementation. Yet the construct of facilitation, involving the facilitator (one or more) and the facilitation process (as a set of strategies and action), is emphasised as the most active variable in the framework (Harvey & Kitson, 2016; Kitson & Harvey, 2016). Its centrality is due to the major impact it has upon the three earlier mentioned constructs according to the framework. Example of facilitation strategies used by facilitators (people who lead the implementation) are focus groups, teaching and training sessions and provision of support. Similar strategies have been reported useful in the implementation of person-centred methods (Moore et al., 2017; Naldemirci et al., 2017)

The construct of innovation in the i-PARIHS framework encompasses the evidence base of the implementation, its advantages, fits and adaptability with local experiential knowledge (Kitson & Harvey, 2016). The construct of recipients includes the people who are affected by and who influence the innovation (Harvey & Kitson, 2016). The features of recipients to be considered include motivation, values and beliefs, goals, skills, knowledge, support, collaboration time, and authority and power. Accordingly, attitudes have been shown to be influential in the implementation of person-centred methods (Moore et al., 2017). Here, equality and respectfulness in communication between HCPs is of particular importance for the adoption of person-centred methods into practice (Brooks et al., 2017; Naldemirci et al., 2017). The construct, context in the i-PARIHS framework encompass culture, leadership and orientation to evaluation and learning (Harvey and Kitson, 2016). In this respect, the ward culture (Bolster & Manias, 2010), leadership and orientation of learning has shown to influence the integration of person-centred care into practice (Moore et al., 2017).

### 1.3 Patient participation

The notions of person-centredness and patient participation have run on parallel tracks in the literature during the last few decades. However, in recent years, the integration of these has begun to emerge, as evidenced in the conceptual papers within which patient participation is viewed as an element of person-centred care (Castro et al., 2016; Kitson et al., 2013). Similar to person-centred care, the enactment of patient participation is regarded both as a professional and psycho-moral ideal and as a legal requirement, as reflected in legislations in many Western countries, in which patients' rights to influence and direct their own care are laid down (Coulter & Magee, 2003).

The issue of patient participation harks back to criticisms made by socio-political movements in the 1960s of prevailing social hierarchies and to a rising interest in unencumbered individual choice (Rothman, 2001). This issue can be traced further back to the Kantian moral ideal of respect for a person's autonomy and the resulting criticism against paternalism. The celebration of autonomy has been emphasised in much of the medical and nursing-ethics literatures of the last 50 years, insistently turning against the view that individuals possessing knowledge and power (here: HCPs) should enact for the good and on the behalf other individuals who are less powerful and less knowledgeable (here: patients), and that HCPs should enact in this way irrespective of the patients' informed consent (Beauchamp & Childress, 2009). In the outdated paternalistic sense of health care, HCPs are regarded as 'providing' care to patients who play minimal and passive roles (Beauchamp & Childress, 2009).

In the Concise Oxford English Dictionary, the basic meaning of 'participation' is outlined as 'to be involved in', or 'to take part in', and is derived from the Latin meaning 'to share in' (Soanes & Stevenson, 2004). In the Merriam Webster Dictionary online (n. d.) the emphasis is upon the participation as a joint venture and explained as 'to take part in or experience something along with other'. According to these dictionary explanation of the term and in view of the resistance to paternalism in health care, patient participation can be defined broadly as: patients' involvement and participation on their own health care, together with HCPs who share their power with patients. This broad definition will be adhered to in this thesis.

Patient participation presents itself in the literature as a multifaceted concept. The terms 'partnership' (Cahill, 1996; Sahlsten et al, 2008) 'involvement' (Entwistle et al, 2008; Thompson, 2007) and 'participation in decision-making' or 'shared decision-making' (Towle et al., 2006) as well as

'patient engagement' (Higgins et al., 2017) have all been considered integral to the concept.

According to two existing concept analysis of 'patient participation', which have been conducted from a nursing perspective, it is emphasised that such participation occurs when all the following four attributes are present: i) an established relationship between nurses and HCPs; ii) HCPs share power with patients; iii) information and knowledge is shared between them; and iv) mutual engagement is in mental or physical activities (Cahill, 1996; Sahlsten et al., 2008). The latter analysis addresses in particular the importance of the patient's opinion and the need to tailor information to each patient in accordance with the person-centred approach. In contrast, this specific emphasis does not exist in the earlier one (Cahill, 1996).

Of interest here is that in the most two recent concept analyses of patient participation, the emphasis is clearly on a person-centred approach as integral to patient participation (Kvæl et al., 2018; Melin, 2018). In other words, the relationship between the two ideals is considered intrinsic conceptually rather than just instrumental or extrinsic. The concept analysis of Melin (2018) outlines the focus on respect for the patient's unique condition, needs and desires as the three main attributes of patient participation. This attribute entails the importance of attending to the patient's life situation in line with a person-centred approach (Leplege et al., 2007). Once again, the association between the ideals is seen as conceptual rather than just empirical. As the analysis of Melin (2018) focuses on rehabilitation, the second attribute highlights active participation, with the underlying assumption being that patients want to be in charge of their own rehabilitation through active engagement. In line with both the first and second attributes, the third attribute is outlined as mutual engagement and exchange between patients and HCPs, for example regarding goal setting, planning and therapy.

In the other recent analysis, which was conducted of elderly patients from an inter-professional perspective (Kvæl et al., 2018), respect for the patient's perspective and preferences is addressed in all the five attributes outlined in accordance with a person-centred approach (Lepege et al., 2007; Kitson et al., 2013). Three of attributes that are outlined (developing multiple alliances, information and knowledge exchange, reciprocal engagement) in the the analysis of (Kvæl et al., 2018), bear a clear resemblance to the attributes in addressed in the analysis Cahill (1996) and Sahlsten (2008). Those are an established relationship, shared information and knowledge and mutual engagement in mental or physical activities. The other two attributes of the

analysis, holistic process with a focus on a biopsychological approach and flexible and interactive organisational structure to patient participation in the analysis (Kvææl et al., 2018), accord more or less with attributes of person-centred care (e.g. Kitson et al., 2013).

Patients' involvement in decision-making, or shared decision-making as a joint venture between patients and HCPs, has been the main focus with regard to patient participation in the medical literature (Towle et al., 2006). The most prominent model of shared decision-making in that literature, the Charles Model, tallies with a person-centred approach in its emphasis on the elicitation of patient preferences. According to this model, the shared decision-making process contains the following key attributes, arranged in stages which all have to be present in order for shared decision-making to have occurred: i) both physicians and patients take steps to participate in the process, entailing that patient preferences are discussed; ii) information is shared between them; iii) deliberation in which patients and physicians review pros and cons of treatment options; iii) a decision is made in which both of them invest (Charles et al., 1997; 1999). In the most recent version of the Charles Model, the attribute of ongoing development of partnership has been added, which is in line with the building of relationships as emphasised as a central attribute of person-centred care Montori, et al., (2006). Since the year 2006, conceptual refinements of patient participation in shared decision-making have been evolving (Stiggelbout et al., 2015). A recent paper synthesises these into four steps as a guidance for applying shared decision-making (Stiggelbout et al., 2015). In all these steps, patients' preferences and support for patients are intertwined: i) the HCPs inform patients that a decision is to be made and that the patients' views are important; ii) the HCPs explain the options and the pros and cons of each option of relevance as well as providing tailored information; iii) the HCPs and patients discuss patients' preferences; the HCPs support the patients in the deliberation; iv) the patients and the HCPs discuss patients' decisional role preferences, make or defer the decision, and discuss eventual follow-ups. These steps align clearly with the attributes of the Charles Model outline above. Yet, a potential patient preference for deferring decision to the HCPs is kept open, while in the Charles Model the shared decision process inevitably ends with a shared decision.

In recent years, the use of the term 'patient engagement', referring to active patient participation in decision making, has proliferated while the use of the term 'patient participation' has decreased at the same time (Finset, 2017). In a recent conceptual analysis of patient engagement, person-centredness is highlighted (Higgins et al., 2017). Accordingly, the first attribute

of patient engagement is 'personalisation' which means that interventions accords as closely as possible to the patient's unique desires and circumstances. This involves efforts at shared decision making and tailoring information to the patient's level of receptivity, interests, resources, capabilities and life circumstances. Emphasis is on the patient as a real person rather than as a utopian image of an autonomously informed and rationally consenting agent. The second and third attributes focus on the ability of the patient and skills to gain information, guidance as well as methods and equipment to secure appropriate and consistent care.

This is a notable and salutary change of emphasis. In sum, earlier concept analyses of the term 'patient participation' almost exclusively described positive attributes of patient participation, such as therapeutic relationships and the ideal sharing of power and information between patients and HCPs. The trend in those analyses was to continuously emphasise a more demanding person-centred approach as central to participation, whether framed simply as 'patient participation', 'shared decision-making' or 'engagement'. However, at the same time, numerous empirical studies showed that patients often experience their participation as involving a strenuous communicational struggle between them and HCPs (e.g. Rosewilliams et al., 2011; Schoot et al., 2005; Yip & Schoeb, 2018). Where such power struggles exist, for example where HCPs compel an unwilling patient to share in decision-making, the participation is question is, *ex hypothesi*, non-person-centred. In these cases, HCPs do not allow the kind of participation the patients prefer or even coerce participation upon them when it is unwanted. Examples of such forced or constrained participation are when patients are coerced to make decisions about their care that they are not prepared for, mentally, intellectually or emotionally (Thorne et al., 2013; Ziebland et al., 2006). On the other hand, research also shows that there exist, even in today's anti-paternalistic climate, more typical cases where patients have to struggle with HCPs, who disregard their will to make decisions (Aasen et al., 2012; Peek et al., 2009). As always, the golden mean is difficult to achieve and ideals tend to sway from one extreme to the other; in this case from strong paternalism to a strong focus on patient informed consent and autonomy which, when taken to its excess, can itself become paternalistic in going against the patient's wishes to defer to authority.

Arguably, a new critical concept analysis of patient participation is required that puts these findings into a theoretical perspective as well as accommodating them. Such analysis would distinguish conceptually between person-centred care and patient participation, without undermining the

normative argument that ideal patient participation remains person-centred at the same time. Overall, there seems to be good reason to construct a conceptual account of patient participation that allows for a clear distinction between such participation when it is (a) ideal and person-centred and (b) when it is non-person-centred and non-ideal.

## **1.4 Existential phenomenology and its application in health care**

The philosophy of person-centredness, which has its theoretical origins in Kantian philosophy, although it could also potentially be given other rationales, forms the philosophical basis for the present thesis. However, the methodological approach chosen owes as much, if not more, to the philosophy of existential philosophy. Indeed, motivating this thesis is the assumption that there is synergy, rather than significant contrasts, between the grounding normative approaches of person-centredness and existential philosophy.

Many philosophers have contributed to the formation and development of existential phenomenology. Of those, (Heidegger, 1927/2010) Merleau-Ponty (1962) and Gadamer (1975/2013) have shaped this philosophy considerably together with their followers (e.g. Dahlberg et al., 2008; Leder, 1990; Toombs, 1993; van Maanen, 1997). Within nursing research, their philosophy has mainly been applied as a research methodology. However, this philosophy can also provide valuable normative insights for use in health-care practices (e.g. Carel, 2011; 2016; Marcum, 2005; Svenaeus, 2000; 2011). Dalbergh et al. (2009) have argued that the clinical application of existential phenomenology can strengthen person-centred care. In line with their view, it will be explained in what follows how the application of existential phenomenology in health care can provide possibilities for consolidating person-centred care.

### **1.4.1 Interpretative and existential phenomenology**

Heidegger understood his phenomenology as constituting a 'fundamental ontology' as well as an epistemology of experience (Heidegger, 1927/2010). His phenomenology, in which existential assumptions are incorporated, centres around people's experiences of everyday life and the meaning of those experiences (Heidegger, 1927/2010; Svenaeus, 2000). Within Heideggerian phenomenology, 'meaning' is understood in two distinct but related senses. First, it is defined as the essence and significance of the lived experience, or the totality of the main structures of that experience, grasped holistically (van Maanen, 1997). Second, 'meaning' denotes the ways people make sense of

their experiences: that is, how they render them meaningful in their contexts of relevance (Heidegger, 1927/2010; Svenaeus, 2011).

In this phenomenology, which includes the existential assumption that we 'are' our bodies (Heidegger, 1987/2006) people's lived experiences and meanings are explored from a first-person point of view through a reflective, narrative, interpretative dialogue with another (Dahlberg et al., 2008; Van Maanen, 1997) In line with the prior discussion, a central aim of the clinical application of this phenomenology can be viewed as exploring patients' lived experience, as embodied beings, of their illness, revealing its central aspects (meanings), as well as exploring how the patients render those experiences meaningful in their contexts of relevance.

Heidegger's fundamental concept was what he calls 'Da-sein', or the 'being-there' of human existence. 'Being-there' means that we are situated in the world where we live. Here the hyphen between 'da' and 'sein' and 'being' and 'there' means that humans and their world form an inseparable unity. According to Heidegger, we are already there (da) in the world where we dwell or which we inhabit in our ordinary everydayness, engaged in the practical affairs of life in a typical pre-reflective way (Heidegger, 1927/2010; Svenaeus, 2000). It is not a world we need to 'enter' as outsiders. In accordance with his ontological stance, Heidegger considered human only be to be understandable via their profound heteronomous connection to the world. He claimed that we should study 'worldliness', that is the ways we are in the world: a worldliness which we understand and give meaning to through our actions. Those actions are, in turn, energised by our interpretative nature which lies at the very essence of all human activities (Smith et al., 2009). Thus, Heideggerian phenomenology is referred to as interpretive (hermeneutic) phenomenology as well as being existential. The world is in Heidegger's sense not an objective, freestanding reality but rather a meaning structure that is basically a mode of our lived experiences, meaning that our self-identity is constructed though the world in which we live and dwell. Through our continuous interpretation and re-interpretation, the everyday world that we are always adapting to and redefining qua structure is continuously changing (Heidegger, 1927/2010; Svenaeus, 2000).

Heidegger investigated and outlined different modes of being, or what he called 'existentials', through which he assumed that we humans make sense of our being in the world. The fundamental categories of existentials comprise understanding; attunement; articulation by language and being with another (Heidegger, 1927/2010); and the body as lived (Heidegger, 1987/2006

Svenaesus, 2000). These existentials, in which the category of understanding is overarching, are thought of as intertwined, as they always work together inseparably (Heidegger, 1927/2010; Svenaesus, 2000). In sum, people strive to understand their existence through their bodies, attunement and articulation through language and dialogue with another.

#### **1.4.1.1 *Understanding and dialogue with another***

The mode of being that strives to understand its own manner of existence in the world is overarching in Heidegger's phenomenology (Heidegger, 1987/2006; Svenaesus, 2000). Here he makes it clear that all our understandings of the everyday world are derived from our interpretations of it (Heidegger, 1927/2010). His view thereby tallies with the more general hermeneutical understanding that every person is situated and has a unique life world, or horizon of being, shaped by virtue of his/her history, culture, relationships and language. Thus, people come with a 'pre-understanding' to each situation, a foundational structure for understanding (Heidegger, 1927/2010). In this context, Gadamer (1975/2013) uses the concept of 'horizon' in order to describe each individual's understanding. He argues that a horizon is the range of vision encompassing everything that can be seen from a particular vantage point which, in turn, presents the meaning perspective of the individual. Patients typically understand their illness in terms of the disruption it has on daily life, for example, with their understandings being shaped by their biography and unique life situation, whereas HCPs tend to understand the illness from the horizon of their expert knowledge as well as from their own life situation (Toombs, 1993).

The existential language (Heidegger, 1927/2010) is of crucial relevance as it is the medium by which self-understandings and communication with others is structured. Moreover, language, in Gadamer's philosophy (Gadamer, 1975/2013), is a key manifestation of the mode of being with another, as the medium in which substantive understandings take place between people through dialogue. In this respect, the dialogical, open, reflective, narrative and interpretative features, through which the lived experience and meanings are explored, is central. According to Gadamer (1975/2013), it is through such a dialogue with persons with different horizons of beings (in this case between HCPs and patients) that their horizons can be fused (Gadamer, 1975/2013), resulting in a profound understanding between them. By fusing their horizons of understanding, participants in the dialogue find the relevant issue to be different, more expansive and more fully discovered than either of them might have previously understood it to be on

their own. Thus, through understanding and language and dialogue with another, HCPs could apply this phenomenology to facilitating an understanding of patients as interpretative beings in order to interpret, understand and make sense of their illness situations, as well as helping the HCPs understand those situations from the patients' perspectives of relevance (Marcum, 2005; Svenaeus, 2011)

Central to phenomenology is the principle of openness, which essentially means attending to phenomena (in this instance, patients' lived experience of illness) as they present themselves to us, in their entirety (Dahlberg et al., 2008). This includes endorsing people's first person-voice by listening to and capturing their narrative descriptions and interpretation of their experience. In order to be open to the other's position, we must be aware of and take into critical account our preconceptions and prejudices due to our own horizons of meaning, outlined above as the pre-understanding we inevitably bring to the conversations. Otherwise, those will block our sight of the phenomena of the patients' experiences of illness and make us view their experiences through an alien gaze, shaped by our professional knowledge and personal experiences or situations (Carel, 2016; Marcum, 2005). By reflecting upon subjective experiences through such a co-operative process – namely by rigorously examining and elucidating the data of experience – the gap between the interviewer and the interviewee can be narrowed and possibly overcome or fused, as suggested above, through 'phenomenological reverberation' (van Maanen, 1997). Thus, it becomes possible for HCPs to come to at least 'some understanding of the patient's experience of illness' (Carel, 2016; Toombs, 1993) and subsequently craft assessments and interventions that take their cue from and reflect this understanding.

The Heideggerian view of persons as self-interpretative beings, for whom things essentially have meanings and significance, truly centres on the person. The association between the Heideggerian interpretative stance and a person-centred view draws support from early classic writings (Frank, 1995; Kleinman, 1988) as well as from many recent empirical studies (Berglund, 2014; Haahr et al., 2011; Kirkevold, 2010). These show, when applied to a health context, that patients' continuous interpretation of their illness and the impact it has on everyday life is usually driven by the patients' quest for establishing a new meaningful order in living with the negative impact of illness. Hence, the approach of supporting patients in interpreting and lending meaning to their illness experiences is clearly an instantiation of a person-centred approach. There is no 'one-size-fits-all' on offer here. That said, approaching patients via their existential understanding is not, as such,

outlined as an attribute of person-centred care in the conceptual papers on person-centredness (described above). The claim made here is, therefore, normative rather than merely descriptive. The claim is not that standard definitions of person-centredness already include or imply the attribute of 'enhancement of interpretation and understanding of the illness situation', but rather than adding it into the conceptual and clinical understanding of a person-centred approach would strengthen such an approach.

According to Heidegger, we are inseparable from the world that we dwell in, which we at the same time continuously adapt to by reconstructing it and our identity at the same time. These assumptions have been confirmed in many studies on experiences of illness, illustrating that adapting to illness is a continuous struggle with re-constructing a new identity (Kitzmuller et al, 2013; Sharpe et al., 2013). Therefore, supporting patients in this identity struggle, as a new meaning-making process, should be a feature of person-centred care. However, such support is not outlined as an attribute in the existing conceptual papers on person-centredness. Arguably, therefore, integrating this support as an attribute of person-centred care advances the conceptual and clinical application of this approach to care.

#### **1.4.1.2 Embodiment and attunement**

Heidegger argued that everything we refer to as our lived body, such as our hormones or muscle fibre, belongs essentially to our mode of existence (Heidegger, 1987/2006; Svenaeus, 2000). Complementing the insights from Heidegger about mind-body unity is Merleau-Ponty's (1962) insistence that we, as humans, are embodied beings, primarily experiencing our body as the subject that we are. In this way, our bodies are our vehicles of being-in-the-world through which we live, interact with and experience and understand that world.

In emphasising embodiment, Merleau-Ponty argued, by drawing on Gestalt psychology, that we develop stable patterns of experience that tell us how to move our bodies in order to respond satisfactorily to various psychological and social situations (Bullington, 2009; Merleau-Ponty, 1962). These patterns build up over time, becoming 'sedimented' and free from immediate attention. Normally, the healthy body is experienced as the subject and as, in a sense, transparent, namely taken for granted and free from conscious awareness. This ability to free our attentions from ourselves, that is from our lived body, has central importance for human beings as it allows them to engage with full attention with the world according to their immediate wishes and desired situations (Bullington, 2009; Merleau-Ponty, 1962). In times of

illness and other challenging situations in our lives, however, we cannot adapt new evolving disruptions into becoming 'sedimented'. Thus we become aware of those patterns as they are no longer absent from our awareness but stand out as disturbing and interfering with our plans and actions (Leder, 1990). In this disruptive illness state, the body is no longer experienced primarily as the subject that we are but rather as an external, protruding object (Gadamer, 1993/1996; Leder, 1990). Consequently, the world of everyday life becomes disturbed, as movements and abilities that are taken for granted fail. In this way, our lived world 'shrinks', as we no longer have freedom to fully attend to it, with the attention focused on our disturbing bodies (Gadamer, 1993/1996).

Experiencing the body as a protruding object in our world means in Heideggerian terms that the body has taken on an alien character that we are not familiar with any more. Drawing upon Heidegger, Svenaeus (2011) has likened experiencing the body in this way to an 'unhomelike' being in the world. In such a state, our 'home' is unfamiliar to us and we do not know the ways for executing everyday practical affairs anymore. Accordingly, Svenaeus has argued that illness can be viewed as an unhomelike being in the world, whereas the healthy state can be symbolised as being at home in the world. A keen understanding of the difference between these two modes can promote HCPs' understanding of what it means to live with a disabling illness, beyond the present conceptual models of person-centred care, hence adding further backbone to the earlier argument that the ideal of person-centredness would be strengthened by an input from hermeneutic, existential phenomenology.

Patients' experiences of illness typically centre around the disturbances and impact the illness has upon everyday life (Toombs, 1993), and through these impacts the meaning of illness is constructed. Toombs (1993) outlines in her classic analysis the central features of living with a body impairment. These are the loss of wholeness, certainty, control, the freedom to act and loss of the familiar world. These losses represent the lived experience of illness that all patients with an intrusive body impairment will experience. However, it is relative to the individuality of each person how obtrusive these losses are to that person and thereby the meaning attached to them. Toomb's analysis has been supported by studies of the lived experiences of different illnesses such as chronic pain (Råheim & Håland, 2006), stroke (Kirkevold, 2010) and Parkinson (Haahr et al. 2011). Here it is of particular importance that being in the world, characterised by the losses Toombs and other identify, is in fact is a form of existential suffering from illness (Harris et al., 2018; Igai, 2018; Kitzmuller et al., 2013). In previous accounts of

person-centredness, the understanding of the illness as existential suffering has not been outlined as an attribute, which arguably weakens those accounts.

The focus on the disturbing impact of illness brings us to the Heideggerian existential or mode of attunement, signifying that patients are attuned to these obtrusive impacts of illness upon everyday life. In this mode, we attend to things as being significant: as mattering (Dreyfus, 1991; Heidegger, 1927/2010), implying that things show up as being of concern to us – as attractive or threatening, useful or stubborn, and so forth (Dreyfus, 1987). Thus, in accordance with the existentials of embodiment and attunement, outlining certain health issues of concern could facilitate patients in describing their embodied being, helping them in framing these disturbances as an important aspect of their illness experiences and as being a major concern to them (Marcum 2005; Toombs, 1993). Asking patients to describe the severity of these disturbances on daily life could provide insight into how well the patients are attuned to the disturbances. Moreover, such discussion, as integral to the phenomenological dialogue already outlined, would be in accordance with Toombs (1993) as enabling HCPs to enter into the patients' worlds of existential losses and sufferings, and the meanings constructed from its impact on everyday life. Capturing the patients' meaning of illness in this way as can arguably provide HCPs with an understanding of what it existentially means to live with an illness which protrudes into people's lives. Consequently, such an understanding may substantially consolidate person-centred care. That said, HCPs tend not to be skilled at gaining such an understanding, perhaps because of lack of training, in spite of being otherwise capable of providing qualified health care (Carel, 2016; Marcum, 2005).

Drawing upon the insights of Merleau-Ponty (1962), Heidegger (1927/2010) and Gadamer (1993/1996), it can be concluded that the disturbances of everyday life due to the physical illness can pose a threat to the meaningfulness of daily life, as they disrupt our freedom to engage fully with our world and life projects according to our desires. Thus, our life is made chaotic, out of order and not fitting into our established context of life (Svenaesus, 2000). Accordingly, in helping patients frame and re-frame those disruptions, as well as viewing them holistically and in context, phenomenological philosophy could enable HCPs eventually to help people make sense of (as opposed to merely accepting) the illness situation through therapeutic practices, by establishing a new stability to their lives. This would involve the creation of more spaces for attending to the world and their life projects according to their desires. Given the view that being in the world with the disturbing impact of illness is a form of existential suffering (Toombs, 1993)

supporting patients in reconstructing their meaning structures by creating new existential spaces can be regarded as a support strategy to relieve patients' suffering.

Drawing upon Sveneus arguments that illness can be likened to an unhomelike being in world, the already outlined reconstructions of the meaning structure of being in the world can be viewed as a method of helping patient to creating a home in the world again. According to Stone & Papadimitriou (2015) HCPs would in this way help patients re-habit a home, in the form of creating a meaningful world to dwell in again.

## **1.5 Rehabilitation**

The word rehabilitation is derived the Latin root 'habil', meaning to enable. Rehabilitation therefore means to 're-enable' or 'restore'. It is this sense of the word that is captured in the various meanings attributed to it (Siegert et al., 2012). Rehabilitation is relatively new as a formal health-care discipline. It emerged and became consolidated over the latter part of the twentieth century, largely due to the survival of many war-wounded soldiers who in previous times would have died from their injuries or their consequences. A main cutting point was the era of the of World War II, which resulted in many injured soldiers surviving the war because of improvements in emergency care and the emergence of antibiotics but who returned home with significant injuries. Consequently, a set of crucial and overwhelming challenges arose for health care and social services, with the establishment of rehabilitation being the major part of the response (McPherson et al., 2015). Since then, rehabilitation has developed from focusing on major war-inflicted injuries to a discipline serving all persons with disabling impairments, including chronic illness, that severely restrict them in their daily activities and social participation.

The terms 'illness' and 'disability' have been used in the context of rehabilitation for health conditions that have major restricting and negative impact on the person's daily life. Yet there used to be clear-cut distinction between them, with 'illness' carrying the common sense meaning of a temporary disease or condition that either could be cured or controlled by treatment, whereas 'disability' was thought of as permanent and moderated only by rehabilitation (Couser, 1997). However, currently the distinction between those terms has become blurred because an increasing number of people are living with chronic illnesses, such as asthma, diabetes and many forms of cancer, that once were fatal. However, in spite of living on, they experience significant disabilities (Kearney et al., 2012). In light of these

historic changes and increased semantic fluidity between these two terms, they will be used interchangeably in this thesis.

Three main perspectives of rehabilitation have emerged since its establishment around the middle of the 20th century. These pertain to how health professions view disabling illnesses and rehabilitation, how those are viewed by the to-be-rehabilitated persons themselves and how those are viewed from the society (Kirkevold, 2015). Studies have shown that patients and rehabilitation professionals tend to view the rehabilitation process differently (Angel et al., 2011; Kvigne et al., 2005). Moreover, it has been shown that when the health-care providers neglect the person's perspective, the rehabilitation is often experienced as unhelpful or even as having a negative impact (Angel et al., 2011). On the other hand, rehabilitation professionals have important expert knowledge and experience which the patient does not possess (Negrini & Ceravolo, 2008; Vaughn et al., 2016). Accordingly, the three main perspectives have been integrated into the current models of rehabilitation, the bio-psychosocial model and the International classification of function of disability and health (ICF) (Taylor & Geyh, 2012; WHO, 2001). In what follows, three major perspectives will be outlined as well as their integration.

### **1.5.1 The professional perspective**

Traditionally, rehabilitation has been physically orientated, and influenced by the medical model, which assumes that a disease or a dysfunction in a part of the body underlies all changes in the person's state of health. Therefore, the focus in this model has been on physical functions. This is an augmentation of the traditional medical model of disease and injuries, upon which the need for rehabilitation is seen to be grounded. The professional perspective on health is grounded in the understanding of the natural sciences of disease and injury, where the focus is on physical functions and disease mechanisms. Health care primarily aims at improving the physical functions, if possible, and, secondly, to compensate for the injuries of the organs (Wade, 2015a)

This perspective is still the most prevailing one in rehabilitation in spite of the establishment of more current models already outlined (Kirkevold, 2015; Wade, 2015a). The purpose of rehabilitation processes is in accordance with this perspective to help a persons to regain their function, for example after hip fracture, heart failure or serious infection. Here professional knowledge regarding the disuse of physical organs such as muscles, which can lead to serious complications, is of primary importance. Furthermore, the importance of professional knowledge in line with the medical model is clear with regard to

the exercising of muscles after paralyses or bone fracture. It includes the physiotherapists' expertise on muscles and muscle exercises which is essential for the rehabilitation. At the same time, other HCPs such as nurses must have knowledge of the bodily functions in order to care for and promote self-care and support body as well as integrating exercises learned in physiotherapy into daily activities (Kirkevold, 2015).

### **1.5.2 The person's perspective**

Currently, the patient's perspective of the illness and rehabilitation process is regarded as central to rehabilitation (Leplege et al., 2007; Pryor & Dean, 2012). The patient is then regarded as main actor in the rehabilitation process, but one who needs help and support during the process. Thus the rehabilitation process has been defined as 'an active and dynamic process by which a disabled person is helped to acquire knowledge and skills in order to maximise physical, psychological and social function. It is a process that maximises functional ability and minimises disability and handicap' (Siegert et al., 2012, p. 4). Similarly, Mauk (2012) describes this process as an 'adaptation or recovery through which an individual suffering from a disabling or functionally limiting condition, whether temporary or irreversible, participates to regain maximal functions, independence and restoration'(p. 2). In accordance with these definitions outlined above, active patient participation, learning and adaptation is regarded central to successful rehabilitation

It has earlier been outlined that addressing the patient perspective in line with a person-centred approach means addressing patients' needs, preferences, beliefs, concerns, expectations and illness experiences from a bio-psychosocial approach. By such means, HCPs gain understanding of the patient's illness situation, through which they develop a supportive connection with the patient. As a result, care is planned and tailored in ways that are meaningful for the patient.

Eliciting the patient perspectives in line with a person-centred approach is not tantamount to eliciting these in line with an existential approach (Dahlberg et al., 2009; Todres et al., 2007). Yet, as argued earlier, the assumption motivating this thesis is that there is synergy, rather than contrasts, between the normative approaches of person-centredness and existential phenomenology. Without that synergy being activated, there is danger of a person-centred approach falling prey to a certain formalistic shallowness, at best, or the perils of constrained participation, at worst.

Numerous studies by use of existential phenomenology have shown that gaining a meaningful existence after illness that disrupts physical function and daily life is an existential struggle (e.g. Angel et al., 2011; Haahr et al., 2011; Larsen et al., 2018). This struggle involves an ongoing interpretation of the experienced disturbances, which is driven by the patient's desire for establishing a new meaningful order with the disabling illness (Angel et al., 2011; Eilertsen, 2010; Kirkevold, 2010). The bodily disruption often involve the patient's sense of not 'knowing herself' anymore, and therefore that she must re-construct her identity for rendering life meaningful anew (Kitzmuller, et al., 2013; Sharpe et al., 2015). This can be a long drawn-out process, and it does not really take off until the person realises that the illness has had a permanent impact on her situation. This reconstruction of one's existential world does often not occur in parallel with changes in the physical function, but can be delayed because of them (Kouwenhoven, 2011). If HCPs are not aware of and attend to this existential challenge which many patients experience, the patients will neither experience understanding nor help. Therefore, many patients feel alone and vulnerable in this situation, in spite of receiving considerable care (Angel et al., 2009; Kouwenhoven, 2011).

Arguably, as demonstrated at earlier junctures in this thesis, by adopting those existential assumptions into rehabilitation, HCPs can potentially develop a deeper understanding of patients' existential struggles and thereby help them reconstruct a meaning structure that makes their life meaningful again. Here the adoption of a narrative interpretative mode of dialogue for enhancing understanding, in accordance with Gadamer (1975/2013), is of particular relevance.

### **1.5.3 The social perspective**

The third perspective, the social perspective, is also of much importance in the rehabilitation context, in spite of not receiving as much attention as the two previously discussed ones. The focus of this perspective is on how society views illness and disability (Kirkevold, 2015). It is related to the rights and responsibilities associated with illness or injury as well as the stigma and discrimination that people with disabling illnesses experience. On this understanding, disability is in fact a social construct and disabled people have historically been an oppressed minority, discriminated against and excluded from participation in society as a result of structural and environmental barriers (Kirkevold, 2015; Olivier, 2009). The assumptions of the social perspective, some of which have been already outlined, are integrated in the social model of disability (Olivier, 2009). In this model, the focus moves from disability as a

loss of physical function, or a sense of loss of personal orientation, to disability as a social construction and sometimes a form of disempowering social oppression as being central to the experience of disability (Olivier, 2009). The enactment of this social model has contributed to changes in policy and legislation which have resulted in the removal of barriers with which disabled person are confronted. Such barriers include physical obstacles in the environment as well as attitudinal impediments (e.g. oppressive attitudes) (Shakespeare, 2006)

#### **1.5.4 Integration of perspectives**

The currently most prominent model of rehabilitation, the biopsychosocial model proposed by Engel (1977), can be seen as an extension and integration of the professional, personal and social perspectives of rehabilitation (Wade, 2015b). Engel (1977) criticised the long-held assumption that only the biological factors of health and disease are worthy of study and practice, arguing instead that psychological and social factors influence physical functioning and play also a role in health and illness also. The ICF (International Classification of function, disability and health) (WHO, 2001), which is grounded in the bio-psychosocial model, is currently the most known and recommended model for rehabilitation (Taylor & Geyh, 2012). The model is comprehensive as it includes various dimensions, i.e. it describes the function of the individual, namely what she does or can do, rather than defining the patient in terms of her disability. The model thus considers function and disability not only from a physical but also from an individual and societal perspective, and importantly includes the environmental and personal context of the individual. The ICF model is essentially both a model and a classification system in which patient data can be documented into. An important advantage of model is that it is developed for inter-professional use. As inter-professional teamwork is central to rehabilitation (Wade, 2016), the model is of substantial relevance for rehabilitation practice. This relevance is supported by widespread use of ICF (e.g. Lee, 2017; Steinhart et al., 2018). Although this model elaborates the personal perspective in line with a person-centred approach, what is missing here, from the perspective of the present thesis, is the existential understanding of the person. The 'person', as more or less understood in the ICF model, is a bearer of preferences, interests and rights (WHO, 2001), rather than a being in search of existential meaning. Accordingly, the model does to a very limited extent or not at all allow for documentation of the existential aspects of patients' illness experiences such as uncertainties and coping challenges and the meaning patients lend to those (Florin et al., 2013). The danger of shallowness, to which the person's

perspective is liable, is thus potentially replicated in the integrated model. Figure 1 depicts the perspectives and the models of rehabilitation already outlined and their interrelation.

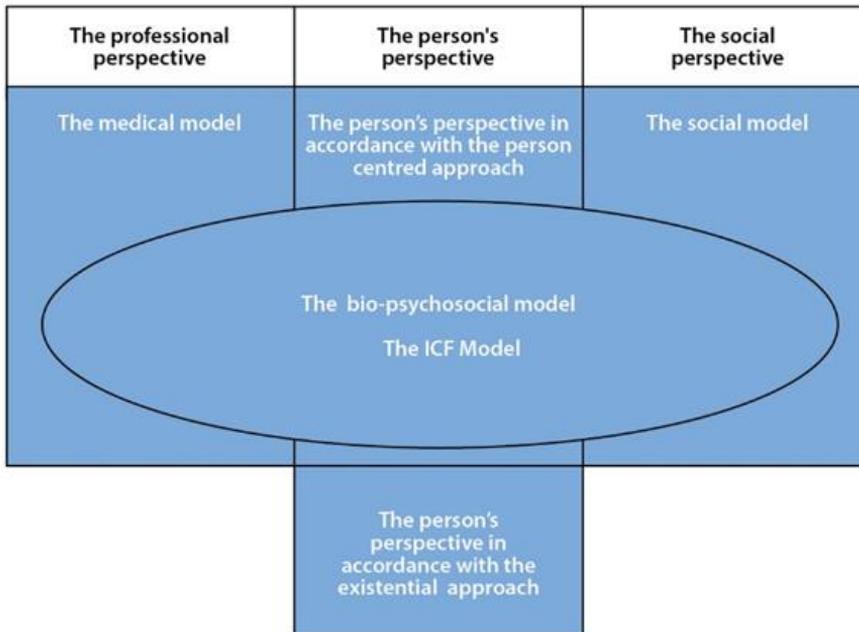


Figure 1: The perspectives and models of rehabilitation

## 1.6 Person-centred assessment tools

As already outlined, a person-centred approach to the participation of patients in assessment and care planning is regarded as fundamental in rehabilitation. Many person-centred assessment tools aim to support communication of the patients' perspectives of their illness, symptoms and needs, in order to integrate those into the making of appropriate health-care decisions. Structured interviews are commonly used, where patients are asked to fill in assessment forms or questionnaires, followed up by an interview (Haywood, et al., 2006).

Experimental studies have shown that in addition to highlighting health-related issues of concern to patients, addressing importance for receiving help with health problems is valuable for improving the outcome of

care (Ruland, 2002; Ruland et al., 2010; Wressle, et al., 2002). Three tools with such features are currently in use in clinical practice (see below). Studies have shown that by the application of these tools, patients' perspectives are more clearly represented; issues of concern to patients are recognised to more extent; and HCPs acquire deeper understanding of patients' illness situations (Børøsdund et al, 2014; Cook et al., 2005; Švajger & Piškur, 2016). Moreover, psychological and -social aspects are explored in more depth (Børøsdund et al., 2014; Švajger & Piškur, 2016), and communication as well as cooperation is improved between HCPs and patients. Three previous assessment methods are of specific relevance to this thesis.

The first of those is the interactive computer-based programme, Choice, which has provided strong evidence for the benefits of obtaining knowledge of patients' perceived problems as well as their preferences for receiving help (Heyn et al., 2012; Heyn et al., 2013; Ruland, 1999; Ruland, 2002). In two experimental studies, patients using the assessment structure of Choice were asked to identify health issues of concern to them from a list consisting of physical activities and self-care (Ruland, 1999; Ruland, 2002). Subsequently, the patients rated the severity of the health problems identified on a Likert scale from 0 to 10, followed by a rating of the perceived importance for receiving help. These studies showed that when patients identified their health-related needs explicitly, nurses' care-plan priorities became more consistent with patients' views. Furthermore, higher congruence between the perceptions of patients and HCPs was associated with increased success in helping patients achieve the results they preferred (Ruland, 1999; Ruland, 2002) and had a positive impact on their physical condition (Ruland, 1999). In recent years, Choice has been implemented as a tailored assessment tool for cancer patients. There it has been shown to reduce symptom distress in cancer patients, reducing their need for symptom management (Ruland et al., 2010), elicit more questions from patients and secure more provision of information (Heyn et al., 2013).

The second assessment tool in question is the Canadian Occupational Performance Measure (COPM) which focuses on occupational challenges (Law et al., 2005). COPM has been widely used in rehabilitation settings to provide an individualised approach to assessing occupational needs and quantifying patient perceptions, functional limitations and outcomes of rehabilitation (Donnelly et al., 2017; Law et al., 2005; Padankatti et al., 2011). Patients are, in a similar manner as in Choice, asked to rate the importance of the problem they have identified, the extent to which they are capable of performing the activity and their satisfaction with their abilities (Law et al.,

2005). The measures are subsequently re-addressed after treatment. In this way COPM is also used as an outcome measure of interventions.

The third assessment tool is the so-called Tidal model, which was developed for use in mental-health nursing. It can be distinguished from the aforementioned approaches by its purported phenomenological underpinnings. Yet the model does not have an explicit and clearly elucidated grounding in existential phenomenology. The Tidal model assumes a narrative form of practice and aims to give 'the voice of the patient' a hearing (Barker, 2001). The assessment in the Tidal model is divided into three dimensions in which experience of health-illness is explored and meanings ascribed. First, a holistic assessment format focuses on the need of the person to feel understood. There, patients are asked to describe in writing (if possible) their perceptions of significant and meaningful events as they occur. Second, a security plan has been developed on a special format within which the kind of support the person needs is identified to ensure personal security. The third dimension then targets the kind of support needed to live an ordinary life. A person-centred care plan is constructed in lay language, co-created by the patient and the nurse (Barker & Buchanan-Barker, 2005). The model is widely practised within mental-health care and the effectiveness is indicated in seven studies by a reduction of critical incidents such as self-harm, suicidal attempts and aggressive events (Barker & Buchanan-Barker, 2010), measuring up to 41-71% reductions of incidents in the most controlled study (Gordon et al., 2005). Moreover, a recent experimental study has showed that that model had a positive impact on coping in patients with alcohol dependency (Savastan & Cam, 2017).

However, challenges have been reported as potentially obstructing the use of person-centred assess methods, such as a lack of teaching suitable for their skilled use, unfavourable work routines and a lack of time (Børøsund et al., 2014; Švajger & Piškur, 2016). Accordingly, the tools in question have in some studies been reported as being distressful by or too problem focused by patients (Cowley & Houston, 2003; Rollans et al., 2013)

## **1.7 Chronic pain and its assessment**

People with chronic pain often need rehabilitation because of its disabling impact on daily life. Assessment of pain is mostly dependent on patients' subjective experiences because of its inherently subjective nature. Several assessment methods employing, generally, a person-centred approach are

recommended for assessing chronic pain and its comprehensive impact (Breivik et al., 2006).

Pain has been defined as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (IASP, 1986). It is a vital warning sign and an accepted part of life, but when it persists over longer periods, it loses its functions as a warning sign. Pain that has lasted more than 3-6 months is generally regarded to be chronic (McCaffery and Passero, 1999). Chronic pain is disruptive to all aspects of health and daily life (Breivik et al., 2006).

The body in pain is perceived as a hindrance to accomplishing desired activities and as an intrusiveness that has major impact on one's life (Crowe et al., 2017). Pain and the associated loss of function have a major negative impact on psychological and social wellbeing and the overall quality of life, an impact that is more significant than the mere physical impact of pain (Crowe et al., 2017; Froud et al., 2014). The main physical impact of chronic pain are inadequate sleep (Breivik, et al., 2006), tiredness and fatigue (Snekkevik et al., 2014), inability to participate in recreational activities and perform domestic chores. Furthermore, chronic pain also impairs cognitive functions, memory and attention (Berryman et al., 2013; Dick & Rashiq, 2007). The main psychological impacts are negative emotions such as distress, loneliness, sorrow (Ojala et al., 2015), depression (Breivik et al., 2006) and difficulties with coping with the pain (Peres & Lucchetti, 2010). The most profound social impact of chronic pain is experienced lack of support (Froud et al., 2014) and difficulties in fulfilling work roles, maintaining relationship and participating in social activities (Breivik et al., 2006). Additionally, the physical and psychosocial impact of chronic pain contributes to a disrupted self-image, which constitutes a considerable aspect of the sufferings associated with pain (Sharpe et al., 2013).

## **1.8 Summary and rationale for the study**

Nightingale and other pioneers in nursing already viewed nursing assessment as fundamental and intrinsic to all nursing care. In accordance with the humanistic focus of the nursing discipline that evolved in the 20th century, a person-centred approach to nursing assessment is advocated in which patients' unique and holistic aspects of health are addressed. Such person-centred approach to patient participation of patients in health assessment entails a supportive connection with the patients, through which planning of care is mutually developed. Yet, numerous studies show (with few exceptions)

that patients generally participate only to a limited extent in nursing assessment and their perspectives scarcely appear. It has also been shown that there are instances in which patients have either to fight for their participation in care planning or they are forced to make decisions regarding their care that they are not prepared for. However, to date, participation that is person-centred has not been sufficiently differentiated from participation that is constrained, at a conceptual level. Due to this lacuna, a new concept analysis is required that identifies these differences and synthesises them into a holistic theoretical perspective.

In rehabilitation, a person-centred approach and the active participation of patients is essential for developing skills for adapting to illness with somatic origins and its disrupting impact on daily life. Many studies show that adaptation to disabling illnesses involves an ongoing interpretation of the experienced disrupting impact of those on daily life. This interpretation is driven by the patient's desire for establishing a new meaningful order with the disabling illness. Here the assumptions of existential and phenomenology are of particular relevance for rehabilitation. These assumptions posit human agents as interpretative beings who strive to understand and make sense of their existence in the world, with the anchor of this existence being their very bodies.

However, in spite of the advocacy of a person-centred approach to the participation of patients in rehabilitation nursing, established person-centred assessment methods for use in this setting have not been developed. Neither has existential phenomenology been applied in assessment practices in rehabilitation, in spite of its argued-for relevance. Thus, the development of a person-centred assessment tool for use in rehabilitation is needed, as well as studies which evaluate such a tool in a systematic fashion.



## 2 Aims

The general aim behind this thesis was twofold. First, it aimed at describing the philosophical and theoretical background and methods used in the development of a person-centred health assessment in nursing rehabilitation. Secondly, the aim was to develop knowledge about the integration and use of the tool in nursing rehabilitation.

The specific aims of individual studies include:

*Study I.* To analyse critically the concept of person-centred participation in health care from patients' perspectives through a review of qualitative research findings.

*Study II.* To develop a theory-based assessment tool, underpinned by phenomenology, in collaboration with nurses, which would enhance a person-centered approach to the participation of patients in nursing assessment and care planning in rehabilitation.

*Study III.* To explore the feasibility of using the assessment tool, named Hermes, to enable a person-centered approach to the participation of patients with chronic pain in their health assessment at admission in rehabilitation nursing.



### 3 Materials and methods

This thesis consists of three interdependent conceptual and qualitative studies of which Table 3 provides an overview. Study I was an integrative review of qualitative studies through which an ideal (person-centred) participation in health care was critically analysed. Study II was an action research study on the development of a person-centered assessment tool, named Hermes, grounded in phenomenology, for use in nursing in rehabilitation. Study III was an ethnographical study on the feasibility of using Hermes to enable a person-centred approach to the participation of chronic pain in health assessment at admission in rehabilitation nursing.

Table 2. Overview of the studies in the doctoral thesis

Study	Methodology	Data collection	Data sources Participants	Data analysis
I	Integrative review and concept analysis		In CINALH, Scopus, Science Direct, PubMed and Sage Journal database.  60 qualitative studies identified	Framework analysis
II	Action research	Focus group and individual interviews  Review of documentation	12 nurses on two rehabilitation wards and a consultant	Directed content analysis
III	Ethnography	Fieldwork observations Individual interviews	14 patients and their 5 nurses in one rehabilitation ward	Thematic analysis

### **3.1 Integrative review and concept analysis (Study I)**

Study I was conducted in the form of an integrative review of qualitative studies from the views of patients who have experienced patient participation within the health care system.

The study aimed at extracting from the existing literature a working definition of patient participation, by synthesising in a systematic way the experiences of the patients involved. Concentrating exclusively on patients' views agrees with Risjord (2009) who claims that to understand concepts relevant to practice, theorists will first have to outline how patients feel and think about them, before the concepts can be developed further. Conceptual analyses of such concepts must, in other words, be conducted bottom-up rather than top-down, in the first instance at least. The integrative review as a research method combines different aspects of the same phenomenon to obtain a constructive account of the concept. Thus the analysis centres on conceptual constructs, definitions and attributes. It is directed by a research question and aims at summarising earlier research by drawing general conclusions from many studies (Broome, 2000). The research question was: How do patients define person-centred participation in health care and what are the attributes of such participation from patients' perspectives?

For analytical as well as theoretical purposes, person-centred participation in health care was preliminarily defined in the analysis, according to a prevailing person-centred framework, as patient participation based on patients' experiences, preferences, values and needs. For simplification, such participation is referred to as person-centred participation. This clarification of the normative framework guiding the concept analysis is in accordance with Paley (1996). He claims that without such prior theoretical orientation, concept clarification will be an uninformed process. Exploration of the neighbouring conceptual terrain, that is, of concepts that are related or contrary to the concept being analysed, is a vital aspect of any constructive concept analysis (Kristjánsson, 1996). Thus, the concept of 'constrained patient participation', which was characterised as involving communication struggles between patients and HCPs, was concurrently analysed as it emerged, and compared with the main concept under analysis.

#### **3.1.1 Sampling**

The sampling in Study I aimed at identifying qualitative research articles in which patient participation was explored from patients' perspectives without

predetermined criteria. The health-care databases that were searched are outlined in Table 3.

The search was initiated with the following terms: 'patient participation', 'patient involvement', 'partnership', 'decision-making', 'shared decision-making', 'patient/person/client-centredness' or 'patient/person/client care/practice'. Those terms were then linked with the terms 'qualitative research', 'qualitative interviews', 'patients' perspective' and 'patient experience'. Only published studies in peer-reviewed journals were included in the search, which covered the period January, 2002–June, 2012. Abstracts and titles were screened and potentially applicable articles were retrieved and read.

Inclusion criteria of research articles selected for the analysis were: (i) a qualitative study design was employed and (ii) patients' experiences of patient participation were explicitly outlined as an aim of the study, or results were overtly interpreted according to a framework of patient participation. In this respect, the terms 'involvement', 'partnership', 'decision-making', 'shared decision-making', 'patient/person/client-centredness' and 'patient/person/client care/practice' were considered integral to patient participation. Exclusion criteria of studies were: (i) patient participation was explored only from the views of HCPs or significant others; and (ii) results could not be linked to a direct contact between patients and HCPs.

The final study sample was comprised of 60 qualitative research articles in which different qualitative methods and approaches were employed. These included phenomenology, qualitative content analysis, grounded theory, ethnography and narrative analysis or unspecified qualitative methods. In most of the studies the sample size was about 20–40 participants. Yet the size varied in the studies as a whole from 7-406 participants. These participants had all had experience of participating in their own health care. Yet their reasons and conditions for receiving health care were different and in some cases wide apart.

### **3.1.2 Data analysis**

The data in Study I were analysed with the method of framework analysis which involves an iterative analytical process (Ritchie & Spencer, 1994). The process is comprised of five stages: familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation. The framework analysis method was initially developed for data analysis in primary qualitative research (Ritchie and Spencer, 1994). However, in recent years it has been

adapted for syntheses of qualitative studies (Dixon-Woods, 2011), as was the case in the present study.

Familiarisation was attained through reading of each study and subsequently, in accordance with Broome's (2000) method, all the original studies in the sample were arranged into matrices according to: aims; study sample; study design; results and conclusion. Through these readings and organisation of data, key issues and recurrent themes were outlined. Derived from the research question and the earlier outlined process of familiarisation, a thematic framework was identified which consisted of three themes. Subsequently this framework served as an index into which the data were indexed in a systematic way. Then charting was initiated, which entailed rearranging the data on charts according to the relevant part of the framework to which they were related. The final stage of the analysis involved mapping and interpretation of the data as a whole. The key process in this final stage entailed reviewing the indexes, charts and research notes, defining concepts, contrasting and comparing the data in the form of the experiences of participants in the studies. Moreover, it involved seeking for patterns and associations between themes as well as searching for explanation for the findings. Through this process, the categories and sub-categories were distilled and refined. Both authors contributed to the analysis process.

### **3.2 Action research (Study II)**

Fundamental to action research is that it encompasses a participatory and democratic process concerned with developing practical knowing in the pursuit of improving human conditions. As a form of research it brings together theory and practice, action and reflection in participation with others, in the pursuit of practical solutions to issues of concern to people (Reason and Bradbury, 2001). Accordingly, it aims at enabling people in gaining a deeper understanding of their own practices and actions for subsequently developing these practices and improving conditions. Action research is considered to be most effective when it involves co-operation of practitioners and consultants or external researchers (McNiff and Whitehead, 2010). Participatory action research centers on raising people to conscious awareness about their environment and circumstances through dialogue and reflection in a group. By these means, the individuals share their experiences and meanings and become empowered through developing and using their own knowledge (Koch and Kralik, 2006; Stringer, 2004).

A participatory action-research (PAR) approach was applied in Study II, consisting of iterative cycles of observing, reflecting, planning, implementing and evaluating (Koch and Kralik, 2006; Stringer, 2004). The active participation of practitioners in the development and transfusion of theoretical knowledge into practice by such repeated reflective cycles is central to this approach. Moreover, practitioners' direct participation in diagnosing the situation that needs improvement is a crucial platform for PAR.

The main research question was: How can an assessment tool grounded in existential phenomenology be developed as a way for enhancing a person-centered approach to the participation of patients in nursing assessment and care planning in physical rehabilitation?

### **3.2.1 Participants and their roles**

In this case, certain assessment practices needing improvements were initially identified at three exploratory meetings with five nurses and the researcher who also served a consultant (the doctoral candidate). Those nurses were to represent the views from all the nurses employed at the wards. In these meetings, the aims of the study were decided in collaboration, including the development of the phenomenological and theoretical background.

All of the 12 nurses employed at the two rehabilitation wards participated in a focus group (referred to as ward group) in the study. The five nurses who had participated in the exploratory meetings formed a smaller focus group (referred to as quality group). The consultant provided solutions in the form of the development of the background of Hermes, its use and structure. In line with empowering aspect of participatory action research (PAR) (Koch and Kralik, 2006), her role was also to facilitate dialogic and productive relationships among the nurses as well as shared understandings and collaborative decision making. The role of the nurses in the quality group was to collaborate closely with the consultant through the study in developing the structure and use of Hermes, as well as supporting the other nurses in testing and evaluating its use in practice. The repeated iterative cycles of PAR were entered into as follows: The consultant's proposals for Hermes were appraised by the focus groups (observation) and reflected upon (reflection); revisions to the structure and use of Hermes and its testing in practice were planned (planning). Hermes was then revised, tested out and evaluated in practice (implementation and evaluation). Included in the consultant's proposal for Hermes was educating the nurses about its phenomenological and theoretical background and its use. This education was continuous through the

study, reinforced by explanation, discussion and reflection. During the study, seven versions of Hermes were tested out through seven action cycles.

### **3.2.2 Data analysis**

A directed deductive content analysis was employed in Study II (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). Such analysis is typically used to validate or extend existing theoretical background and is usually guided by fairly structured themes and questions (Hsieh & Shannon, 2005). This approach to analysis was relevant for use in the study because the highlighted themes pertained to the realisation of the phenomenological background of Hermes. In accordance with the method in question, familiarisation with data was achieved by reading through all the data. Subsequently, the data were reviewed for content that related to the themes. During this process, data related to the themes were clustered into several categories. In accordance with PAR, the participating nurses contributed directly to the data analysis (Koch & Kralik, 2006) as well as all the authors. Four persons who were not directly involved in the study were consulted at the final stage of the data analysis for enhancing critical reflection of the study. Moreover, four of the participating nurses checked the final analysis.

### **3.3 Ethnography (Study III)**

The translation of theoretical knowledge into practice, as in the case of the adoption of Hermes into nursing rehabilitation, is a complex and challenging process (Harvey & Kitson, 2016). Ethnography as a research method was chosen in Study III because of its faculty to capture and provide a deep understanding of this complex adoption of theoretical knowledge. Here, the key data collection method of ethnography is of particular importance as allows for observing people (in this case nurses and patients) in their natural surroundings in a contextual and holistic way (Mol, 2008; Pols, 2012). Focused ethnography was deemed of most relevance for the study because of its specific focus of exploring, comprehensively, distinct experiential issues (the use of assessment tool Hermes) with(in) a particular group (nurses and patients with chronic pain) in a specific setting (rehabilitation nursing) (Higginbottom et al., 2013; Knoblauch, 2005). Through its specific focus, focused ethnography aims at enhancing understanding of experiences and shared behaviours within the group related to the distinct experiential issue. In this specific ethnography, the researcher should be familiar with the phenomenon of selected attention (Knoblauch, 2005). This was the case in the current study as the doctoral candidate had completed the development of

Hermes in cooperation with nurses at the respective rehabilitation a few years earlier. She was thus considered to be both an insider and an outsider.

The overall aim of Study III was to explore the feasibility of using Hermes to enable a person-centred approach to the participation of patients with chronic pain in their health assessment at admission in rehabilitation nursing. More specifically, the study aimed to explore the feasibility of Hermes in assisting rehabilitation nurses in: i) assessing and discussing health issues of concern with patients with chronic pain; ii) enhancing their and the patients' understanding of the illness situation; and iii) involving patients with chronic pain in planning of their own care.

### **3.3.1 Participants and context**

In Study III, all the five nurses (N1–N5), who were employed on a 22-bed ward in rehabilitation for patients with somatic illnesses, participated in the study. Moreover, 14 patients with chronic pain who had been admitted to this rehabilitation ward, which is a part of a small rehabilitation centre, participated in the study. The majority of the patients at the ward suffer from somatic illnesses of neurological, musculoskeletal or cardiovascular origin. The chronic pain patients were chosen to explore the use of Hermes as they represented the largest patient group on the ward. These patients, of whom 12 were women and two men (PT1-PT14), were a part of a cohort of patients with chronic pain who were admitted to a 14-day group programme. In the programme, which was limited to six patients at a time, their condition was assessed from a multi-disciplinary perspective. The patients that participated were diagnosed with either fibromyalgia or low back pain and their ages ranged from 28–61 years. Two of the nurses at the ward (N1 and N2) performed most of the admission interviews with patients with chronic pain through the use of Hermes. These nurses were part of the inter-professional team caring for those patients. The other nurses on the ward sometimes also conducted admission interviews with the chronic pain patients through the use of Hermes. Two of the nurses (N1 and N2) and two of the chronic pain patients (PT1 and PT6) served as key informants in the study.

### **3.3.2 Data collection**

Data were collected in Study III through fieldwork observations and semi-structured interviews. The data collection was conducted during three six-day periods which were distributed over 10 months in 2011 and 2012. The data collection was informed by the framework of patient-centred participation, identified in Study I. All the data collection that consisted of fieldwork

observations and semi-structured interviews was employed by the doctoral candidate, who adopted the role of an observer.

Fieldwork observations concentrated on how the admission interviews were conducted. Here, particular focus was upon how the nurses used Hermes and in what ways the patients participated in the interviews. In addition, the admission interviews were also digitally recorded, and subsequently transcribed verbatim. Moreover, the nurses' daily work, including their contact and meetings with patients, were observed. These observations were mainly scheduled on the days when the admission interviews were conducted. Informal conversations with the patients and nurses were part of the observations. During the study period, 86 hours of observations were undertaken overall. Field notes were primarily recorded in a booklet in which an expanded account was written within 24 hours of completing each period of observation. In addition, a reflective journal was kept by the doctoral candidate during the study.

Semi-structured interviews were conducted with five nurses and the 14 patients. The interviews with the nurses centred on the ways in which the use of Hermes facilitated person-centred participation of patients during the admission interviews. The interviews with the patients, which were conducted between seven and nine days after their discharge, centred on their experience of participation in the admission interviews through Hermes. All those interviews were recorded and subsequently transcribed verbatim.

### **3.3.3 Data analysis**

In Study III data analysis was undertaken by a hybrid thematic approach (Miles & Huberman, 1994), drawing inductively from the data but simultaneously the analysis was informed by the framework of person-centred participation constructed in Study I. The phases outlined by Braun & Clarke (2006) guided the thematic analysis. In the first one, that of familiarisation, data were read repeatedly for creating a holistic understanding. In second phase a list of codes was developed that pinpointed aspects of the data that were of relevance to the aims of the study. These codes were subsequently clustered into potential themes and a preliminary thematic map for the analysis was created. In the map the codes pertaining to each theme or sub-theme were listed in detail as well as the data sources from which they were obtained. Through the analysis, the themes and codes were either clustered, divided or new ones developed and then redefined through an iterative process. In accordance with the analysis of ethnographical data, some sub-codes of primary codes were identified (Saldaña, 2015). At the final stage of the analysis, the codes were

found to form a consistent pattern within each theme or sub-theme. In this final stage, all researchers reviewed the data and consensus was reached about the extracts that illustrated examples of the themes. The final analysis was approved by the nurses who were key informants in the study.

### **3.4 Ethics**

Formal ethical approval to conduct Study II was obtained from The Bioethics Committee at Akureyri Hospital Iceland (10/2013) [Siðanefnd heilbrigðisrannsóknna á Sjúkrahúsinu á Akureyri] which informed the Icelandic Data Protection Authorities of the study [Persónuvernd]. Furthermore, permission for the study was obtained from the chief executive of Nursing and Medicine at the Akureyri Hospital.

Formal ethical permission for Study III was granted from The Bioethics Committee at Akureyri Hospital Iceland (No. 152) [Siðanefnd heilbrigðisrannsóknna á Sjúkrahúsinu á Akureyri]. The Data Protection Authorities [Persónuvernd] were also informed of the study (S5219). Furthermore, permission for the study was obtained from the chief executive of Nursing and Medicine at the Akureyri Hospital.

These approvals already outlined permissions for Study II-III in accordance with the declaration of Helsinki (World Medical Association, 2013).

In Studies II-III, rehabilitation nurses were invited by written and oral information to participate. There it was outlined, for example, that their participation and information disclosed during the studies would not impact on their employment at the wards. Prior to data collection in Studies II-III, an informed consent was obtained from all participants. The patients with chronic pain that participated in Study III belonged to a vulnerable group of participants. Thus, the ethical aspect of their participation was outlined in an introductory letter and explained in detail to them. Moreover, the patients were informed that if difficult emotions arose in the interviews or during the fieldwork observations, a professional support person was available to them. Methods for ensuring identity protection included, but were not limited to, the following: the doctoral candidate only knew the participants' identities; all information that could identify participants was removed from the transcripts and fieldwork notes; and tape recordings from the interviews were deleted as soon as they had been transcribed.



## **4 Results**

The main results of the studies were that a person-centred assessment tool, Hermes, was developed, facilitating the use of a person-centred approach to the participation of patients in health assessment in nursing rehabilitation. Moreover, the philosophy of phenomenology was operationalised for use in assessment practice.

### **4.1 Patients' perspectives on person-centred participation in healthcare**

According to the results of Study I, person-centred participation in health care manifested itself via three phases, the human connection phase, the phase of information processing and the action phase. Respect and equality were intertwined into these phases. Person-centred participation is regarded as an ideal participation from patients' perspectives. The relationship between phases and stages of person-centred participation turned out to be dynamic and iterative in nature, exemplified in a cone-shaped framework with a dynamic spiral inside, where the human connection phase is at the bottom but the action phase at the top.

However, the analyses also yielded the result that not all patient participation is perceived as person-centred but can be characterised by a communicational struggle with HCPs who either do not allow patients as much participation as they prefer or force them into unwanted participation. Such participation, the latter kind of which has hitherto not been given much attention in the literature, is referred to as 'constrained'.

The initial stage of the human connection phase was 'inviting environment perceived', which encompassed friendly and approachable HCPs and respect in the health-care ethos being felt. The second stage, 'genuine attention and interest felt', meant to patients that they were heard and seen, their views respected and taken seriously, with HCPs showing encouragement and support, and patients being given enough time. The final stage of human connection phase, 'being respected and recognised as equal human being', manifested itself through the importance of being viewed in these ways. Furthermore, being viewed and understood as a unique individual from a holistic perspective was intrinsic to this stage, through which the establishment of a meaningful relationship was facilitated, together with respect and equality.

The second phase of person-centred participation was that of information processing in which information was exchanged and knowledge constructed. The first stage of this phase, 'seeking and receiving appropriate information', entailed patients asking questions and seeking information and understanding of their condition. Moreover, it encompassed HCPs being knowledgeable and providing appropriate information and explanation. At the initiation of the second stage, 'information giving, dialogue and knowledge building', patients provided information regarding their health problems and participated in a prolonged dialogue with HCPs. As this stage progressed, a confidence in self-knowledge matured as well as a need for deep understanding or comprehension.

The final phase of ideal participation was the action phase, which involved taking action towards health problems. The first stage of this phase encompassed 'confidence in oneself, and accepting or delegating responsibility as desired'. The second stage involved 'shared decision-making as desired' which ranged from passive consent, to active shared decision-making. This final level of shared decision-making was regarded as a direct continuation of the ongoing dialogue described earlier, but in this stage it ended with decision-making in the form of selection of treatment choices in line with patients' preferences. By contrast, some studies showed that patients experienced their participation as constrained. In these cases patients had to struggle for their involvement in the decision-making or were forced or compelled into making decisions for which they were not prepared.

The third stage of the action phase, 'perceived control over care', encompassed first influencing one's own health care as desired. This was associated with receiving care considered as necessary which was tailored to individual needs. Second, it entailed 'accepting and conforming to care according to wishes' and finally it involved 'managing one's care in a person-centred way', which meant to patients that they carried out physical and/or mental activities in line with their preferences, needs and values.

## **4.2 Development of Hermes**

During the research period described in Study II, Hermes was developed and became the standard of care for all patient groups in the two rehabilitation wards. The three main themes that pertained to the phenomenological background of Hermes were: the use of language and being with another supported, embodiment and attunement supported; and understanding of the patients' situation enhanced.

Through its use, the structure of Hermes focuses on helping patients communicate and interpret the disturbing impact of illness and its significance (see an example in Table 1). This structure was fine-tuned during the study. The final tool consisted of 27 broad health-related issues in which all the FHPs of Gordon (1994) were covered. The Hermes guided interview is initiated by inviting patients to provide a narrative description of the health issues that they consider most disruptive to daily life or otherwise inconvenient. When those issues are identified, patients are asked to describe the disturbance in more detail. Here patients' own narrative descriptions of health issues of concern to them and dialogues with the nurses are intended to help nurses and patients in interpreting and understanding the illness situation. Furthermore, the patients are asked to address the severity of the disruption by use of a verbal scale. Subsequently, the patients are asked to address the importance of receiving help if the disruption is considerable. Moreover, Hermes was to be used also for evaluation at discharge. The assessment time of the final version of Hermes was on the average 30-40 minutes. In Table I, the assessment structure of Hermes is depicted pertaining to two FHPs, elimination (no. 3) and sleep (no. 5). An example of a recorded assessment is also illustrated.

Through use of the tool, the first-person perspectives of the patients, regarding health issues of concern, appeared clearly in the patients' lay language which had not been the case prior to the use of Hermes. Furthermore, the assessment appeared, in general, to be detailed and thorough. Accordingly, the patients participated in the assessment to a greater extent than had previously been the case. During the developmental period, the most challenging task was to develop an interview technique in the use of Hermes that would not hinder the flow of the assessment interviews in spite of being semi-structured. In the end, there was a consensus among the nurses that the final version of Hermes was useful in guiding the assessment interview and for discussing health issues of concern.

Table 3. Example of the structure of Hermes and recorded assessment  
 FHP\* refers to the relevant number of the Functional Health Patterns (Gordon, 1994)

Which health-related issues disturb your life or cause you the most inconvenience?					Minimal disturbance	Moderate disturbance	Substantial disturbance	Severe disturbance
Do the following health-related issues disturb your life or cause you inconvenience?								
FHP No.		No	Yes	Further comments				
3	<b>Urination.</b> Do you have problems with urination, such as incontinence, being unable to urinate?  Do you urinate at night?		x	<b>Date of admission</b>  I cannot control my urine any more. I use pads but the urine often leaks out of them.  <b>Date of discharge</b>  The exercises and the new pads have helped.		x		x
5	<b>Sleep.</b> Do you have difficulty falling asleep? Is your sleep interrupted? Do you feel rested after sleep?		x	<b>Date of admission</b>  I often wake up in the middle of the night and cannot fall asleep again. The day is often difficult when I have slept badly.  <b>Date of discharge</b>  I still have sleeping problems but days are not as difficult.		x		x

In line with term ‘embodiment’, one of the terms upon which the structure of Hermes was grounded, patients generally identified and communicated the disturbances that their illness had upon their lives from a physical and psychosocial perspective through the Functional Health Patterns. The emergence of health issues of concern in Hermes was reported as a real advantage by the nurses, as it enabled them to identify the patients’ real problems more promptly and rule out those that were less relevant. Yet a clear indication of a sustained discussion of the importance of receiving help with

health problems (as had been aimed for) did not appear, neither in the observation of the documentation on Hermes nor the interviews with the nurses.

Addressing the severity of the disturbing impact of illness on a verbal scale was intended to provide insight into how well the patients were attuned to these disturbances. This method was regarded helpful by the nurses as it facilitated the realisation of the severity of the problem and turned out to be as useful and meaningful, both for themselves and the patients, when the progress was evaluated at discharge.

Enhanced insight and understanding of the patient's situation was what the nurses saw as the most enabling impact of Hermes. This impact contributed substantially with their overall satisfaction with the tool during the developmental period. Here the nurses referred to that interviews conducted through Hermes, and/or the subsequent reading of them, provided them with holistic understanding of how the patients experienced their illness situation

#### **4.3 The use of Hermes in health assessment of patients with chronic pain**

As described in Study III, the impact of chronic pain was explored through supportive connection and dialogue with open, reflective and interpretative features; understanding of the illness situation was enhanced; and possibilities provided in adjusting to health issues of concern.

In the beginning of the admission interviews through Hermes, the nurses centred on developing a connection with the patients, by reviewing their health history and social circumstances thorough empathic and supportive features. Before the patients participated in a dialogue about health issues of concern, the nurses explained the structure of Hermes and emphasised that the assessment of these issues was a co-produced effort. Subsequently, if the patient assessed that a health issue had disturbing impact on daily life, the nurses either asked in more detail about the issue of disturbances or rephrased the patient's words. In this way the patients were asked confirm the nurse's interpretation or comment on it. The nurses also asked the patients to rate how severely they experienced the disruptive the health issue to be.

The observations illuminated that the nurses often consciously remained silent thereby giving the patients opportunity to think and reflect for a while upon their answers. This approach was observed as enhancing the openness of the interview. However, both the openness and depth of the discussions varied widely, from being in the form of a reflective and in-depth

dialogue to being factual and straightforward. The interviews were claimed to be good in general by the patients and some described them as comfortable and facilitating them to discuss openly health issues of concern.

Through the structure of Hermes, the physical and psychosocial impact of illness on patients' daily lives was revealed and explored in 30–40-minute interviews. Most often, the permeating impact of pain on the various health issues was communicated, such as sleeplessness, difficulties with coping and performing domestic chores. According to the nurses, the structure of Hermes provided 'hints' that opened up discussions of various health issues from the patient's perspective in a short period of time.

Interviews with the nurses revealed that the main advantage of Hermes was how it promoted specific insights into, and an overall understanding of, the patients' situations, as perceived by the patients themselves. Increased understanding of the situation was not highlighted as much by the patients. Yet some patients claimed that the admission interviews through Hermes had helped them become more aware of their situations.

After the admission interview, the nurses recorded in more detail on the Hermes formats what they had written down during the interviews. By these means, health issues that disturbed daily life were described in the patient's language, which was helpful for the nurses in recording nursing diagnosis in accordance with the patient's health concerns.

However, during the study period the nurses were never observed discussing the nursing diagnoses that they had recorded with the patients. During the latter portion of the study period, the nurses were observed at summarising the issues that were perceived to be of most disturbance to the patients at the end of interview. Subsequently, the nurses discussed with the patients if it was important for them to receive help with those issues. For some of patients, this discussion was considered useful as it facilitated them in identifying and understanding better which problems should be prioritised in terms of interventions.

## **5 Discussion**

The studies in this thesis present a pivotal platform for the development and evaluation of a new person-centred health assessment tool for general use in nursing rehabilitation. The novelty of the tool, named Hermes, is that as well as being based on a framework of patient participation from patients' perspectives, constructed in Study I, the tool is firmly grounded in existential phenomenology. During the developmental phases, in which action research was employed (Study II), several of its person-centred and phenomenological underpinnings were already supported. These findings were confirmed and extended in Study III, through ethnography, where the feasibility of the tool in the use for people with chronic pain was explored. The framework of person-centred participation in health care constructed in Study I informed Studies II-III. The originality of the new framework lies in it being the first integrative review in which patients' experiences of such participation are synthesised from a person-centred perspective through an analysis of interdisciplinary qualitative studies. As well as providing the grounding for Studies II-III in this thesis, the framework has already contributed substantially to the furthering of knowledge of patient participation, as evidenced by extensive citations in the literature on patient participation (e.g. Oxelmark, et al., 2018; Tobiano et al., 2016) and person-centred care (e.g. Arakenal et al., 2017; Flagg et al., 2015).

### **5.1 Successful adoption of Hermes into practice**

The assessment tool, Hermes, was developed and adopted into practice through action research with the active participation of all nurses at two rehabilitation wards, and a consultant (Study II). During the study, which lasted 18 months, seven versions of the Hermes tool were tested through seven action cycles (Study II). I-PARISH is an explanatory framework for evaluating successful implementation of evidence-based knowledge into practice (Harvey and Kitson, 2016; Kitson and Harvey, 2016), including person-centred frameworks (Hebert, et al., 2018). In accordance with the explanatory framework, successful implementation is determined by the achievement of agreed implementation goals, the innovation being embedded into practice, and by variations related to context appearing as minor across implementation settings (Harvey and Kitson, 2016; Kitson and Harvey, 2016). In light of these criteria, the adoption of Hermes must be regarded as a successful, as its main person-centred and phenomenological aims were reached, the tool was

intergrated into clinical practice and variations in its use were minor between the two wards that participated in its development. The success of the implementation is according to the i-PARISH framework dependent on how the constructs, innovation, recipients and the context (inner and outer) enable or restrict the implementation. However, the construct of facilitation, involving the facilitator (one or more) and the facilitation process (as a set of strategies and action), is emphasised as the most active variable in the framework (Harvey and Kitson, 2016; Kitson and Harvey, 2016). Its centrality is due to the major impact it has upon the three other more specific variables according to the model. In this respect, the success of implementation is dependent upon the capability of the facilitator and the facilitation process to facilitate recipients, within their specific context, to adopt and apply the innovation (Harvey and Kitson, 2016; Kitson and Harvey, 2016). In the development of Hermes, the facilitation team consisted of the consultant and five of 12 nurses working at two rehabilitation wards (Study II). The main facilitation strategies were focus groups in which the structure and uses of Hermes were discussed and evaluated. Moreover, those consisted of collaborative learning and training sessions. Individual support was also provided to the nurses in testing and evaluating its use in practice.

As the facilitation construct in the i- PARIHS model is central to successful implementation, strategies used by the facilitators must be deemed useful for a positive verdict on the development of Hermes (Study II) to emerge. The construct of innovation in i- PARIHS encompasses the evidence base of the implementation, its advantages, fits and adaptability with local experiential knowledge (Kitson & Harvey, 2016). The evidence base of Hermes was based on three earlier assessment tools and an integrated review of person-centred participation (Study I) which was strengthened by its phenomenological background (Study II). Its relevance and potential advantages were discussed and agreed upon by the participating nurses who adapted Hermes into practice. Arguably, the evidence base of Hermes was relevant to its use and fitted with the local experiential knowledge as advocated in the i- PARIHS framework (Kitson & Harvey, 2016).

The construct of recipients includes the people who are affected by and who influence the innovation (Harvey and Kitson, 2016). The features of recipients to be considered include motivation, values and beliefs, goals, skills, knowledge, support, collaboration time, and authority and power. In the development of Hermes, it must be regarded as a strength that all 12 nurses at the wards participated in the project (Study II). Therefore, the vision in terms of the aims of its development could be determined in collaboration, which in

turn enhanced the nurses' motivation in adopting it. The main restriction of the adoption of Hermes into practice was how long it took to administer the tool, a feature exacerbated by the nurses having limited skill in using the tool during the first stages of its testing (Study II). Hence, there was a period of negative attitudes developed towards the tool at this juncture as described in Paper II. By responding to this negative impact, through amendments of the tool and via collaborative teaching methods and support, those hindrances could be overcome and positive attitudes to the tool became more prominent. This is no small matter, as attitudes have been shown to be influential in the implementation of person-centred methods (Moore et al., 2017). Equality and respectfulness in communication between HCPs, which is central to a person-centred approach (Scholl et al., 2014), is of particular importance for the adoption of person-centred methods into practice (Brooks et al., 2017; Naldimirci et al., 2017). The collaboration methods used in action research, in which the nurses' suggestions were responded to by adapting and fine-tuning Hermes in light of their evaluation, is conducive to the realisation of such equality.

The construct context encompasses culture and leadership (Harvey and Kitson, 2016; Kitson et al., 2008). In addition to providing managerial support, the nursing managers at both wards were in the group of facilitators (the quality group). Such leadership support is regarded to have contributed substantially to development of Hermes as these aspects are vital established as vital for successful implementation and sustainability (Schein, 2010).

## **5.2 Developing a connection**

Through the ethnographic fieldwork observations employed in Study III, it was revealed that at the initiation of the Hermes-guided interview, the nurses established a connection and rapport with the patients by conveying empathy and support and by reviewing briefly with the patients their health history and social circumstances. These methods were regarded as integral to facilitating patients' co-operation in identifying and discussing the various disturbing impacts of illness, through Hermes. Those findings concur well with the communication features in the connection phase of person-centred participation (Study I) upon which Hermes was grounded. Furthermore, they agree with an earlier ethnographical study where the establishment of initial connection and rapport was viewed as integral to use of a structured assessment tool (Gamlen & Arber, 2013). These findings imply that connecting with patients and gaining a general overview of their health story and social situation should be regarded as integral to the use of Hermes.

### **5.3 Participation in a dialogue and exploration of patients' perspectives**

The nurses in Study II-III claimed that Hermes was helpful in guiding the interview and enhanced dialogue of health issues of concern. During the original study, when Hermes was first tested in practice (Study II), the nurses claimed that patient participation in the assessment was enhanced to a great extent compared with the time prior to its testing. Moreover, there was an increase in the elicitation of the patients' perspectives in the documentation on Hermes, where lay phrases were common. The enactment of a person-centred approach through Hermes is supported by the enhancement of the first-person perspective which is central to the person-centred background approach (Leplege et al., 2007) as well as to the phenomenological approach more generally (Dahlberg, et al., 2008; van Maanen, 1997). This area of impact concurs well with the properties of the previous person-centred tools upon which Hermes drew (Cook et al., 2005; Heyn et al., 2013; Law et al., 2005). Here, the appearance of patient's lay language in Hermes tallies in particular with the emphasis and use of the Tidal Model (Barker, 2001; Cook et al., 2005).

The participation of patients in the nursing assessment, within which the focus was on their first-person perspective, was confirmed in Study III where those findings were extended through ethnographic fieldwork. The patients' perspectives of the impact of illness were explored through an open and empathic approach and dialogue features that are deemed as inherent to 'ideal participation' (Study I). Furthermore, the features of the interview methods used by the nurses, such as listening actively and explaining and rephrasing patients' answers, agree with interview techniques fostering patient participation and motivation (Miller & Rollnick, 2012). Those methods also contributed to the maintenance of flow in the interviews despite its inbuilt formal structure. The important finding that the interviews were satisfying for all the patients in the study further justifies the conclusion that person-centred participation was realised through the use of Hermes.

Conducting the concept analysis of patient participation in Study I from a person-centred perspective yielded the novel finding that not all patient participation is experienced as person-centred. Such participation, referred to as constrained participation, involves (as previously explained) a communicational struggle between patients and HCPs who either force patients into unwanted participation or do not allow patients as much participation as they want.

The first two versions of Hermes that were tested in practice were reported by the nurses to be too long, tedious, and tiresome and causing themselves as well as the patients distress. Similar distress in the use of person-centred tools has been reported previously (Børø Sund et al., 2014; Rollans et al., 2013), and there is evidence of the discontinuation of a person-centred tool after a study revealed its overall negative communicational impact on patients (Cowley & Houston, 2003). Hence, it must be concluded that while the patients in Study II participated in the assessment through the first version Hermes, they did so in a constrained way, by having to participate in an overly long and tiresome assessment. This resulted also in the nurses' dissatisfaction with Hermes and was in fact the most prominent barrier to its development. This dissatisfaction was responded to by integrating some specific health issues in the first versions of Hermes into one broader issue, which resulted in the nurses becoming more content with the tool and beginning to focus more on its positive impact. This finding implies that nurses using Hermes and other structured assessment tools should be aware of their potential of causing constrained participation. This also implies that 'constrained participation' is not just an abstract and hypothetical theoretical construct but one with significant practical import. These implications were supported in Study III, where the nurses using Hermes several years after its development claimed that they were continuously searching for new ways to motivate the patients' participation in the assessment.

#### **5.4 Providing possibilities for exploration of meanings**

Observation of the documentation on Hermes in Study II and interviews with the nurses in Studies II-III revealed that health issues disturbing the patients clearly emerged in Hermes. Given that 'disturbances' are the most significant issues of the illness experience, signifying its very meaning (Toombs, 1993), it can also be argued that by illuminating the disturbances, Hermes helps patients communicate their personal meanings of illness to the nurses.

The fieldwork observations from Study III supported the finding that the meanings of the illness, in terms of its disrupting impact of chronic pain, were revealed through open, reflective and interpretative dialogical features that characterise a phenomenological dialogue (Dahlberg et al., 2008). Facilitated by the nurses' open approach, the patients often provided narrative descriptions of the disruptive impact of illness, to which the nurses then responded by an interpretation of those narratives, upon which in turn the

patients then reflected. This process constituted, therefore, a virtuous cycle of interpretation and reinterpretation.

These findings speak against a common misinterpretation of hermeneutical philosophy in general, and phenomenological hermeneutics in particular, as claiming that each individual's horizon marks out some sort of a 'beetle in a box' (Wittgenstein, 1953) inside his or her mind that will remain completely opaque and incommunicable to others. In fact, nothing was further from the mind of phenomenologists such as Heidegger (Paley, 1998). They saw meaning precisely as belonging to an inter-human world: in principle accessible to all human beings qua their interpretative faculties (cf. Wittgenstein, 1953). The problem is, however, that within this inter-human world, individual horizons rarely overlap completely. For example, it is important to be aware of the decisive gap that tends to exist between patients' experiences of illness and the way in which the illness is conceptualised and understood by HCPs (Toombs, 1993). It can be argued that by being able to identify and describe the relevant disturbances, the patients portrayed their perspectives and horizons of meaning to the nurses, thereby contributing to a fusion of horizons between them.

However, it must be reiterated here that the depth of the discussion through Hermes varied considerably, from being a straightforward factual discussion to encompassing a reflective and interpretative reflective dialogue. That said, the overall interpretative nature of the interviews stood out, despite variances in length and depth. These findings, about the interpretative nature of the interviews through Hermes, must be regarded as novel. As such, they suggest that using Hermes as an assessment tool can promote patients' understandings of illness, in addition to collecting assessment data for care planning.

## **5.5 Communicating the holistic impact of illness and its severity**

The Functional Health Patterns (FHPs) which were adopted into Hermes, were regarded as presenting the bodily psycho-social patterns underpinning embodiment (Merleau-Ponty, 1962) and disruption of those in illness (Leder, 1990). Observations of the documentation on Hermes (Study II) and fieldwork observations from the interviews through the tool (Study III) revealed that, in accordance with the existential phenomenology upon which the structure of Hermes was grounded, patients generally communicated physical and psychosocial issues that had a disturbing impact on daily life. Thus, this impact

is a firm indication of the penetration of the chosen phenomenological approach into practice. Moreover, this quality represents a clear enactment of an ideal participation, outlined in Study I, which is highlighted in all person-centred approaches (e.g. Kitson et al., 2013; Leplege et al., 2007; Morgan & Yoder, 2012): namely, the elicitation of patients' perceptions of the impact of their illness from a holistic perspective.

As might be expected, all the patients with chronic pain in Study III communicated the pain as being disruptive to daily life. Other issues that patients with chronic pain communicated (Study III) most often entailed tiredness, difficulties with coping, sleeplessness, psychological discomfort and stress, lack of concentration and memory, difficult social circumstances, as well as difficulties in performing domestic chores. The disruptiveness of these issues to this patient group is supported in the literature, within which all these issues are accounted for as common impacts and symptoms of chronic pain (Berryman et al., 2015; Breivik et al., 2006; Froud et al., 2014; Peres & Lucchetti, 2010; Snekkevik, et al., 2014).

In addition to disclosing the typical impacts of chronic pain, the patients communicated several health issues that had a disturbing impact on daily life but which have not been directly associated to chronic pain, such as difficulties relating to circulation and smoking cessation. These findings suggest that Hermes can facilitate disclosure of the specific impact of illness as well as capturing individual difficulties from the patients' own perspectives through a 30-40 minute assessment interview. It must be emphasised that those findings were revealed within the chronic-pain group, as the only patient cohort that participated in the study, and transferability to other patient groups is still pending.

## **5.6 Understanding enhanced and the evaluation of progress facilitated**

According to the nurses in Studies II-III, the chief advantages of Hermes encompassed the ways through which it promoted insight into the illness situation as experienced by the patients. In this respect, addressing the disturbing impacts from a holistic perspective, as well as their severity, was found to enhance understanding. In fact, during the development of Hermes, this quality was seen as the most enabling impact of Hermes, contributing substantially to the nurses' satisfaction with the tool. In other words, this impact was considered one of the main facilitators in the testing and implementation of Hermes. This perception of impact was fortunate for present purposes, as

increasing understanding was one of the tool's core aims. This enhanced understanding was also viewed to be of significant value when planning care in line with patients' perceived needs. HCPs' enhanced understanding of the patients' situations has also been reported for other person-centred tools (Børøsdund et al., 2014; Cook et al., 2005; Švajger & Piškur, 2016).

This impact of Hermes is of significant and direct relevance for assessment practice, in line with the prior discussion of the potential of facilitating a 'fusion of horizons' and thereby enhancing mutual understanding between nurses and patients. According to the core assumption of hermeneutic phenomenology, upon which Hermes drew, people continuously strive to understand their existence through the different existentials (Heidegger, 1927/2010). Thus, Hermes has arguably enriched nurses' understanding of the patients' situations through the very existentials upon which the tool was based. This is one more indication of the overarching aim of the whole research project, to synthesise theory and practice, having been achieved. This is a particularly important observation in the context of existential and phenomenological philosophies which are often seen as obscure and intractable to practical (e.g. health-based) applications.

In addition to aiming at enhanced understanding by HCPs, Hermes aimed at enhancing patients' understandings of their own illness situations, since such understanding is a highly valued aspect of person-centred participation (Study I), as well as being central to its phenomenological underpinnings, as already addressed. In Study III, in which patients' views of this impact were explored, some patients reported that the Hermes-guided assessment interview had improved their understanding of their illness situation. These patients were interviewed just after the admission interviews and could recall this impact of Hermes. However, most of the patients who were interviewed seven to nine days after their discharge claimed that they did not recall this potential advantage of Hermes. Thus, the study was limited in this temporal respect, which calls for further exploration of this potential impact of Hermes, known to be highly valued by patients (Study I). It was observed in Study III that the nurses did not explain the main aims of the use of Hermes qua assessment tool, which might have limited the realisation of its potential for facilitating patients' understanding of their illness situation. This is a strong reminder of the need for reinforcement of the collaborative training and teaching methods used in the original development of Hermes.

As outlined above, previous studies have found that HCPs gain insight into the patients' situations by use of person-centred assessment tools. However,

no study was found in the literature search which explored whether such tools can promote patients' understandings of their own illness situations. This quality of Hermes is of particular salience, as many studies (cf. Study I) have shown that for patients with disabling illness, their primary motivation is to understand and make sense of their illness situations (Angel et al., 2011; Haahr et al., 2011; Larsen et al., 2018), as part of a trajectory towards retrieving the sense of a meaningful life (Angel et al., 2011; Kirkevold, 2010; Kleinman, 1988). The potential quality of Hermes to support patients' drive for understanding and making sense of their illness situations is, therefore, arguably of substantial clinical value.

In Study II, it was revealed that addressing the severity of the issues that disturbed daily life at admission often turned out to be rewarding and was emphasised by the nurses as advantageous and meaningful, both for themselves and the patients, when the progress was evaluated at discharge. In fact, for some of the nurses, this was the most satisfying aspect of working with the tool. This reflective sense of progress can be explained along phenomenological lines by how meaningful it was for patients to become aware of how the decline of the obtruding disturbing impacts increased their freedom to engage with the world (Gadamer, 1993/1996). Arguably here, the use of Hermes has demonstrated real potential as aimed for; namely in helping patients reframe their disruptions by creating new interpretative spaces, and enabling them to engage with their world anew in meaningful ways.

The usefulness of Hermes for evaluation of progress tallies with the utility of COPM for the re-evaluation of occupationally focused performances, as firmly established across patient groups in many studies (Law et al., 2005; Padancatti, 2011). Moreover, COPM has been confirmed as being a valid and reliable outcome measure (Donnelly et al., 2017; Law et al., 2005). Hermes aims primarily at exploring patients' experiences and meanings through interpretative dialogue as well as how patients render those experiences meaningful. Thus, it has not adopted the sort of structured measurement methods, required for establishing psychometric properties, which are built into COPM. Nevertheless, the lack of measurement outcomes through Hermes is a limitation of the tool with respect to the outcome-driven nature of current rehabilitation practices (Siegert & Adams, 2012). In this way, by necessity, the nature of Hermes as a tool remains stuck methodologically between the rock of structured psychometrics and the hard place of gauging qualitative life experiences.

## **5.7 Limited use of the potential for person-centred care planning**

Studies II-III revealed that health issue of concern to the patients (the disrupting impact of illness) emerged clearly on Hermes. This feature was claimed to be useful, in particular, by the nurses when it came to selecting nursing diagnosis in accordance with the patients' perceived needs in line with a person-centred approach. Nevertheless, Studies II-III revealed that the importance for receiving help with health problems, as had been aimed for, was seldom or never discussed. This lack of engagement with the importance of receiving help for health issues of concern limits Hermes's potential to advance the person-centred participation of patients into the action phase of such participation (Study I). In that phase, patients share decisions with HCPs as preferred and thereby influence the care provided. Here the use of Hermes unfortunately still lags behind the tools upon which it drew, in which the importance of receiving help with health problems is clearly addressed (Barker, & Buchanan-Barker, 2005; Law et al., 2005; Ruland et al., 2010).

However, in a few instances, the nurses in Study III were observed experimenting with synthesising the assessment interview through Hermes just after it had been conducted and discussing the importance of receiving help. In those few cases, the patients found this discussion helpful in sorting out what problems to focus on.

Facilitating the sharing of decisions is central to person-centred care (Kitson et al., 2013; Scholl et al., 2014) and particularly to active patient participation which is essential for successful rehabilitation (Negrini & Caravolo, 2008). Thus, the limited facilitation of shared decisions through Hermes must be regarded a substantial shortcoming of its use.

## **5.8 Contribution of the analysis of term person-centred participation**

The term person-centred participation in health care, which was constructed by an integrated review through which patients' experiences of such participation were synthesised, provided the theoretical background for Studies II-III. This synthesis of patients' understanding of this concept, which has been central to this thesis, follows Risjord (2009) who claims that in order to understand concepts of relevance to practice, theorists must first and foremost gain knowledge of how patients comprehend them. Concept analyses of practice-relevant terms must thus never be understood as mere philosophical exercises.

The new analysis agreed well with but also complemented and even challenged earlier analyses of concepts that were defined as integral to person-centred care. It was useful as a background for the clinical studies (Study II-III) in particular, as it provided detailed attributes of ideal participation, to which the findings could then be compared.

Prior to this analysis, the concepts of person-centredness and patient participation had mainly run on parallel tracks without mutual engagement, in spite of very similar attributes (e.g. Mead and Bowers, 2000; Sahlsten et al., 2008;). Yet, since the on-line publication of Study I, patient participation is more widely regarded as a conceptual element of person-centred care (Castro et al., 2016; Kitson et al., 2013; Waters & Buchanan, 2017). Moreover, recent concept analysis of patient participation have added person-centred components, such as patient preferences, into their analysis (Kvæl et al., 2018; Melin, 2018). In addition, the term patient engagement, which seems to be overtaking the term participation (Finset, 2017), highlights personalisation as central to engagement (Higgins et al., 2017). Thus, it could be argued that Study I has influenced this trend in the synthesis of the terms person-centred care and patient participation, through which the personalisation of patient participation has gained increased traction. That said, Study I also showed that patients often experience patient participation as constrained. Studies II-III showed that nurses' awareness of constrained participation in health assessment motivated them to develop assessment methods that facilitated more distinctively person-centred approaches to such participation.

## **5.9 Strengths and limitations**

The thesis has several strengths and limitations, in the author's own view. The main strengths of the thesis are twofold. First, through the methods used, a theoretically based and phenomenologically derived assessment tool, Hermes was developed for use in rehabilitation nursing. Second, the findings showed that, through its sustained use, its person-centred and phenomenological groundings were supported. In accordance with Morse (2015) the criteria of validity and reliability for the evaluation of the rigor of qualitative research will be used in the following discussion for a more fine-grained analysis of strengths and limitations.

A noteworthy strength of the thesis is that it studies involved triangulation, at the levels of method, data, investigators and theory. It is known that triangulation at each level enhances studies' validity and reliability (Morse, 2015). At a method level, three different qualitative methods, qualitative

integrative review (Study I) action research (Study II) and ethnography (Study III), were triangulated. At a data level, Studies II-III comprised of several data collection methods that were triangulated in each study (i.e. fieldwork observations and interviews), and at an investigator level, two–four researchers contributed to the data analysis in each study. Finally, at a theory level, person-centred patient participation and existential phenomenology were triangulated as underpinnings that informed data collection and analysis in Studies II-III. Explicit outlining of these underpinnings in Studies II-III and charting of the thematic frameworks or maps in Study I and Study III contributed to the maintenance of a decision trail which enhances the studies' validity and reliability (Morse, 2015). Moreover, the validity of Studies II-III was enhanced by prolonged engagement of the researcher in Study II (18 months) and Study III (10 months) and the participation of all the nurses at the respective wards in those studies. Nevertheless, it is a limitation of Study III that only two nurses conducted the interviews through Hermes and its use was only explored during the admission period. Furthermore, it is also a specific limitation of the study that the doctoral student, who collected all the data, was directly involved in the development of Hermes, which poses a threat of research bias to Studies II-III. In spite of the reflexivity employed in Studies II-III, which enhances the overall rigor of qualitative studies and facilitates the bracketing of prior assumptions, elimination of research bias cannot be assured in such cases (Holloway & Wheeler, 2010).

In addition to aiming to acquire new knowledge, action research aims to change practice. Therefore, the validity of such research is pragmatic as it is deemed by the extent to which the practice has been changed through the study (Mattson & Kemmis, 2007; McNiff & Whitehead, 2010). The fact that Hermes was adopted into practice in Study II, where its use was sustained, supports its pragmatic validity which can be regarded a significant strength of Study II. This strength is noteworthy in particular as the qualities of Hermes revealed through Study II were supported and extended in Study III which was conducted several year later. These extensions of the findings from Study II were obtained in many instances from the ethnographic fieldwork observations in Study III for which the methods in Study II did not allow. The value of these extended findings is supported by the relevance of ethnography in studying the adoption of complex interventions (such as Hermes) into practice (Mol, 2008; Pols, 2012). Thus the use of ethnographical methods may be regarded a particular strength of the thesis.

This thesis is limited, however, insofar as it does not provide findings in the form of quantitative outcomes. It goes without saying that the qualitative

methods used do not provide evidence in this form. Furthermore, due to the selection of those methods and the small samples, the findings about the use of Hermes cannot be generalised for its use in alternative settings. However, the fact that the tool has already been adopted into two other rehabilitation settings tentatively supports the conclusion that the findings of Studies II-III can be meaningfully applied to HCPs and patients in other rehabilitation settings (Speziale et al., 2011). That said, it remains a clear limitation that the use of Hermes was only evaluated for patients with chronic pain in Study III, and its use in nursing only but not its inter-professional use (Studies II-III), was explored. Finally, it can be regarded as a limitation that more structured methods, such as conversational analysis that can be employed in ethnographic studies (Koenig & Robinson, 2014), were not used to analyse the interviews through Hermes in Study III. Note that more detailed lists of strength and limitations are described in each of the individual papers making up this thesis.

## **5.10 Implications**

Prior to the studies of which this thesis is comprised, person-centred assessment methods in rehabilitation nursing had not been developed for general use for patients with illnesses of somatic origin. The finding that the person-centred assessment tool, Hermes, explored in this thesis, could be successfully adopted into rehabilitation nursing, must thus be regarded of substantial clinical importance. Although more research is needed to establish its benefits for patients' well-being, its person-centred and phenomenological groundings were supported through its use. Findings from Studies II-III showed that assessment interviews conducted using Hermes enhanced patients' communication related to physical and psychosocial issues that had a disturbing impact on daily life. This communication is of clinical importance as it enhanced nurses' understanding of the patients' situation, which in turn facilitated the nurses in the planning of care.

The qualities of Hermes for exploring patients' perspectives holistically is of central importance for nursing practice (Manley, 2011) and rehabilitation practices (Negrini & Caravolo, 2008; Wade, 2015b), as well as being one of the main pillars of quality in health care (Institute of Medicine, 2001). According to existential phenomenology, the disturbing impact of illness signifies the meaning of the illness experience and the suffering associated with it (Carel, 2016; Toombs, 1993). Importantly, Hermes facilitated patients in communicating this meanings and their suffering. Such communication has not been explicated and studied through the use of assessment tools in this way

before. These potentials of Hermes to reveal core aspects of the illness experience, which facilitate HCPs in understanding the patients' existential world of living with an illness (Carel, 2016; Marcum 2005), are of specific clinical significance. This is a particularly important finding in the context of existential and phenomenological philosophies which are often seen as obscure and intractable to practical (e.g. health-based) applications.

Patients' illness trajectories typically involve their ongoing interpretations of the illness situation, driven by their quest for making sense of and establishing a new meaningful order in living with their illness (Berglund, 2014; Haahr et al., 2011; Kirkevold, 2010). However, this existential aspect of adapting to illness tends to be neglected by HCPs (Angel et al., 2011; Carel, 2016). Therefore the interpretative quality of Hermes is arguably of relevance for practice as it can potentially encourage nurses and other HCPs to attend to patients' existential needs. This interpretative feature has particular relevance for rehabilitation nursing, where one of the main roles of nurses is to help patients interpret and make sense of their illness situations (Kirkevold, 2010; 2015). The fact that the interpretative nature of Hermes was useful for exploring the holistic impact of chronic pain in Study III suggests that Hermes has specific relevance for the health assessment of this patient group.

The communication techniques that the nurses used in the present studies of Hermes proved to be useful. However, they were continuously searching for ways to improve them. Since interpersonal competencies are central to person-centred care (Kitson et al., 2013; McCormack & McCance, 2006), teaching, training and development in the communication methods used must be regarded of particular clinical salience. Furthermore, as emerged in the findings from Studies I and II, the application of Hermes into clinical practice still needs considerable fine tuning and development. In this respect, future research on the use of the tool and its further development should ideally be integrated, for example through action research.

Teamwork is central to rehabilitation (Negrini & Caravolo, 2008; Wade, 2016) and person-centred care (Kitson et al., 2013). Thus, it is essential that the health issues of concern that patients communicate through Hermes are shared in the inter-professional teams in rehabilitation. However, this aspect of the use of Hermes was not explored in the present thesis. Arguably, the similarities in the structure and use of Hermes and in the occupational assessment method, COPM (Law et al., 2005) upon which Hermes drew, can facilitate inter-professional teamwork in rehabilitation. The ICF model contributes to an inter-professional teamwork, views patients in the lights to

their functional abilities as well as viewing them from different perspectives (professional, personal, social) (WHO, 2001). In spite of these substantial advantages the model perspective does to a very limited extent address the existential aspects of illness (Florin et al., 2013). Arguably, the existential background of Hermes, or other existential frameworks could provide insight into further development of the ICF-model.

In spite of the conclusion that the adoption and use of Hermes cannot be generalised beyond the present sample and settings, the tool has already been put into use at two other rehabilitation centres, beyond the one where it was originally developed. Thus one may hopefully expect that Hermes can be of benefit in other rehabilitation settings. For example, Hermes might be relevant for discussing health issues of concern to patients in other health care contexts, such as primary and home care. Established guidelines, teaching material and training methods have been established for the use of the person-centred assessment COPM (Law et al., 2005) and the Tidal model (Barker & Buchanan, 2005) upon which Hermes drew. The development of such teaching and training materials is regarded essential for the further development and adoption of Hermes into other settings.

### **5.11 Further studies**

The present studies of the development and use of Hermes are the first to be conducted on the use of the tool. Thus, further studies are urgently needed in further establishing its empirical grounding and development. In this further early stage of the development of Hermes as an assessment tool, qualitative and exploratory studies of its use are suggested, which would extend the present studies. Those would ideally include ethnographic and qualitative studies which would explore the use of Hermes for other patients group than patients with chronic pain throughout the rehabilitation period. Its use for facilitating shared decision and evaluating progress at discharge are important aspects to explore as well as its use in inter-professional teamwork. Moreover, it is worth exploring the quality of interviews through Hermes further, using conversational analysis. Action research is suggested in the adoption of Hermes into new settings, but ideally with direct participation of patients, which was not the case in the original development of Hermes.

At later stages in the development of Hermes, quantitative and experimental studies of its impact and effectiveness are needed. Here it is important to explore, for example, how the implementation of Hermes is associated with outcomes that are linked to person-centred care, such as

patient satisfaction, well-being, self-care ability and empowerment. These association could be measured pre- and post-implementation of Hermes or with an experimental design with an intervention group and one or two comparison groups.

## 6 Conclusions

This thesis provides understanding of how a new philosophically and theoretically derived person-centred assessment tool was developed and adopted for general use in rehabilitation nursing. The thesis also presents the first findings about the use tool, which was named Hermes. Those findings revealed the tool's overall usefulness for exploring patients' perspectives of the impact of illness in nursing assessment in rehabilitation, which in turn enhanced nurses' understanding of the patients' situations. These actualised and demonstrated person-centred features of Hermes must be regarded of substantial clinical relevance, as a tool with such qualities has been lacking for general use in rehabilitation nursing. Moreover, they also indicate the viability of a health-care relevant operationalisation of a philosophical approach, namely hermeneutical existential phenomenology, which has often been considered obscure and intractable to practical application.

In line with the existential phenomenology upon Hermes was grounded, dialogues with open and interpretative features were realised through its use, as well as the communication of the disturbing impact of illness, arguably exemplifying the very meaning and suffering of illness. Such existential features, through the use of an interpretative dialogue, have not been revealed through the use of health assessment tools before. Mindful that the existential aspect of illness tends to be neglected in health care, these existential features of Hermes arguably open up substantial possibilities for attending to patients' existential needs.

The usefulness of Hermes is supported by its sustained use and its adoption into two other rehabilitation settings, beyond the one where it was developed. Thus, the tool must be deemed to have relevance for rehabilitation nursing, as well as potential, if yet to be fully confirmed, benefits in other health care settings. Nevertheless, it must be emphasised that the overall usefulness of Hermes revealed in the thesis should be interpreted with caution as only exploratory research methods were used. Moreover, the tool is still in its early developmental stage. Thus, several aspects of its use need considerable fine-tuning and further research.

However, it can be concluded with reasonable certainty that, similar to the messenger God Hermes, who served as mediator between the Greek Gods

and human beings, the assessment tool Hermes can serve as a mediator of patients' illness experiences and meanings between patients and nurses.

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## Original publications

