



THE JOANNA BRIGGS  
INSTITUTE



THE UNIVERSITY  
*of* ADELAIDE

# The Quality of Husserlian Phenomenological Research in the Health Sciences: A Methodological Systematic Review

Catalin Tufanaru

August 2013

School of Translational Health Science

Joanna Briggs Institute

Faculty of Health Sciences

University of Adelaide

Thesis Supervisor

Professor Alan Pearson AM

School of Translational Health Science

Joanna Briggs Institute

Faculty of Health Sciences

The University of Adelaide

## Table of contents

• Abstract of the thesis	page 1
• Statement	page 3
• Acknowledgement	page 4
• Chapter 1: Introduction	
○ Background/Context of the review	page 5
○ Review Objective/Question	page 9
○ Definitions of terms	page 9
• Chapter 2: The Systematic Review	
○ Review Questions/Objectives	page 11
○ Inclusion Criteria	page 11
○ Review Methods	page 12
• Chapter 3: Results	page 24
• Chapter 4: Discussion and Conclusions	page 41
• Appendices	page 45
• References	page 123

## **Abstract of the thesis**

The objective of this Thesis was to provide a narrative synthesis of the literature on the quality of existing Husserlian phenomenological research studies in the health sciences. A methodological systematic review was performed. Only studies that focus on adult patients' experiences of preventive, screening, diagnosis, treatment or rehabilitation interventions/procedures were considered to serve as a paradigm 'case' of the use of the Husserlian phenomenological approach within the broad field of health.

The review question was: What is the quality of existing Husserlian phenomenological research studies in the health sciences? For this review, quality refers to the extent to which there is congruence between the Husserlian phenomenological approach and the content of Husserlian phenomenological research studies.

This review considered studies that included adults (aged 18 years old or older), regardless of gender or ethnicity, cognitive abilities or impairments/dysfunctions, principal diagnosis and co-morbidities, severity or stage of the disease or co-morbidities, who had received preventive, screening, diagnostic, treatment or rehabilitation interventions regardless of healthcare setting and type and specifics of interventions/procedures. Only studies with the experiences from the patient's perspective were considered for inclusion in the review. Qualitative research studies grounded in the work of Husserl, including studies that utilise the Giorgi's or Colaizzi's approach (or any similar phenomenological descriptive approach) were considered for inclusion in the review.

The search was limited to English language publications from January 1960 to September 2012. A three-step search strategy was utilised in this review, an initial limited search of MEDLINE and CINAHL, followed by a second search using all identified keywords and index terms undertaken across databases, and a third search of reference list of all identified articles.

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using a standardised critical appraisal instrument from the Joanna Briggs Institute. Data were extracted from papers included in the review using a standardised data extraction tool from Joanna Briggs Institute. Methodological critique of the included studies was performed during the data synthesis stage of the review. The purpose of the methodological critique of included studies was the examination of their congruence with the central tenets of Husserlian phenomenological approach. Given the objective of the systematic review no studies were excluded after critical appraisal. Thirty studies were included.

The review of the included papers identified clear inconsistencies between the tenets of Husserlian philosophical phenomenology and the research approaches used in included studies but the creative adaptation and transformation of phenomenological ideas and approaches for the specific purposes of qualitative scientific research are justified and the results of the research are useful if the circumstances and consequences of these adaptations and transformations are understood. Deficiencies found in included studies were examined with the intention to clarify the conditions for better application of the phenomenological method. Recommendations are provided for future health research motivated by this specific philosophical perspective.

## **Statement**

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library catalogue and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Catalin Tufanaru

21<sup>st</sup> of August 2013

## **Acknowledgement**

My sincere thanks and deepest appreciation to Professor Alan Pearson AM, my Supervisor, for his guidance, encouragement, support, and endless patience.

## Chapter 1: Introduction

### *Background/Context of the review*

Phenomenology is a philosophical movement (Spiegelberg 1975). A philosophical movement is a fairly broad but identifiable change in philosophical thought often without a unified set of ideas to which all participants agree. There is only a broad approach that tends to be shared. This systematic review focuses on Husserlian phenomenology. The objective of Husserlian phenomenology is the direct investigation of phenomena as consciously experienced from the first-person perspective (Spiegelberg 1975; Lauer 1958; Moran 2000; Moran 2005; Husserl 1907/1999; Woodruff Smith 2007). Husserlian phenomenology is a descriptive approach directed towards discovering essences of meaning (Spiegelberg 1975; Lauer 1958; Moran 2000; Moran 2005; Husserl 1907/1999; Woodruff Smith 2007). Husserlian phenomenology represents an approach to examining what properties are essential. It is not a factual approach as there is no interest in describing the properties of a particular example. Concrete particular examples are examined in Husserlian phenomenology only as examples in the effort to find what is essential. The approach aims to provide description of phenomena as free as possible from presuppositions (Spiegelberg 1975; Lauer 1958; Moran 2000; Moran 2005; Husserl 1907/1999; Woodruff Smith 2007). No causal explanations are considered nor are theories (Spiegelberg 1975). The focus is on clarification not on causal explanation. Phenomenology is concerned with experiences and descriptive phenomenological clarification of the essentials is based only on the examination of how things are given in our experience.

The understanding of Husserlian phenomenology for the purposes of this review draws on the study of English translations of Edmund Husserl's own published works and also on commentaries from internationally recognized phenomenological scholars and Husserlian phenomenological scholars. This systematic review draws also from the structured framework provided in the six 'existential uses of phenomenology' and the seven 'steps of the phenomenological method' as described by Herbert Spiegelberg (Spiegelberg 1975; Spiegelberg

1982). Details on Husserlian phenomenology and Spiegelberg's structured framework are presented in the synthesis section of the review.

Spiegelberg's framework is especially useful for understanding Husserlian phenomenology and for providing an explicit and clear structure for the synthesis component of the review. Spiegelberg describes six 'existential uses of phenomenology': descriptive phenomenology, essential phenomenology, phenomenology of appearances, constitutive phenomenology, reductive phenomenology and hermeneutic phenomenology (Spiegelberg 1975, p.57-70). The seven 'steps of the phenomenological method' as presented by Spiegelberg are: investigating particular phenomena; investigating general essences; apprehending essential relationships among essences; watching modes of appearing; watching the constitution of phenomena in consciousness; suspending belief in the existence of the phenomena; interpreting the meaning of the phenomena (Spiegelberg 1982, p.681-715).

Phenomenology is not only a philosophy but also a qualitative research methodology used around the world in very diverse fields such as nursing, medicine and health research in general (Crotty 1996; Finlay 2011; Toombs 2001; Cohen & Omery 1994). Examination of the existing phenomenological health research literature reveals that there is a significant proportion of this literature claiming to be Husserlian phenomenological research. Some of these studies explore patients' experiences. Other studies explore nurses', or healthcare providers' or family members' experiences. Some studies examine the experiences of learning, or experiences of communication or interactions. For this methodological systematic review, only a small sample of existing studies were considered to serve as a paradigm 'case' of the use of the Husserlian phenomenological approach within the broad field of health.

In recent years the evidence-based health care movement has increasingly recognised the importance of evidence from qualitative research and especially the evidence related to patients' lived experiences (Pearson 2010; Pearson, Field and Jordan 2007; Pearson, Robertson-Malt and Rittenmeyer 2011). Based on an



assessment of the existing literature (specifically the trend observed in the last years) it would appear that there is no evidence to suggest that Husserlian phenomenological research will not be used in the future as a mainstream approach in health research studies.

There is an impressive diversity of phenomena explored in phenomenological research in health studies: from mothers' experiences of postpartum care, to experiences of eating after esophagectomy; from experience of youths with hemoglobinopathy to the lived experience of patients with rheumatoid arthritis or pregnant women's experience of the decision-making process related to completing or terminating pregnancy; and from perianesthesia experience from the patient's perspective to the experiences of older people on discharge from hospital following assessment by the public health nurse (Bondas-Salonen 1998; Beck 1992; Jaromahum and Fowler 2010; Bryant et al 2011; Hershberger and Kavanaugh 2008; Wiederhold et al 2011; Esbensen et al 2008; Iaquina and Larrabee 2004; Logan et al 2006; . Notter and Burnard 2006; Mitchell and Turton 2011; Litr e and Gjengedal 2008; Herlin and Wann-Hansson 2010; Kjelsvik and Gjengedal 2011; Wall et al 2011; McKeown 2007; Davidson 1994).

Qualitative researchers have become increasingly concerned about the way phenomenological research is conducted in health, the most articulate and the most aggressive in their critiques (specifically on nursing phenomenology) being Crotty, Yegdich and Paley (Crotty 1996; Paley 1997; Paley 2005; Yegdich 2000). These critiques refer to the meaning of fundamental concepts or specific approaches used in Husserlian phenomenology such as intentionality, experience, phenomenological reduction, bracketing, natural attitude, and the essential structure of a phenomena to name but a few. Michael Crotty claims that there are two phenomenologies (Crotty 1996). One is the phenomenology of the phenomenological movement emerged from the works of Edmund Husserl. The other is a 'new phenomenology'. Crotty's strong claim is that the 'new phenomenology' used in nursing research is a different phenomenology that uses the vocabulary of phenomenology but the meanings attached to the fundamental concepts are different (Crotty 1996). According to Crotty the 'new

phenomenology' is compatible with the epistemological perspective that phenomenology explicitly refutes. John Paley claims that nursing researchers misunderstand the concepts of phenomenological reduction, phenomena and essence and therefore the version of Husserl's phenomenology as presented in these research studies is not consistent with the original Husserlian phenomenology (Paley 1997). In 2000 Tania Yegdich published an article claiming inconsistencies between Husserl's phenomenology and nursing interpretation of this phenomenological approach (Yegdich 2000). Similarly, Paley alleges in another article that there are discrepancies between the philosophical claims presented by nursing phenomenologists in what nurses call 'phenomenology' and 'nurse-phenomenology' research practice (Paley 2005).

A search of the Joanna Briggs Institute's Library of Systematic Reviews, the Cochrane Library of Systematic Reviews, Medline, CINAHL and Mednar, performed in February and March 2012, did not identify any existing research synthesis on the specific topic proposed for this systematic review. A recent systematic review by Norlyk and Harder investigates only peer-reviewed empirical phenomenological nursing studies and the objectives of the review, the focus of interest, the methodological approach, the inclusion criteria, the search strategy, the critical appraisal tools and data extraction tool are different from those used in this review (Norlyk and Harder 2010). In the review by Norlyk and Harder the objective was to systematically review the presentations of phenomenology as a research approach (regardless of phenomenological approach) and to discuss possible peer review scientific criteria for publication of phenomenological research studies; inclusion criteria specified published empirical studies from peer-reviewed journals (within the timeframe from January 2006 to June 2007) with nurse researchers listed as first or corresponding author.

### ***Review Objective/Question***

The objective of this methodological systematic review was to provide a narrative synthesis of the quality of existing Husserlian phenomenological research studies in the health sciences. As a methodological systematic review, only studies that focus on adult patients' experiences of preventive, screening, diagnosis, treatment or rehabilitation interventions/procedures were considered to serve as a paradigm 'case' of the use of the Husserlian phenomenological approach within the broad field of health.

The review question was: What is the quality of existing Husserlian phenomenological research studies in the health sciences?

The motivation for this systematic review was not to fault authors of existing Husserlian phenomenological research, but to explore the problems encountered in existing research literature, if any, and to provide guidance to authors for future health research guided by this specific philosophical perspective.

### ***Definitions of terms***

In order to avoid repetition, the term 'Husserlian phenomenological approach' as used in the thesis refers to the approach described by Edmund Husserl in English translations of his own published work; or as described in English language commentaries by internationally recognized scholars; or by Husserlian phenomenological scholars including the structured framework presented by Spiegelberg. Each time the 'content of Husserlian phenomenological research studies' is used in the text it should be understood to mean 'content of Husserlian phenomenological research studies as reflected in the stated philosophical perspective, research methodology, data collection methods, data analysis methods, presentation and interpretation of the results, and the conclusions'.

Definition of terms:

1. Husserlian phenomenological research studies refers to primary qualitative research studies that are explicitly grounded in the work of Husserl reflected in explicit statements or descriptions by the authors.
2. Quality refers to the extent to which there is congruence between the Husserlian phenomenological approach and the content of Husserlian phenomenological research studies.

These stipulative definitions are intended to preclude the need to cite the scientific literature as there is no need to demonstrate their 'validity' or 'acceptability' by the communities of scholars. These definitions are not based on consensus across qualitative research communities; rather, they are presented as useful stipulative definitions that underpin the methodological systematic review and serve to avoid confusion regarding the use of the terms in the specific context of this systematic review.

## **Chapter 2: The Systematic Review**

### ***Review Questions/Objectives***

The objective of this systematic review was to provide a narrative synthesis of the quality of existing Husserlian phenomenological research studies in the health sciences. As a methodological systematic review, only studies that focus on adult patients' experiences of preventive, screening, diagnosis, treatment or rehabilitation interventions/procedures were considered to serve as a paradigm "case" of the use of the Husserlian phenomenological approach within the broad field of health.

The review question was: What is the quality of existing Husserlian phenomenological research studies in the health sciences?

### ***Inclusion Criteria for Considering Studies for This Review***

As a methodological systematic review, types of participants and phenomena of interest mentioned in inclusion criteria were used not to define clinical aspects of interest but to specify the limits of the paradigm 'case'.

### ***Types of Studies***

All existing primary qualitative research studies that are explicitly grounded in the work of Husserl according to the explicit statement or description by their authors were considered for inclusion in the review. Studies that utilise Giorgi's or Colaizzi's approach (or any similar phenomenological descriptive approach) and that are explicitly grounded in the work of Edmund Husserl according to the explicit statement or description by their authors were considered for inclusion in the review (Finlay 2011; Giorgi 2009; Colaizzi 1978). All studies using (according to the explicit statement or description by their authors) an existential phenomenological approach or a hermeneutical phenomenological approach (for

example, such as the Van Manen approach) were excluded from the review (Finlay 2011; Van Manen 1990).

### ***Types of Participants***

This review considered studies that include adults (aged 18 years old or older), regardless of gender or ethnicity, cognitive abilities or impairments/dysfunctions, principal diagnosis and co-morbidities, severity or stage of the disease or co-morbidities, who receive preventive, screening, diagnostic, treatment or rehabilitation interventions regardless of healthcare setting and type and specifics of interventions/procedures.

### ***Phenomena of Interest***

This review considered studies that investigate patients' experiences of any preventive, screening, diagnosis, treatment or rehabilitation interventions/procedures. Only studies with the experiences from the patient's perspective were considered for inclusion in the review. Studies with experiences from health professionals' perspectives, or family members' perspectives, or others' perspectives (not the patients' perspective) were excluded from the review.

### ***Review Methods***

#### ***Search Strategy***

The initial search strategy aimed to find both published and unpublished studies. Given the methodological focus of the review and the fact that 30 published studies were identified and it was considered that these studies provided enough rich evidence for the paradigm 'case' the planned search for unpublished studies was not performed.

The search was limited to English language publications from January 1960 to September 2012. The most recent critique of phenomenological health research emerged in the period 1996-2005 and the search timeframe for the systematic review intended to identify the literature published before, during and after the 1996-2005 debate.

A three-step search strategy was utilised in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe article. A second search using all identified keywords and index terms was undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies.

The initial proposed search strategy aimed to include the following databases: Medline, CINAHL, Scopus, PsychInfo, British Nursing Index, Academic Search Premier, and Health Source Nursing/Academic Edition. Given the methodological focus of the review and the fact that 30 published studies were identified and it was considered that these studies provided enough rich evidence for the paradigm 'case' the search was performed only in PubMed and CINAHL.

The initial proposed search strategy included also Mednar and organisations involved in phenomenological research. The search was performed only in Mednar.

The initial search strategy aimed to include a specific search for phenomenological theses and dissertations. The planned search for theses and dissertations was not performed.

The initial search strategy aimed to include journal-specific searches performed on: Social Science in Medicine, Qualitative Health Research; Journal of Phenomenological Psychology; The Indo-Pacific Journal of Phenomenology; Phenomenology & Practice; Phenomenology and the Cognitive Sciences;

Research in Phenomenology. The search was not performed in the journal Social Science and Medicine.

Initial keywords to be used were: phenomenology; phenomenological; Husserlian phenomenology; Husserl; Giorgi; Colaizzi; descriptive phenomenology; phenomenological description; experience; patients' experiences; clients' experiences; lived experiences; adults.

Details of the search strategy used in PubMed and CINAHL are provided in Appendix 1.

### ***Critical Appraisal***

Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardised critical appraisal instrument from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix 2). Any disagreements between the reviewers were resolved through discussion. For this systematic review the secondary reviewer was involved only in this stage of the review process, specifically the critical appraisal of retrieved papers using the generic critical appraisal tool from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).

Given that the objective of the systematic review was to synthesize the evidence on the quality of the existing studies no studies were excluded after critical appraisal.

This critical appraisal performed during the stage of assessment of methodological quality should not be confused with the methodological critique of the included studies that was performed during the data synthesis stage of the review. Methodological critique is not the same as critical appraisal. Critical appraisal performed during the stage of assessment of methodological quality is a



first order assessment. Critical appraisal is based on the 10 standardised critical appraisal questions from the Joanna Briggs Institute Qualitative Assessment and Review Instrument. The goal was to assess the methodological validity as considered in the qualitative research.

### ***Data Extraction***

Data was extracted from papers included in the review using the standardised data extraction tool from Joanna Briggs Institute Qualitative Assessment and Review Instrument JBI-QARI (Appendix 3). Only data as reported in studies was used, there was no attempt to contact the authors for missing or unclear data. The data extracted include specific details about philosophical perspective, the objectives of the research, the research questions, the phenomena of interest, the methodology, the sampling procedures, the data collection methods, the data analysis methods, and the reporting of results and conclusions and implications or recommendations for practice or research. All these details were necessary for the methodological critique of the included studies performed during the data synthesis stage of the review.

### ***Data Synthesis***

Because of the review focus on quality, it was anticipated that the synthesis of the results would be presented in narrative form. The narrative summary of the results of the methodological critique of the included studies is presented in the results section.

Methodological critique was guided by the Husserlian phenomenological approach. The understanding of Husserlian phenomenology for the purposes of this review draws on the study of English translations of Edmund Husserl's own published works and also on commentaries from internationally recognized phenomenological scholars and Husserlian phenomenological scholars. The

narrative synthesis of the results of the methodological critique was specifically guided by the Spiegelberg's structured framework provided in the six 'existential uses of phenomenology' and the seven 'steps of the phenomenological method' (Spiegelberg 1975; Spiegelberg 1982).

Methodological critique of the included studies was performed during the data synthesis stage of the review. The purpose of the methodological critique of included studies was the examination of their congruence with the central tenets of the Husserlian phenomenological approach (unlike the process of critical appraisal, where the focus was on the generic aspects of validity as considered in the qualitative research). The assessment of congruence was performed by carefully reading and re-reading the full text of all included articles and examining compatibility between the Husserlian phenomenological approach and the content of each included Husserlian phenomenological research study, for example:

- consistency between the Husserlian phenomenological approach and the stated phenomenological philosophical perspective as stated, reported or described by the authors;
- consistency between the Husserlian phenomenological approach and the research objectives/questions as stated by the authors; and
- consistency between the Husserlian phenomenological approach and the data collection methods as stated, reported or described by the authors.

### *The Husserlian Approach to Phenomenology*

The understanding of Husserlian phenomenology used for the methodological critique draws on the study of English translations of Edmund Husserl's own published works (Husserl 1967; Husserl 1999; Husserl 1931; Husserl 1960; Husserl 1965; Husserl 1970; Husserl 1980; Husserl 1983; Husserl 1989; Husserl 2006) and also on commentaries from internationally recognized phenomenological scholars and Husserlian phenomenological scholars (Buckley 1997; Cerbone 2006; Dreyfus and Wrathall 2006; Embree 1997; Kersten 1997;

Kisiel 1997; Kockelmans 1967; Kockelmans 1994; Levinas 1967; Lauer 1958; Moran 2000; Moran 2005; Macann 1993; Mohanty 1997; Natanson 1973; Scanlon 1997; Schmitt 1967; Spiegelberg 1975; Spiegelberg 1981; Spiegelberg 1982; Woodruff Smith 2007). The resulting understandings of Husserlian phenomenology used for the methodological critique is presented here as a narrative summary of my own understanding of the essential ideas set out in Husserlian literature (Husserl's own published works and commentaries from scholars).

#### *First person perspective*

Phenomenology is an inquiry from the first person perspective. Phenomenology is from the perspective of I. In transcendental phenomenology the experience is always my experience as Husserl considered only the experience of an 'I': I see, I imagine. In transcendental phenomenology the experience is the first person experience. The description in phenomenology is from my first person perspective. I see. I experience. My phenomenological description is not the description of the objects but the description of the objects as I experience them, the description of objects as they appear to me, to the I.

#### *Spiegelber's vicarious experience*

Spiegelberg contends that the transcendental phenomenological approach is a first person approach but proposes an extension of traditional phenomenology by suggesting that an inquiry of a phenomenologist exploring others' experiences is possible and not in contradiction to the spirit of phenomenology (Spiegelberg 1975, pages 35-53, Phenomenology through vicarious experience).

#### *Husserl's natural attitude*

Husserl claimed that the implicit belief, that always is present in all human actions, beliefs and assumptions, is the human belief that the world exists. This general implicit thesis is called the general thesis. The natural attitude is the implicit prejudice/belief that the world exists independent of any human person experiencing it. Everyday life as well as the sciences is grounded on this natural attitude. In my 'natural' attitude my entire attention and thinking is focused on the

things as existing outside me in an objective world. In natural attitude there is no doubt that the world is an objectively existing world regardless of my awareness or not. In natural attitude I know that world exists and I know that my consciousness is something separate from the world. In natural attitude I know that the objective outside world is reflected in my consciousness. This is the natural attitude considered as fundamental thesis by Husserl in transcendental phenomenology. In natural attitude I am an 'I' in an existing natural world. In transcendental phenomenology I have to purify my 'I' of this assumption of the existence of an objective world. My transcendental 'I' is the same 'I' but all my existence is not related to the presupposition that my consciousness reflects an objective world. Presupposition is not rejected but also not accepted, it is ignored. In transcendental phenomenology I must return to the immediate original data of my consciousness, ignoring the 'natural' implicit assumption of the existing world.

#### *Pure Phenomenological Description of the direct intuited*

In transcendental phenomenology I use only intuition of the phenomena. I don't use induction or deduction. I use only description of the phenomena. In transcendental phenomenology I have to describe what is given in my experience as experienced in direct first person intuition without inductive or deductive manipulations.

#### *Transcendental Phenomenology and the validity of knowledge*

According to Husserl what is directly intuited in my consciousness in my first person experience is a valid source of knowledge for science and should be examined and considered as such. This position contrasts with Giorgi's position that only accounts from others are valid source of knowledge because the community of researchers perceives first persons account as purely subjective accounts of private experiences.

#### *Phenomenology as descriptive science*

Phenomenology implies what is directly observed as experience in my consciousness and opposes speculative thinking. The claim that phenomenology

is a descriptive science of the first person experience is justified by the undeniable facts that subjects' phenomenological experiences are explored in an attitude of openness that allows what is experienced to be experienced directly as it is and phenomenological descriptions are available for inter-subjectively verification.

### *The Husserlian epoche*

The transcendental-phenomenological epoche is the suspension or the bracketing of the thesis or belief of the natural attitude. The thesis or the belief of the natural attitude is the belief I have in my consciousness that the world is an actually existing world. In transcendental-phenomenological epoche the world is reduced to the transcendental phenomenon world experienced in transcendental subjectivity. The transcendental-phenomenological epoche is the way of making the transition from worldly focus of consciousness of world and its things to the phenomenological pure transcendental consciousness. In Husserlian epoche the natural attitude is in parentheses, it is not used. The epoche is not used to negate or refute the general thesis of the natural attitude but to put it in brackets, to suspend it. My interest as transcendental phenomenologist is to explore my experience of the objects, regardless of the fact that the experience is actual, imagined or dreamed. My interest as transcendental phenomenologist is to explore my experience regardless of the fact that objects actually exists or are only imagined. In epoche the world is put in suspension in a neutral attitude; the world in and for itself is not considered, not rejected, not accepted, but suspended. In epoche the only possible way to experience the self and the world is to see the objects as intuited in my consciousness without rejecting or accepting the reality of an objective world. My own consciousness, my I, is the fundamental starting point. I make sense of the world and its things regardless of the status of my consciousness in the world, as actuality or possibility in a possible objective world. My I, my consciousness is primordial, is transcendental, is more fundamental than the world and its things. My consciousness is a pure possibility, not constrained to factuality in a world that exists in and for itself. In epoche the world is not accepted, is not rejected, but is suspended in a neutral way. My I, my consciousness as pure possibility

regardless of its self perception in the world is considered by Husserl as the transcendental consciousness and therefore pure phenomenology is a science of transcendental consciousness. The mundane consciousness or psychic is considered by Husserl the worldly consciousness as self apperceived in the world and therefore psychology is an empirical factual science of worldly consciousness.

*Eidetic reduction, eidetic transcendental phenomenology and Husserl's essences*

Husserlian phenomenology is an eidetic transcendental phenomenology. After the epoche is performed, in transcendental reduction the world and its things are intuited in my transcendental consciousness. Epoche is the neutral suspension of the natural attitude and transcendental reduction is the way I explore the experienced as just one experienced example of pure possibilities. Transcendental-phenomenological reduction operates only in my pure transcendental consciousness. Eidetic reduction is the approach used in transcendental phenomenology to make the transition from worldly facts to universal ideal essences. Husserlian phenomenology is an exploration of universal ideal essences as what is essential, what is universal and necessary, what is a priori. In phenomenology I experience the world in a pre-philosophical and pre-scientific experience as a world existing independent of thoughts and speculations about it. World is experienced in the form of individual particulars things or facts. According to phenomenology knowledge of particular facts is based on comprehension of essences that allows me to classify and structure the particular facts. Phenomenology requires the change of my focus from particular facts to essences and essential structures. Phenomenology implies a change of my focus from the actual world to the awareness of how the world is intuited in my pure transcendental consciousness. In transcendental phenomenology, I assume that I have an implicit preliminary initial knowledge of the essences but that the knowledge is partial, incomplete, and not clear. The implicit knowledge of essences is vague, confused, and obscure. The variation in imagination provides me with the chance to grasp in a more clear and explicit way the essences, to see the essences of objects as objects immediately given. This variation of particulars in order to identify what is identical despite all imaginable variations intends the

direct intuition of essences of objects or states of affairs. These essences are not to be discovered in the world of particulars but in the pure transcendental consciousness.

Any experienced instance (actual instance or in imagination) is treated in my pure transcendental consciousness as an object of pure imagination without any reference to actual space, time, or actual causality. Phantasy is used to subject the experienced instance to different variations. The goal is to explore the essence, what is identical despite all imaginable variations. I examine what is identically repeatable in all imaginable individual different instances, in different particulars. In transcendental phenomenology I start with a perceived or imagined fact and in an act of pure phantasy or pure imagination I investigate the changes that can be made without making the fact ceasing to be what it is. In this way I discover what is necessary and sufficient for something to be exactly that something. I will discover what is immutable, what is invariant. Through this intuition in phantasy I discover the essence. This essence is unique. It is identical for all things that are the same thing. These essences are result of variation in phenomenological phantasy. Variation in phantasy is not a method of the experimental or observational sciences of natural facts. Essences explored in pure transcendental phenomenology are not empirical facts about natural world or cultural world.

#### *Phenomenological description*

The phenomenological description is a description that captures the essences of things as purely or neutrally as they appear without distortion or falsification. The phenomenological description is a description of essences not of particulars or examples. The phenomenological description is a description of what is unique, universal, necessary and sufficient.

#### *Husserlian phenomenological psychology*

It is important to clarify that in usual philosophical and research discourse Husserlian phenomenology refers to phenomenological philosophy, specifically transcendental phenomenological philosophy. Husserl explored also what is called phenomenological psychology. Husserl proposed a worldly and eidetic

psychology called phenomenological psychology. Transcendental phenomenology involves the pure transcendental consciousness; phenomenological psychology explores the human mundane consciousness. In phenomenological psychology the focus is on subjective psychic life as part of the 'real', 'objective' world. In transcendental phenomenology subjectivity is purified to transcendental subjectivity. Transcendental phenomenology is an inquiry guided by the goal of absolute certainty. Phenomenological psychology aspires to clarify psychological aspects of human consciousness. Descriptive phenomenological psychology is performed in a phenomenological psychological attitude. In phenomenological psychology the human experience is studied as experienced. An actual case of psychic experience is considered as a pure possible example of consciousness in a possible world describing the essential psychic possibilities and impossibilities and necessities.

#### *Phenomenology of the natural attitude*

According to Embree, phenomenology of the natural attitude as the foundation of the human sciences was proposed by Alfred Schutz. Schutz contended that his focus was not based on Husserl's transcendental consciousness but on the natural attitude. In this approach it is possible to explore the experience of interest without having to use the transcendental phenomenological attitude. For Schutz, phenomenology is a phenomenology in the natural attitude, not transcendental, examining the world and its things without transcendental grounding. Therefore, it is possible to adapt Husserlian reflective and eidetic approach and concepts without the goals of transcendental phenomenological philosophy. Embree claims that such phenomenology of the natural attitude is common in the phenomenological movement and remarks that in the future much of the phenomenology will be conducted as worldly phenomenology, the phenomenology of the natural attitude (Embree 1997).

#### *Spiegelberg's framework*

Spiegelberg's framework of Husserlian phenomenology was used as an explicit and clear structure for presentation of the results of the synthesis component of the review (Spiegelberg 1975, p.57-70; Spiegelberg 1982, p.681-715).



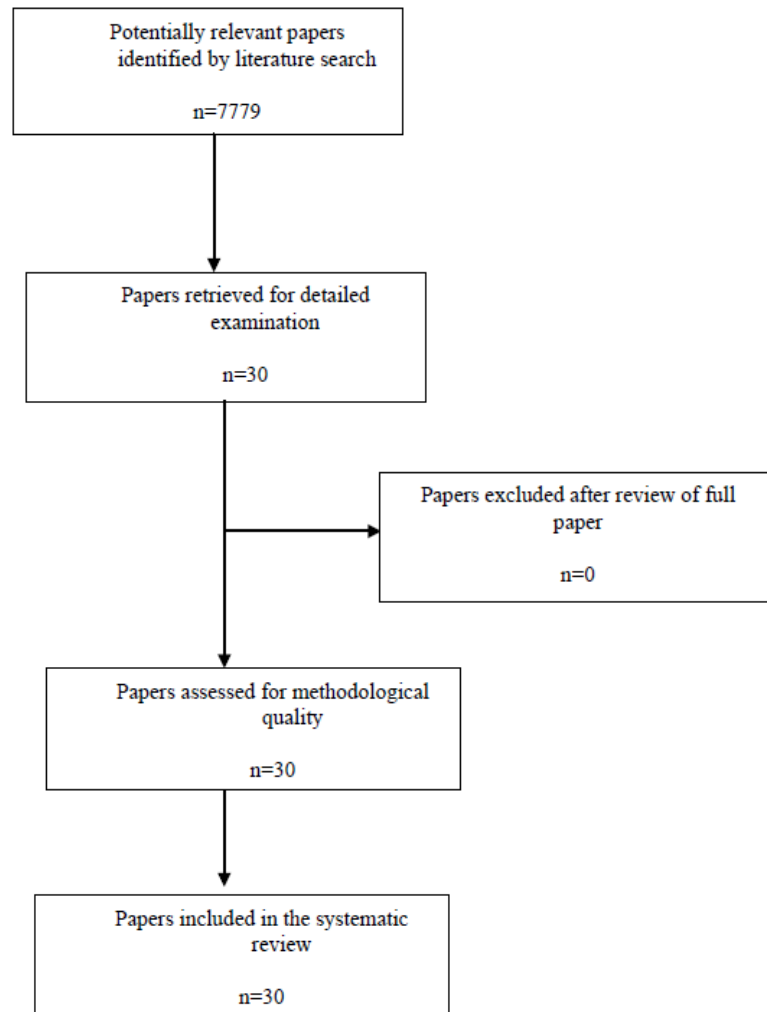
Spiegelberg's framework refers to transcendental philosophical phenomenology. Spiegelberg speaks about reductive phenomenology that is implicitly present in all other stages of the phenomenological approach. Reductive phenomenology refers to the bracketing or suspension of the natural attitude. Particular phenomena immediately given are investigated as given. The goal of investigation is to describe particular phenomena as immediately intuited. As phenomenology is the attempt to find the essential structures of the phenomena and the essential relationships within and among them, specific concrete examples are used only in order to facilitate insight into essences. Exploration of essences is based on free variation in the imagination. On the basis of free variation it is determined what is essential and what is accidental. The ways in which phenomena appear are identified and the dynamic transition from first impressions to a full picture of phenomena is examined. Hermeneutic phenomenology was not explicitly used nor rejected by Husserl. Hermeneutic phenomenology component of the framework (seeks access to meanings of the phenomena which are not directly perceived) was not used in the methodological critique.

## Chapter 3: Results

### *Description of Studies*

30 full text papers were critically appraised. Given the methodological focus of the review no papers were excluded after critical appraisal. Details of included studies are provided in Appendix 4.

Figure 1. Selection flowchart



## *Characteristics of the included studies*

### *Types of participants*

Included studies considered adults who receive preventive, screening, diagnostic, treatment or rehabilitation interventions regardless of healthcare setting and type and specifics of interventions/procedures. For details regarding the types of participants see Tables 1 to 3 from Appendix 4.

Some studies included only women (for example pregnant women) or only men (for example men who received prostate specific antigen test results). Caucasians, African Americans, and Hispanics were included in studies. Age of participants varied from 19 to 87.

Patients with different diseases or conditions were examined in included studies, for example:

- patients who had received equivocal prostate specific antigen test results
- patients who had undergone liver transplantation
- participants in a cardiac rehabilitation program
- women diagnosed with breast cancer, and received one or more of the surgery, chemotherapy or radiation treatments
- patients who received unilateral lower extremity amputation
- patients who received first-time allogenic kidney transplant
- patients subjected to elective coronary bypass surgery
- patients who had completed cognitive screening tests while hospitalised
- patients diagnosed with cervical cancer, who had completed a course of internal radiation
- women who had undergone a breast diagnostic investigation and had received a definitive diagnosis.

### ***Phenomena of interest***

Varied phenomena were examined in the included studies. For details regarding phenomena of interest for all included studies see Tables 1 to 3 from Appendix 4.

Some examples of phenomena of interest:

- experience of prenatal diagnostic procedures used to determine foetal status performed after an elevated maternal serum-fetoprotein screening result
- experience of receiving equivocal results when participating in prostate specific antigen testing
- experience of cardiac therapy for men with coronary artery disease
- the experience of African American women living with breast cancer following the primary diagnosis and while undergoing initial treatment
- experience of undergoing surgical treatment of colorectal cancer liver metastasis
- experience of acupuncture as a part of the treatment for substance abuse
- the experience of the cognitive screening test
- the experience of undergoing internal radiation for cervical cancer
- experience of autologous haematopoietic stem cell transplant
- the experience of ginger compresses for osteoarthritis
- the experience of women undergoing 2<sup>nd</sup> trimester pregnancy interruption for foetal anomalies.

### ***The objectives of the research***

The objectives of the research were explicitly specified in most of the included studies. Some examples of research objectives:

- “To explore the lived experiences of a sample of 16 pregnant women who obtained an elevated maternal serum alpha-fetoprotein screening and had further prenatal diagnostic procedures to determine foetal status” Altender et al 1998, page 180
- “The purpose of the study was to acquire a deeper understanding of patients’ lived experiences of eating after surgical esophagectomy” Jaromahum & Fowler 2010, page 96

- “To describe the experiences of African American women living with breast cancer following the primary diagnosis and while undergoing initial treatment” Lackey et al 2001, page 519
- “The aim of this study was to describe and understand the lived experience of people with lower extremity amputation” Liu et al 2010, page 2152
- “The purpose of this study was to gain insight into the lived experience of a group of patients who experienced major surgery for the treatment of CRC liver metastases” McCahill & Hamel-Bissell 2009, page 66
- “the purpose of this study was to uncover the lived experience of cardiac therapy for men with coronary artery disease” Keaton & Pierce 2000, page 64
- “The purpose of this study was to describe the experiences of women undergoing interruption of pregnancy in the 2nd trimester” Bryar 1997, page 561
- “The purpose of this study was to better understand the experience of low-dose rate brachytherapy for women with gynecologic cancer” Velji & Fitch 2001, page 744
- “The aim of the study was to explore and describe the perceptions and experiences of women undergoing restorative proctocolectomy” Notter & Burnard 2006, page 150.

### ***The research questions***

The research questions were explicitly specified in some of the included studies: Altender et al 1998, Keaton & Pierce 2000, Lackey et al 2001, and Bryar 1997. For example in Altender et al 1998 the question was: What is the lived experience of women for whom prenatal diagnostic studies resulted from elevated MSAFP screening? Keaton & Pierce 2000 asked What is it like being a man recently diagnosed with coronary artery disease and experiencing cardiac therapy? Lackey et al 2001 used the question: What is the lived experience of the initial discovery, diagnosis, and treatment of breast cancer for African American women?

There was no explicit research question in all other studies.

### ***The Research Methodology***

Phenomenology was the research methodology in all included studies. Authors stated the methodology in an explicit way or provided a description of the methodology compatible with phenomenology.

Altender et al 1998 used the 'qualitative method of phenomenology'. Archer and Hayter 2006 adopted 'a phenomenological approach'. Dudley et al 2007 used 'a phenomenological design'. Jaromahum and Fowler 2010 used a 'phenomenology approach'. Keaton and Pierce 2000 performed a 'phenomenological inquiry'. Liu et al 2010 used a 'phenomenological research design'.

### ***Data Collection Methods***

In all included studies interviews were used as data collection methods. Some authors used In-depth interviews. Some authors mentioned semi-structured interviews.

### ***Data Analysis Methods***

Studies used Colaizzi's approach, Giorgi's approach or a descriptive phenomenological approach. Colaizzi's analysis method was used for example in studies by Altender et al 1998, Archer and Hayter 2006, Dudley et al 2007, Jaromahum and Fowler 2010, Keaton and Pierce 2000, Sintay 2011, Lackey et al 2001, Liu et al 2010, McCahill and Hamel-Bissell 2009, Wall et al 2011, Ward-Smith 1997, and Wiederhold, Langer and Landenberg 2011.

Giorgi's analysis method was used for example in studies by Backstrom et al 2006, Bernstein 2000, Billhult and Maatta 2009, Herlin and Wann-Hansson 2010, Jonsson et al 2011, Krohne et al 2011, Logan et al 2006, Notter and Burnard 2006, Persson and Hellstrom 2002, Therkleson 2010, Therkleson and Sherwood 2004, Velji and Fitch 2001, and Worster and Holmes 2008.

A descriptive phenomenological approach was used in studies by Bryar 1997, Forsberg et al 2000, and Jonsen, et al 1998.

### ***Results - Findings and illustrations from included studies***

Findings and illustrations extracted from included studies are presented in Appendix 5.

### ***Results of critical appraisal***

#### ***Tabular presentation of the results of critical appraisal of included studies***

Study column refers to the authors' names and publication year for included studies.

Q1 column refers to the answer to question 1 from standardized JBI QARI critical appraisal instrument ("Is there congruity between the stated philosophical perspective and the research methodology?").

Q2 column refers to the answer to question ("Is there congruity between the research methodology and the research question or objectives?").

Q3 column refers to the answer to question 3 ("Is there congruity between the research methodology and the methods used to collect data?").

Q4 column refers to the answer to question 4 ("Is there congruity between the research methodology and the representation and analysis of data?").

Q5 column refers to the answer to question 5 ("Is there congruity between the research methodology and the interpretation of results?").

Q6 column refers to the answer to question 6 ("Is there a statement locating the researcher culturally or theoretically?").

Q7 column refers to the answer to question (“Is the influence of the researcher on the research, and vice-versa, addressed?”).

Q8 column refers to the answer to question (“Are participants, and their voices, adequately represented?”).

Q9 column refers to the answer to question 9 (“Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?”).

Q10 column refers to the answer to question 10 from standardized JBI QARI critical appraisal instrument (“Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?”).



Table 10. Results of critical appraisal of included studies using Colaizzi's analysis method

<b>Study</b>	<b>Q1</b>	<b>Q2</b>	<b>Q3</b>	<b>Q4</b>	<b>Q5</b>	<b>Q6</b>	<b>Q7</b>	<b>Q8</b>	<b>Q9</b>	<b>Q10</b>
Altender, Kenner, Greene, and Pohorecki, 1998	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Archer and Hayter, 2006	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Dudley, Chaplin, Clifford, and Mutimer, 2007	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Jaromahum and Fowler, 2010	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Keaton and Pierce, 2000	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Sintay, 2011	Y	Y	Y	Y	Y	N	N	N	Y	Y
Lackey, Gates, and Brown, 2001	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Liu, Williams, Hsueh-Erh Liu, and Chien, 2010	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
McCahill and Hamel-Bissell, 2009	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Wall, Glenn, and Poole, 2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Ward-Smith, 1997	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Wiederhold, Langer and Landenberg, 2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Y = Yes; N = No; U = Unclear; NA = Not Applicable

Table 11. Results of critical appraisal of included studies using Giorgi's analysis method

<b>Study</b>	<b>Q1</b>	<b>Q2</b>	<b>Q3</b>	<b>Q4</b>	<b>Q5</b>	<b>Q6</b>	<b>Q7</b>	<b>Q8</b>	<b>Q9</b>	<b>Q10</b>
Backstrom, Wynn, and Sorlie, 2006	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Bernstein, 2000	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Billhult and Maatta, 2009	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Herlin and Wann-Hansson, 2010	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Jonsson, Stenberg and Frisman, 2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Krohne, Slettebo and Bergland, 2011	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Kwok-wei So and , Chui, 2007	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Logan, Hackbusch-Pinto and De Grasse, 2006	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Notter and Burnard, 2006	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Persson and Hellstrom, 2002	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Stephens, 2005	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Therkleson, 2010	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Therkleson and Sherwood, 2004	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Velji and Fitch, 2001	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Worster and Holmes, 2008	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Y = Yes; N = No; U = Unclear; NA = Not Applicable

Table 12. Results of critical appraisal of included studies using other\* analysis methods

\*not Giorgi's or Colaizzi's analysis method

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Bryar, 1997	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Forsberg, Backman and Moller, 2000	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Jonsen, Athlin and Suhr, 1998	Y	Y	Y	Y	Y	N	N	Y	Y	Y

Y = Yes; N = No; U = Unclear; NA = Not Applicable

***Results of the methodological critique***

The intention was to provide a narrative summary of the included studies as a single, integrated 'case'; thus, the summary refers to the entire set of studies. Analysis of the text of all included studies (using the Spiegelberg framework) resulted in an aggregative synthesis across these studies.

Spiegelberg describes six 'existential uses of phenomenology': descriptive phenomenology, essential phenomenology, phenomenology of appearances,

constitutive phenomenology, reductive phenomenology and hermeneutic phenomenology (Spiegelberg 1975, p.57-70). The seven 'steps of the phenomenological method' as presented by Spiegelberg are: investigating particular phenomena; investigating general essences; apprehending essential relationships among essences; watching modes of appearing; watching the constitution of phenomena in consciousness; suspending belief in the existence of the phenomena; interpreting the meaning of the phenomena (Spiegelberg 1982, p.681-715). Hermeneutic phenomenology was not explicitly used nor rejected by Husserl. Hermeneutic phenomenology component of the framework (seeks access to meanings of the phenomena which are not directly perceived) was not used in the methodological critique.

### ***The quality of included studies when assessed using Spiegelber's framework***

#### ***Transcendental Phenomenology***

*Is there consistency between the Husserlian phenomenological approach and the stated phenomenological philosophical perspective as stated, reported or described by the authors of the included studies?*

The philosophical perspectives are presented in vague and imprecise terms in included studies. Clearly what is presented in included studies is inconsistent with Husserlian transcendental phenomenology.

According to Husserl what is directly intuited in my consciousness in my first person experience is a valid source of knowledge for science and should be examined and considered as it is. This position contrasts with Giorgi' position that only accounts from others are valid source of knowledge because the community of researchers perceives first persons account as purely subjective accounts of private experiences. Included studies considered only accounts from others.

Husserlian phenomenology is an eidetic transcendental phenomenology. Eidetic reduction is the approach used in transcendental phenomenology to make the transition from worldly facts to universal ideal essences. This aspect is not presented in the included studies.

Husserlian phenomenology is an exploration of what is essential, what is universal and necessary, what is a priori. For Husserl the essence is not about empirical realities. These essences are not to be discovered in the world of particulars but in the pure transcendental consciousness. For Husserl the essence is about possibility independent of empirical experience. This aspect is not presented in the included studies. Authors speak about essence but the essence in their presentations is not the ideal transcendental universal indicated by Husserl. For authors essence is a kind of empirical generality. There is no indication from the included studies that authors intended to explore essences in the Husserlian sense. It seems that authors intended what is typical or common, not what is universal or ideal.

There is no indication from the included studies that authors are aware of the differences between transcendental philosophical phenomenology and phenomenological psychology. Also, there seems to be a lack of awareness that Giorgi's descriptive phenomenology was inspired by Husserlian phenomenological psychology.

The distinction between phenomenology of the natural attitude and the transcendental phenomenology is not presented in included studies. Authors of the included studies seem to implicitly accept that phenomenology is phenomenology of natural attitude.

### ***Reductive phenomenology***

Bracketing or suspension of the natural world is implied in all stages of the transcendental phenomenological inquiry. The natural attitude is the implicit prejudice/belief that the world exists independent of any human person experiencing it. In included studies this point regarding natural attitude as

explored in transcendental phenomenology is missed. There is no discussion of the fact that natural attitude refers to this presupposition of the existence of the objective world. In transcendental phenomenology I must return to the immediate original data of my consciousness, ignoring the 'natural' implicit assumption of the existing world. In included studies the approach is to reject theories, explanations or interpretations prior to the conduct of the research. It is implied in these studies that natural attitude refers to these prejudices or pre-conceptions. There is no indication that the interpretation of the natural attitude is similar with the interpretation used in transcendental phenomenology.

### ***Investigating particular phenomena***

*Is there consistency between the Husserlian phenomenological approach and the data collection methods as stated, reported or described by the authors?*

In all included studies inquiry was performed in the natural world and particular phenomena were explored through accounts obtained from others. In transcendental phenomenology the inquiry is a first person inquiry of the transcendental consciousness after the suspension of the natural attitude. In transcendental phenomenology I am the researcher. I describe my experience. In included studies all descriptions were obtained through interviews from other persons. In included studies the experience is the experience of others, never an 'I' experience. Authors obtained descriptions from others. There is clear inconsistency with the traditional transcendental phenomenology as proposed by Husserl. Spiegelberg contended that the transcendental phenomenological approach is a first person approach but proposed an extension of traditional phenomenology by suggesting that a vicarious experience of a phenomenologist exploring others' experiences is possible and not in contradiction to the spirit of phenomenology. If Spiegelber's proposal of extension of phenomenological inquiry through vicarious experience is accepted as valid then the empirical approach used in included studies is consistent with a variation of phenomenology. This aspect is not discussed in the included studies. For the authors the idea that traditional phenomenology is a first person inquiry seems to

not constitute an issue. Even if Spiegelberg position is unique authors seems to ignore this as a justification for their own approach. Amedeo Giorgi justified the use of accounts from others using as one argument Spiegelber's proposal.

### ***Descriptive phenomenology***

In transcendental phenomenology I have to describe what is given in my experience as experienced in direct first person intuition without inductive or deductive manipulations. It seems that this aspect of pure phenomenological description is not recognized by the authors of the included studies. In included studies induction and deduction are used to manipulate the descriptive data obtained from others.

### ***Essential phenomenology***

*Is there consistency between the Husserlian phenomenological approach and the research objectives/questions as stated by the authors?*

The goal of transcendental phenomenology is to provide absolute knowledge, descriptions of essences understood as universal a priori necessary characteristics. The included studies aimed to explore the experiences in natural world of specific groups of patients in order to generate local knowledge without any aspiration to absolute certainty. There is evident inconsistency. Concrete examples were examined in included studies but it seems that the intention was never to explore essences as conceived by Husserl. Rather, concrete examples were explored in order to provide a summary of them.

Included studies intended to examine the human mundane experience without any claims of certainty. While not acknowledged as such the approach used in included studies is close to phenomenological psychology but is inconsistent with transcendental phenomenology.

*Is there consistency between the Husserlian phenomenological approach and the data analysis methods as stated, reported or described by the authors?*

In transcendental phenomenology the variation in imagination or phantasy is used in order to separate what is essential from what is accidental. The intuited essence is represented by what is universal and a priori necessary. These phenomenological essences are ideal, not about empirical world, not about collections of facts. In included studies authors identifies what is typical, common, or frequent. These are not essential, universal characteristics. There is inconsistency of the included studies with the transcendental phenomenology.

From the included studies there is no evidence that a procedure that mirrors the free variation in imagination was performed. It seems that themes were identified through a compare and contrast procedure and classification procedures based on similarity/dissimilarity of meaning. Free variation in imagination is used in transcendental phenomenology to discern what is essential or necessary and what is accidental. In included studies there was no evidence of such clarification. Descriptions from concrete examples were obtained but there was no indication that authors separated the essential in the Husserlian sense of the term. Some authors presented the essence of a specific phenomenon but this appears more like a summary of common elements and not a distillate of what is necessary and sufficient.

In included studies authors explored communalities not what is identical in variation of individuals or circumstances. The procedures used to construct themes from individual accounts are not a reflection of the phantasy variations used in transcendental phenomenology. It seems that in included studies there is no concern for discovering what makes an experience to be that experience not a different one.

*Is there consistency between the Husserlian phenomenological approach and the findings and illustrations extracted from included studies?*



It is evident that findings and illustrations refers to worldly facts. There is inconsistency between the search for universal invariants in philosophical transcendental phenomenology and the exploration of mundane facts as performed in the included studies.

*Is there consistency between the Husserlian phenomenological approach and the conclusions and implications for practice as stated, reported or described by the authors?*

Transcendental phenomenology aims absolute knowledge. This knowledge is about ideal possibilities. Phenomenological statements are not about empirical facts. There is contradiction between the aims of transcendental phenomenology and the conclusions and implications for practice as stated, reported or described by the authors of the included studies.

### ***Phenomenology of appearances***

Phenomena were examined from different perspectives, an approach that respects the idea of phenomenology of appearances.

### ***Constitutive phenomenology***

In most of the included studies authors included descriptions of the transitions from different impressions at specified moments to other impressions at later moments but no explicit presentation of the phenomenological transition from first vague impressions to full clear pictures was found.

### ***Summary***

There is inconsistency between the Husserlian phenomenological approach and the content of Husserlian phenomenological research studies.

The inconsistencies between the Husserlian approach and the included studies are presented in a comparative table of the essential characteristics.

Table 13. Comparison of the essential characteristics of Husserlian approach and the included studies

	Husserlian phenomenological approach (Husserlian Transcendental Phenomenology)	Content of Husserlian phenomenological research studies
Essential Characteristics	<ul style="list-style-type: none"> <li>• First person inquiry</li> <li>• Suspension of the natural attitude</li> <li>• Transcendental consciousness</li> <li>• Essences as a priori, universal, necessary and sufficient characteristics</li> <li>• essences refer to ideal possibilities</li> </ul>	<ul style="list-style-type: none"> <li>• Accounts from others</li> <li>• Others provide description in natural attitude</li> <li>• Mundane worldly consciousness</li> <li>• Themes and Conclusions about communalities</li> <li>• themes and conclusions refers to facts in natural world</li> </ul>

## **Chapter 4: Discussion and Conclusions**

### ***Discussion***

It is clear that examined studies are not consistent with the core aspects of the Husserlian transcendental phenomenology. It is argued that in reality it is impossible to practice transcendental phenomenology as research practice and that transcendental phenomenology is a philosophy not a research approach. Transcendental phenomenology is a philosophy but is also a research practice because there is a systematic approach of inquiry and the results are available for public inter-subjective examination.

This review was inspired by previous critique of phenomenological research. Our results are similar with previous ones with regards to the inconsistencies between transcendental phenomenology and phenomenological research as practiced by qualitative researchers. However, a phenomenology of natural attitude is possible and not in contradiction to the broad scope of Husserlian phenomenology. If a phenomenology of natural attitude inspired by the phenomenological psychology is practiced then this should be acknowledged and in this way confusions with transcendental phenomenology approach are avoided.

Exploration of others' experiences is consistent with Spiegelber's vicarious experience. It has to be accepted that for practical reasons in health sciences is easier to collect data from others instead of training participants to become phenomenological researchers ready to perform descriptions from first person perspective. This data collection approach is a creative adaptation to the specific realities in health sciences.

Suspension of the fundamental implicit presupposition of the natural world is a difficult concept and procedure. Qualitative researchers transformed in a creative way the suspension of the natural attitude in a suspension of prejudices and prior knowledge.

The free variation procedure of transcendental phenomenology was replaced with a compare and contrast approach for meaning identification. Universal essence as a priori necessary conditions discovered by transcendental consciousness was replaced by qualitative researchers with themes, categories and sometimes with summary statements regarding essential characteristics of empirical facts. Essences discovered in empirical research are at best empirical generalizations but even such results are useful as tools for clarification.

These adaptations are justified by the circumstances of the qualitative research as applied in health sciences. If these adaptations and transformations are understood there is no harm.

### ***Limitations of the review***

Only studies published in English were included. The review was limited to the published studies; theses or dissertations were excluded. A limited number of databases were searched.

### ***Conclusions***

There is inconsistency between the Husserlian phenomenological approach and the content of Husserlian phenomenological research studies.

There is clear inconsistency between the Husserlian transcendental philosophical phenomenology and the phenomenological research approaches used in included studies but the creative adaptation and transformation of phenomenological ideas and approaches for the specific purposes of qualitative scientific research are justified and the results of research are useful if the circumstances and consequences of these adaptations and transformations are understood.

### ***Implications for Practice***

Users of qualitative research should be aware of the differences between transcendental phenomenology and qualitative research. Results of qualitative research are context specific and not universal eidetic phenomenological truths.

### ***Implications for Future Methodological Research***

This review focused on studies that examined adult patients' experiences of preventive, screening, diagnosis, treatment or rehabilitation interventions/procedures. Only a small sample of 30 studies was examined as a 'case'. Future reviews may explore other age groups and other types of experiences. Only through such empirical research is possible to discover the reality of phenomenological research in health sciences.

### ***Implications for Practice of Qualitative Research***

Included studies proved that this kind of qualitative research is valuable. Researchers should understand the differences between transcendental phenomenology and qualitative research. If phenomenology of natural attitude is performed this should be explicitly stated. The meaning of terms and the content of methods used should be explicitly clarified in order to avoid confusion between transcendental phenomenology and phenomenology of the natural attitude.

### ***Recommendations for future practice of qualitative research***

#### ***Husserlian transcendental approach***

Husserlian transcendental phenomenology is not only a philosophy but also a scientific inquiry.

If the intention is to perform transcendental phenomenological inquiry then researchers should follow the guidance from Husserl's publications or the explicit guidance provided by modern scholars such as Spiegelberg (1975; 1982) and Reeder (2010).

If the intention is to perform transcendental phenomenological inquiry and if the intention is to work collaboratively, doing group phenomenology in order to enhance the practice of phenomenological skills and to use the opportunities of

inter-subjective verification then the phenomenological workshop approach proposed by Spiegelberg is recommended (Spiegelberg 1975, pages 24-31).

If the intention is to perform phenomenology through vicarious experience then the phenomenological approach proposed by Spiegelberg is recommended (Spiegelberg 1975, pages 35-53, Phenomenology through vicarious experience).

***Eidetic approach from first person perspective in natural attitude***

If the intention is to perform phenomenology from first person perspective in the natural attitude then the guidance proposed by Embree is recommended (Embree 2011).

***Proposed Checklist for Peer Review Questions for Husserlian phenomenological qualitative research studies (Guidance Criteria)***

These guidance criteria may be used by peer reviewers of submitted Husserlian phenomenological research papers as a first checklist for the assessment of the consistency between the Husserlian approach and the content of the article. This is an additional peer review checklist to be used in addition to the usual peer review checklists/instruments.

Proposed questions:

- *Is there consistency between the Husserlian phenomenological approach and the philosophical perspective?*
- *Is there consistency between the Husserlian phenomenological approach and the research objectives/questions?*
- *Is there consistency between the Husserlian phenomenological approach and the data collection methods?*
- *Is there consistency between the Husserlian phenomenological approach and the data analysis methods?*
- *Is there consistency between the Husserlian phenomenological approach and the findings and conclusions?*

## ***Appendix 1: Details of the search strategy***

### *Details of the search strategy used in PubMed*

Filters activated: Publication date from 1960/01/01 to 2012/09/30, Humans, English, Adult: 19+ years

#23 Search #21 AND #22

1094

#22 Search #16 OR #17 OR #18 OR #19 OR #20

#21 Search #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15

<u>#20</u>	Search rehabilitation Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>144449</u>
<u>#19</u>	Search treatment Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>2205369</u>
<u>#18</u>	Search diagnostic Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>2323614</u>
<u>#17</u>	Search screening Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>1668371</u>
<u>#16</u>	Search prevention Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>280567</u>
<u>#15</u>	Search lived experiences Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>936</u>
<u>#14</u>	Search clients' experiences Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>199</u>
<u>#13</u>	Search patients' experiences Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>2720</u>
<u>#12</u>	Search phenomenological description Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>122</u>
<u>#11</u>	Search descriptive phenomenology Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>70</u>
<u>#10</u>	Search Colaizzi Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>69</u>
<u>#9</u>	Search Giorgi Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>827</u>

<u>#8</u>	Search Husserl Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>30</u>
<u>#7</u>	Search Husserlian phenomenology Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>5</u>
<u>#6</u>	Search phenomenological Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>2936</u>
<u>#5</u>	Search phenomenology Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; English; Adult: 19+ years	<u>1501</u>
<u>#4</u>	Search phenomenology Filters: Publication date from 1960/01/01 to 2012/09/30; Humans; Adult: 19+ years	<u>1667</u>
<u>#3</u>	Search phenomenology Filters: Publication date from 1960/01/01 to 2012/09/30; Humans	<u>3768</u>
<u>#2</u>	Search phenomenology Filters: Publication date from 1960/01/01 to 2012/09/30	<u>4849</u>
<u>#1</u>	Search phenomenology	<u>5156</u>

*Details of the search strategy used in CINAHL with full text (EBSCO HOST)*

English language Publication date from 1960/01/01 to 2012/09/30

S1 phenomenology

3,306

S3 phenomenology (Publication date from 1960/01/01 to 2012/09/30)

3,212

S4 phenomenological

9,293

S5 Husserlian phenomenology

37

S6 Husserl

57

S7 Giorgi

118

S8 Colaizzi

116

S9 descriptive phenomenology

514



S10 phenomenological description  
440

S11 patients' experiences  
11,126

S12 clients' experiences  
1,477

S13 lived experiences  
2,797

S14 prevention  
296,751

S15 screening  
57,415

S16 diagnostic  
56,769

S17 treatment  
325,930

S18 rehabilitation  
91,630

S19 prevention OR screening OR diagnostic OR treatment OR rehabilitation  
706,315

S20 phenomenology OR phenomenological OR Husserlian phenomenology  
OR  
Husserl OR Giorgi OR Colaizzi OR descriptive phenomenology OR  
phenomenological description OR patients' experiences OR clients' experiences  
OR lived experiences  
23,084

S21 (prevention OR screening OR diagnostic OR treatment OR rehabilitation)  
AND  
(phenomenology OR phenomenological OR Husserlian phenomenology OR  
Husserl OR Giorgi OR Colaizzi OR descriptive phenomenology OR  
phenomenological description OR patients' experiences OR clients' experiences  
OR lived experiences)  
5,685

## Appendix 2: Critical Appraisal Instrument

### JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer ..... Date .....

Author ..... Year ..... Record Number .....

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:  Include  Exclude  Seek further info.

Comments (Including reason for exclusion)

---



---



---

### **Appendix 3: Data Extraction Instrument**

#### **JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year .....

Journal ..... Record Number .....

#### **Study Description**

Methodology

---

---

Method

---

---

Phenomena of interest

---

---

Setting

---

---

Geographical

---

---

Cultural

---

---

Participants

---

---

Data analysis

---

---

Authors Conclusions

---

---

Comments

---

---

Complete

Yes

No

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes

No

## Appendix 4: Included Studies

Table 1. Summary of the characteristics of included studies using Colaizzi's analysis method

<b>Study</b>	<b>Participants</b>	<b>Phenomena of interest</b>	<b>Data Collection Methods</b>	<b>Data Analysis Methods</b>
Altender, Kenner, Greene, and Pohorecki, 1998	16 pregnant women, age range from 19 to 37 years, mean age of 26.4 years; twelve Caucasians, three African Americans, one Hispanic;	experience of prenatal diagnostic procedures used to determine foetal status performed after an elevated maternal serum-fetoprotein screening result	Interviews	Colaizzi's analysis method plus procedural additions
Archer and Hayter, 2006	Seven men, age range from 50 to 69 years, who had received equivocal prostate specific antigen test results	experience of receiving equivocal results when participating in prostate specific antigen testing	In-depth interviews	Colaizzi's analysis method
Dudley, Chaplin, Clifford, and Mutimer, 2007	Eight patients who had undergone liver transplantation for hepatitis C virus infection; six men, two women, age range at the time of liver transplantation from 44 to 60 years; all Caucasians; first transplant for all patients;	the experience of quality of life after liver transplantation	In-depth interviews	Colaizzi's analysis method
Jaromahum and Fowler, 2010	Seven patients, two women (age range from 35 to 61 years), five men (age range from 58 to 80 years), who had undergone esophagectomy for cancer (six patients) or for a benign stricture (one patient);	experiences of eating after surgical esophagectomy	Interviews	Colaizzi's analysis method

Keaton and Pierce, 2000	Five men, 60 to 70 years old, diagnosed with coronary artery disease, who actively participated in a cardiac therapy program	experience of cardiac therapy for men with coronary artery disease	Interviews	Colaizzi's analysis method
Kennard M. Sintay, 2011	Seven patients, three women, four men, participants in a cardiac rehabilitation program; age range 21 to 77 years, median age of 49 years;	experiences of cardiac rehabilitation	Interviews	Colaizzi's analysis method
Lackey, Gates, and Brown, 2001	13 African American women, age range from 30 to 66 years; diagnosed with breast cancer, and received one or more of the surgery, chemotherapy or radiation treatments;	the experience of African American women living with breast cancer following the primary diagnosis and while undergoing initial treatment	Interviews	Colaizzi's analysis method
Liu, Williams, Hsueh-Erh Liu, and Chien, 2010	22 patients who received unilateral lower extremity amputation; 68% of participants were men; mean age 70.6 years; age range from 56 to 84 years;	experience of Taiwanese people with lower extremity amputation, from the pre-amputation phase to six months after surgery	Semi-structured interviews	Colaizzi's analysis method
McCahill and Hamel-Bissell, 2009	Seven men and five women, mean age of 63 years, age range from 43 to 75 years, previously treated with both chemotherapy and major surgery for the treatment of colorectal cancer liver metastases	experience of undergoing surgical treatment of colorectal cancer liver metastasis	Interviews	Colaizzi's analysis method
Wall, Glenn, and Poole, 2011	15 men, 16 women, patients diagnosed with non-Hodgkin lymphoma; mean age of 56 years, age range from 29 to 79 years;	experience during the period leading up to the diagnosis of non-Hodgkin lymphoma	In-depth interviews	Colaizzi's analysis method
Ward-Smith, 1997	Eight patients with primary malignant brain tumors	experience of undergoing the	Interviews	Colaizzi's analysis

		Gamma Knife type of stereotactic radiosurgery for malignant brain tumors		method
Wiederhold, Langer and Landenberg, 2011	10 patients, 4 women, 6 men, who received first-time allogenic kidney transplant; average age of 53.6 years, age range from 41 to 66 years;	experience immediately following a first-time allogenic kidney transplant before being discharged from the hospital	Semi-structured interviews	Colaizzi's analysis method

Table 2. Summary of the characteristics of included studies using Giorgi's analysis method

<b>Study</b>	<b>Participants</b>	<b>Phenomena of interest</b>	<b>Data Collection Methods</b>	<b>Data Analysis Methods</b>
Backstrom, Wynn, and Sorlie, 2006	Nine patients who had been subjected to elective coronary bypass surgery, seven men, two womwn, white, aged 50-70 years	experience of coronary bypass surgery care	Interviews	Giorgi's analysis method
Bernstein, 2000	Eight substance abusers, four men, for women, ages range from 28 to 51 years; seven	experience of acupunctre as a part of the treatment for substance abuse	Interviews	Giorgi's analysis method

	Caucasian, one Hispanic;			
Billhult and Maatta, 2009	Eight patients with severe manifest anxiety at the time of inclusion in the study, seven women, one man, mean age of 48 years, range from 33 to 65 years;	experience of receiving massage	Interviews	Giorgi's analysis method
Herlin and Wann- Hansson, 2010	Nine patients, undergoing haemodialysis treatment, five men, four women, mean age of 37 years, range from 30 to 44 years old;	experience of dependence on haemodialysis treatment	Interviews	Giorgi's analysis method
Jonsson, Stenberg and Frisman, 2011	13 patients, age range from 52 to 87 years old;	experience of the early postoperative period after colorectal cancer surgery	Interviews	Giorgi's analysis method
Krohne, Slettebo and Bergland, 2011	18 patients who had completed cognitive screening tests while hospitalised; 9 men, 9 women, 65 years old or older;	the experience of the cognitive screening test	Interviews	A modified version of Giorgi's analysis method
Kwok-wei So and	Eight female patients, diagnosed	the experience of undergoing internal radiation	Interviews	Giorgi's analysis method



Chui, 2007	with cervical cancer, who had completed a course of internal radiation; age range from 38 to 72 years;	for cervical cancer		
Logan, Hackbusch-Pinto and De Grasse, 2006	20 Caucasian women who had undergone a breast diagnostic investigation and had received a definitive diagnosis	experience of spirituality for women who undergone a breast diagnostic experience	Interviews	Giorgi's analysis method
Notter and Burnard, 2006	50 women	experience of undergoing restorative proctocolectomy	Interviews	Giorgi's analysis method
Persson and Hellstrom, 2002	Nine patients, five men, 4 women; age range from 44 to 67 years;	experiences in the early weeks after recovery from stoma surgery	Interviews	Giorgi's analysis method
Stephens, 2005	Five patients, two men, three women, mean age of 53.8 years, age range from 38 to 63 years;	experience of autologous haematopoietic stem cell transplant	Interviews	Giorgi's analysis method
Therkleson, 2010	10 adults who had been diagnosed with osteoarthritis for at least 1 year; over 45 years old;	the experience of ginger compresses for osteoarthritis	Interviews	An adaptation of Giorgi's analysis method

Therkleson and Sherwood, 2004	Three men, four women, middle-class Caucasians, age range from 21 to 54 years; patients with no known diagnosed mental illness, physical disability or drug addiction;	experience of receiving a ginger compress as applied by anthroposophically trained nurses	Interviews	An adaptation of Giorgi's analysis method
Velji and Fitch, 2001	10 women with the diagnosis of cancer of the endometrium or cervix who had completed a course of external radiation treatment and who were receiving low-dose rate brachytherapy for the first time; age range from 36 to 75 years, age mean of 59.2 years;	the experience of low-dose rate brachytherapy for gynaecological cancer	Interviews	Giorgi's analysis method
Worster and Holmes, 2008	Twenty Caucasian patients, 10 men, 10 women, age range 50 to 82 years, who had undergone surgery for	the experiences of preoperative period for patients who had undergone surgery to remove a portion of bowel with end-to-end anastomosis	Interviews	Giorgi's analysis method

	colorectal cancer			
--	-------------------	--	--	--

Table 3. Summary of the characteristics of included studies using other\* analysis methods

\*not Giorgi's or Colaizzi's analysis method

<b>Study</b>	<b>Participants</b>	<b>Phenomena of interest</b>	<b>Data Collection Methods</b>	<b>Data Analysis Methods</b>
Bryar, 1997	three women ages 30 to 40 years, married, white, middle class college graduates	the experience of women undergoing 2 <sup>nd</sup> trimester pregnancy interruption for fetal anomalies	Interviews	A descriptive phenomenological approach
Forsberg, Backman and Moller, 2000	12 patients, nine women, three men; mean age of 51 years, range from 24 to 63 years; first transplant; mentally lucid and orientated at the time of study; one student, four on disability pension;	experiences of having a liver transplant	Interviews	A descriptive phenomenological approach
Jonsen, Athlin and Suhr, 1998	11 liver transplant FAP patients, nine men and two women, mean age 46	experiences of familial amyloidotic polyneuropathy (FAP) and of the liver transplantation	Interviews	A descriptive phenomenological approach

	years, range 25 to 59 years;			
--	------------------------------------	--	--	--

Table 4. Research objectives for the included studies using Colaizzi's method

<b>Study</b>	<b>Research objectives</b>
Altender, Kenner, Greene, and Pohorecki, 1998	<p>“To explore the lived experiences of a sample of 16 pregnant women who obtained an elevated maternal serum alpha-fetoprotein screening and had further prenatal diagnostic procedures to determine fetal status” Altender et al 1998, page 180</p> <p>“The purpose of this qualitative study was to describe the actual experiences of women who have undergone prenatal diagnostic studies” Altender et al 1998, page 184</p>
Archer and Hayter, 2006	<p>“This study aims to describe the experiences of men living through an equivocal PSA result following PSA screening and discuss how this understanding adds to the debate about the health screening agenda” Archer &amp; Hayter 2006, page 126</p>
Dudley, Chaplin, Clifford, and Mutimer, 2007	<p>“We aimed to identify factors, described by patients, that may influence quality of life after liver transplantation” Dudley et al 2007, page 1300</p>
Jaromahum and Fowler, 2010	<p>“The purpose of the study was to acquire a deeper understanding of patients' lived experiences of eating after surgical esophagectomy” Jaromahum &amp; Fowler 2010, page 96</p> <p>“The aim of this study was to describe patients' experiences of eating after esophagectomy” Jaromahum &amp; Fowler 2010, page 96</p>
Keaton and Pierce, 2000	<p>“the purpose of this study was to uncover the lived experience of cardiac therapy for men with coronary artery disease” Keaton &amp; Pierce 2000, page 64</p>
Sintay, 2011	<p>“This phenomenological study allows us to appreciate and understand the true meaning of cardiac rehabilitation. The lived experiences of patients allows us to see how they express the uniqueness of their experience in all its physical and psychological force” Sintay 2011, page 59</p>
Lackey, Gates, and Brown, 2001	<p>“To describe the experiences of African American women living with breast cancer following the primary diagnosis and while undergoing initial treatment” Lackey et al 2001, page 519</p>
Liu, Williams, Hsueh-Erh Liu, and Chien, 2010	<p>“The aim of this study was to describe and understand the lived experience of people with lower extremity amputation” Liu et al 2010, page 2152</p> <p>“The purpose of this study was to describe and understand the lived experience of Taiwanese people with LEA from the pre-amputation phase to six months after surgery” Liu et al 2010, page 2153</p>

McCahill and Hamel-Bissell, 2009	“The purpose of this study was to gain insight into the lived experience of a group of patients who experienced major surgery for the treatment of CRC liver metastases” McCahill & Hamel-Bissell 2009, page 66
Wall, Glenn, and Poole, 2011	“The aim of this study was to identify and describe the essences of patients’ experiences during the period leading up to the diagnosis of non-Hodgkin lymphoma” Wall & Poole 2011, page 2364
Ward-Smith, 1997	“It is the purpose of this study to explore the lived experience of undergoing the Gamma Knife type of stereotactic radiosurgery” Ward-Smith 1997, page 117
Wiederhold, Langer and Landenberg, 2011	“The purpose of this phenomenological study is to describe patients’ experiences after kidney transplantation before being discharged from the hospital and to identify topics for patient instruction and education” Wiederhold et al 2011, page 417

Table 5. Research questions for the included studies using Colaizzi’s method

<b>Study</b>	<b>Research questions</b>
Altender, Kenner, Greene, and Pohorecki, 1998	“The following research questions were posed: (1) What is the lived experience of women for whom prenatal diagnostic studies resulted from elevated MSAFP screening? (2) What are the maternal perceptions of this experience?”  Altender et al 1998, page
Archer and Hayter, 2006	No explicit question
Dudley, Chaplin, Clifford, and Mutimer, 2007	No explicit question
Jaromahum and Fowler, 2010	No explicit question
Keaton and Pierce, 2000	“The research question that guided this study was: What is it like being a man recently diagnosed with coronary artery disease and experiencing cardiac therapy?”  Keaton & Pierce 2000, page
Sintay, 2011	No explicit question
Lackey, Gates, and	“The overall research question for this study was “What is the lived

Brown, 2001	experience of the initial discovery, diagnosis, and treatment of breast cancer for African American women?"  Lackey et al 2001, page
Liu, Williams, Hsueh-Erh Liu, and Chien, 2010	No explicit question
McCahill and Hamel-Bissell, 2009	No explicit question
Wall, Glenn, and Poole, 2011	No explicit question
Ward-Smith, 1997	No explicit question
Wiederhold, Langer and Landenberg, 2011	No explicit question

Table 6. Research objectives for included studies using Giorgi's method

<b>Study</b>	<b>Research objectives</b>
Backstrom, Wynn, and Sorlie, 2006	<p>"The purpose of this study was to examine how coronary bypass surgery patients experienced their care" Backstrom et al 2006, page 140</p> <p>"In the present study, we wished to examine whether patients subjected to elective coronary bypass surgery were satisfied with their care. We also wanted patients' evaluation of how the theatre nurses worked, in order to examine if and how treatment routines could be improved" Backstrom et al 2006, page 141</p>
Bernstein, 2000	"To explore the meaning of substance abusers' experience while receiving acupuncture as a part of the treatment for substance dependence" Bernstein 2000, page 267
Billhult and Maatta, 2009	<p>"The present study described the experience of receiving massage for eight patients with GAD [generalised anxiety disorder]" Billhult &amp; Maatta 2009, page 96</p> <p>"The objective of this study was to describe how patients with generalised anxiety disorder or severe anxiety</p>

	experience to receive light pressure massage” Billhult & Maatta 2009, page 97
Herlin and Wann-Hansson, 2010	“The aim of this study was to describe how haemodialysis (HD) patients, between 30 and 45 years of age, experience their dependence on HD treatment” Herlin & Wann-Hansson 2010, page 693
Jonsson, Stenberg and Frisman, 2011	“The purpose of this paper was to describe how patients experience the early postoperative period after colorectal cancer surgery” Jonsson, Stenberg & Frisman 2011, page 248
Krohne, Slettebo and Bergland, 2011	“The aim of this study is to explore the cognitive test experience from the older patients’ perspective” Krohne et al 2011, page 679
Kwok-wei So and , Chui, 2007	“This paper is a report of a study to explore the experiences of women undergoing internal radiation for cervical cancer” Kwok-wei So & Chui 2007, page 154  “The aim of this study was to explore the of women undergoing internal radiation for cervical cancer” Kwok-wei So & Chui 2007, page 155
Logan, Hackbusch-Pinto and De Grasse, 2006	“To explore perceptions of spirituality in women who had undergone a breast diagnostic experience” Logan et al 2006, page 121  “The current study explored the lived experience of spirituality for women who had undergone a breast diagnostic experience” Logan et al 2006, page 121
Notter and Burnard, 2006	“The aim of the study was to explore and describe the perceptions and experiences of women undergoing restorative proctocolectomy” Notter & Burnard 2006, page 150
Persson and Hellstrom, 2002	“The aim of this study was to explore the patient’s experiences in the early weeks after recovery from stoma surgery” Persson & Hellstrom 2002, page 104
Stephens, 2005	“The main aim of this study was to explore the lived experience of patients who have undergone HSCT” Stephens 2005, page 206
Therkleson, 2010	“The aim of the study was to explicate the phenomenon of ginger compresses for people with osteoarthritis” Therkleson 2010, page 2226
Therkleson and Sherwood, 2004	“The purpose of this study was to note the experience of patients receiving the ginger compress with particular interest in warmth, pain, breathing, mobility, stimulation of metabolism and the effect on the skin” Therkleson &

	Sherwood 2004, page 3
Velji and Fitch, 2001	<p>“To explore and document the lived experience of receiving low-dose rate brachytherapy for gynecologic cancer” Velji &amp; Fitch 2001, page 743</p> <p>“The purpose of this study was to better understand the experience of low-dose rate brachytherapy for women with gynecologic cancer” Velji &amp; Fitch 2001, page 744</p>
Worster and Holmes, 2008	<p>“post-discharge experience was the primary focus” Worster &amp; Holmes 2008, page 418</p> <p>“the purpose was to investigate postoperative experiences following surgery for bowel cancer” Worster &amp; Holmes 2008, page 419</p>

Table 7. Research questions for included studies using Giorgi’s method

<b>Study</b>	<b>Research questions</b>
Backstrom, Wynn, and Sorlie, 2006	No explicit question
Bernstein, 2000	No explicit question
Billhult and Maatta, 2009	No explicit question
Herlin and Wann-Hansson, 2010	No explicit question
Jonsson, Stenberg and Frisman, 2011	No explicit question
Krohne, Slettebo and Bergland, 2011	No explicit question
Kwok-wei So and , Chui, 2007	No explicit question
Logan, Hackbusch-Pinto and De Grasse, 2006	No explicit question
Notter and Burnard, 2006	No explicit question
Persson and Hellstrom, 2002	No explicit question
Stephens, 2005	No explicit question
Therkleson, 2010	No explicit question



Therkleson and Sherwood, 2004	No explicit question
Velji and Fitch, 2001	No explicit question
Worster and Holmes, 2008	No explicit question

Table 8. Research objectives for included studies using other\* methods

\*not Giorgi's or Colaizzi's analysis method

Study	Research objectives
Bryar, 1997	<p>“To systematically explore the processes operating within the experience of women undergoing 2nd –trimester pregnancy interruption for fetal anomalies” Bryar 1997, page 559</p> <p>“The purpose of this study was to describe the experiences of women undergoing interruption of pregnancy in the 2nd trimester” Bryar 1997, page 561</p>
Forsberg, Backman and Moller, 2000	<p>“The aim of this study was to investigate the subjective experiences of the meaning of having a liver transplant, 1 year after the transplantation” Forsber et al 2000, page 327</p> <p>“The aim of this study was to search for subjective experiences of the meaning of being liver transplanted, 1 year after the transplant” Forsber et al 2000, page 328</p>
Jonsen, Athlin and Suhr, 1998	<p>“The purpose of this study was to explore and describe the experience of the disease and the liver transplantation from the FAP patient's perspective” Jonsen et al 1998, page 52</p> <p>“This study aimed at a deeper understanding of FAP patients' lived experiences of these phenomena [disease and liver transplantation]” Jonsen et al 1998, page 53</p>

Table 9. Research questions for included studies using other\* methods

\*not Giorgi's or Colaizzi's analysis method

Study	Research questions
Bryar, 1997	<p>“A qualitative study used phenomenologic methods to answer the question, “What are the experiences of women undergoing 2nd-trimester pregnancy interruption for fetal anomalies?”</p> <p>Bryar 1997, page</p>

Forsberg, Backman and Moller, 2000	No explicit question
Jonsen, Athlin and Suhr, 1998	No explicit question

## *Appendix 5: Findings and illustrations*

Altender 1998

Finding: Initial Reaction-Fear and Anxiety

When the screening results are first known, an initial reaction occurs, which is clearly determined to be negative. "Scared," "nervous," "panicked," "upset," "fear," "dread," "hysterical," and "paranoid" are the words used by many of the mothers.

One mother said:

Yeah, I prayed and I was crying at first, man. I was just praying constantly every night, every night. And sometimes during the day too. Please God, just let the baby be okay and this and that. Because I really wanted a little boy. And I was like, I don't care even if it is a girl, now-just as long as it's normal and healthy.

As one mother reported:

When I got to the waiting room at the hospital, I sat in the waiting room and cried. I felt I could not help myself. I felt nauseous. I felt sick. And at that particular time I reached down and sort of held on to my stomach.

Finding:Support Reaction

As one mother explained:

They explained to me more, because I kept calling them and I wanted to know more about it. So I would get on the phone and I would call the doctor's office and ask, you know, one of the ladies if they had explained it all to me.

Finding:Delayed Reaction-Uncertain News

When I called for the appointment, she said, "When do you want to come in?" If you told me to come in at 1 o'clock in the morning-if you told me to come in wearing something weird, I'd do whatever you told me, just so I could come in.

\* And another thing was waiting the 2 weeks. Why does it take so long? But he told me they had to actually grow it up-the chromosome or whatever-to grow them up to see. And like he told me they could actually determine the sex with the chromosome test. I guess each male has a certain amount and each female. He told me there's 46. But, I don't know, there's somehow a way they can tell the sex.

\* And that 10 days ... that was just constant... every day. Every day, I'd see little babies. I'd think about mine. A constant reminder 24 hours a day.

\* There was nothing that made me feel better. I mean if I was working ... my mind was so bad that I couldn't even concentrate on anything. If I was to go back to work. I could not do my job. It was just constantly... not out... I was ... I was out of concentration. I couldn't think into anything I was doing. My mind wouldn't connect with it.

Finding: Perfect Baby Reaction

This perspective about a perfect child can be observed in one woman's comments:

It was really amazing exactly how healthy your baby is. The ultrasound was so good that it showed the inside of the baby. All the bones and stuff in there. The heart was beating, the little mouth moving and the brains. The bladder, whatever. Everything was there.

Archer 2006

Finding: Pre-conceptions: 'The earlier the better'

They've had a big campaign in the press ... making people more aware

(Interviewee 3)

There were a lot in (the) paper about it, this test for men

(Interviewee 2)

Early detection is the only real chance that you've got, I think . If you leave it too late I don't think you've any chance.

(Interviewee 5)

It's one of best things that's could come out for, for as regards men.

(Interviewee 2)

Finding: Responsibility: 'It's for my benefit'

You've got to go for a PSA test, which is beneficial for everybody. You, your family, every-body. It's beneficial for the doctors to find out, understand more about it. That's got to be beneficial hasn't it?

(Interviewee 7)

For my well-being to have it checked

(Interviewee 4)

I've had this chance now to be tested. Better take it, because otherwise if I don't and something does happen, will I regret it for the rest of my days?

(Interviewee 5)

If they choose not to take it then, they're foolish in my opinion

(Interviewee 4)

There's no way anybody should turn it down, I don't think. I mean. if it were possible, I should make it compulsory.

(Interviewee 2)

If you have to you'll do what's right; you'll take the treatment and you'll try as hard as you can to win it, beat it.

(Interviewee 5)

It was her (*his wife*) who prompted me to go for the second biopsy. She says 'you get off.' I want to know what's happening (laughs). She's concerned isn't she? (laughs).

(Interviewee 7)

Finding:Uncertainty: 'The waiting and not quite sure'

It's not being told you've got cancer, it's the constant (emphasises) wait, and this went on from June to January

(Interviewee 1)

She got angry because it took so long and it was so sketchy ...

(Interviewee 1)

I can't say you haven't he says, and I can't say you have.

(Interviewee 6)

I'm still thinking aye, aye, what's (the) hospi-tal's next trick

(Interviewee 6)

Everybody fears (the) worst don't they?

(Interviewee 2)

It's always in the back of your mind, thinking about it.

(Interviewee 7)

You can't get on with your life ... I don't know where I am . you don't know how you're fixed .

(Interviewee 1)

Before it does save their lives they're going to go through agony, all this waiting and waiting and uncertainty.

(Interviewee 1)

Finding:Stoicism: 'You've just got to keep going'

It's just a case of saying well if I have, I have and if I haven't, I haven't. I'll have the tests and go through all the procedures and see what the situation is at the end of it. If they come out the same as they did last time, or if better then good, or if worse and I have to go back for more tests, then I'll go for them .

(Interviewee 3)

Very uncomfortable ... the last three of that were tremendously painful . I jumped when the snip went. You have a blood discharge both in urine and back passage, well this went on ... over a period of about two weeks. I had a lot of discomfort then ... passing water ...

(Interviewee 6)

I try to cover it up ... I like to keep personal things personal as much as I possibly can.

(Interviewee 6)

He's not messing about. He's going to get to the bottom of it (describing when a doctor took some biopsies which were very painful). He wasn't, like, gentle.

(Interviewee 5)

Finding:Reassurance: 'Being looked after'

I jumped at the chance. Find out one way or the other. Have I got it or haven't I got it?

(Interviewee 3)

If you're on this study (the Protec T study) you'll get the best attention, the best know=ledge . you'll be the first to receive them (drugs) for being on this study . it does mean that you're being looked after.

(Interviewee 5)

I'm glad I had that. At least I know I'm alright.

(Interviewee 2)

Knowing what I know now, I wouldn't have gone.

(Interviewee 1)

Dudley 2007

Finding: Longer term health problems

I said to M 'if this is a transplant I wish I hadn't had it' ...yes the worst was, defeatist-wise, was after-wards when I told you I felt ....'well I don't feel any better in fact I feel worse'.

you'll feel good some times, you'll feel bad some-times, it won't all be bad, expect that you're going to have a rollercoaster ride I wouldn't expect to do a lot for a year.

I've got no regrets about having the transplant...no my life, although it's slowed down....it would have anyway....I'm having a great time now.

Finding: The stigma of liver disease

if you said you got cirrhosis of the liver - oh piss artist heavy drinker - immediately I said I'm not drinking they seemed like they didn't believe me.

yes well I think if you abuse yourself and you been warned and you don't take it on board ....I don't think really you deserve a transplant to be honest it was only fair that I should refuse because I put meself in the position that I was in if I hadn't been using needles I wouldn't have caught hep C in the first place.

Finding: Living with uncertainty

Having experienced the deaths of other transplant patients, the majority of participants described a sense of uncertainty about their future health and life expectancy. Frequently, this was implicit in their recollections of ensuring that domestic and financial affairs were in order. However, many were quite explicit:

I know it's going to pack in some day, I mean I've been told that, I mean you know someone was saying a while back 'we can't give you times on it....but you know we've known people go 12, 15 years', you know, so it's that's a good life, you know, 15 years I had it done 4/5 years ago, 50s now, if I make 60, I'll have had a good innings.

you know I haven't said nothing to nobody, but it's always been in the back of my mind that what happens if my liver rejects does it mean another transplant?

Finding: A new outlook on life

Every day I wake up and see the sun it's a bonus to me.

I think they have recognised that we're mortal...in fact I think it's taught, I think, them and us really to appreciate what matters and what doesn't matter and that has been an extremely good thing.

it's made me think about things different myself, I think about there's more to life than money and all this, I look at things differently...not planning too far down the road not to be putting yourself out on a limb...I think it's definitely the transplant because you see your life flashing in front of you. so anyway for her his wife it's been a real life- changing experience for both of us I've got much more take it as it comes, do it today because you might not be there tomorrow to do it, I'm far easier going.

Finding: The donor and donor's family

how do you say thank you enough, like, on a piece of paper, you know, how do you do that, but you do the best you can.

well the death of a person so that you could live that's something that I found hard to come to terms with I found it upsetting at the time you know I just used to keep thinking about this person all the time.

Jaromahum 2010

Finding: Physical Eating Experienced

It's almost like a "gas bubble" sitting right here (epigastric) where they created that attachment...it's going to be uncomfortable for a while.

It goes down you feel a little bloated.

It's like I need to burp and what I do is get up and walk and it's fine.

I feel bloated down there, but it didn't hurt, it just feels unpleasant

This morning, I felt full. it's a little tight in chest going all the way down.

Fullness is a lot different. I used to be able to eat a lot of food; now I can't get even half of this stuff in (pointing to meal tray).

What's most surprising is how quickly you get filled up and I hadn't realized that when I was full when I am full.



I don't know if I am still eating too fast.

I'm full; as much as I want to eat I can't eat anymore.

Finding: Psychosocial

I just don't think I'm ready to go home.

I am worried about my wife, she's not a nurse.

I am afraid to go home (pause crying). I am afraid I am going to start to vomit.

Finding: Psychological

I was happy that I can actually put something in my mouth. It makes me happy that I can eat.

It feels good to be able to swallow after surgery.

I was confident that I would be able to swallow and I felt good that I was right.

I know I've gotta keep eating, that's why I'm eating.

The biggest thing you are trying to accomplish is being able to eat.

You need to eat to get stronger.

I've given eating a lot of thought. It's not easy. I have a lot of learning to do and trying to get myself back to society, going to parties...

I am eating to live... that's how I look at it.

Some food I've got to eat so I eat.

I'm determined; being optimistic helps.

I know that I am going to change my way of life to a certain extent but I am prepared.

When I go home, I anticipate being frustrated. But it's something I know I have to do.

I am happy. I called my wife right away that I am going home.

My husband is very supportive and I think once I get home I'll get readjusted there.

Keaton 2000

Finding: Feelings of Fear and Disbelief

Finding: Being Aware of Mortality

"I think it brings it home to you that you are getting closer to the end of the game."

Finding: Losing Control of Self

"You've got no choice, you've got to sit back and let other people do for you."

Finding: Halting of Usual Activities and Future Plans

"I have to sit back and watch people do things that I normally used to do," and another said, "This disease has kind of knocked my plans out. I haven't been able to do anything I or we've planned."

Finding: Heightening Awareness of Spirituality and Belief in a Higher Power

"Spiritually, I feel when the doctors give up, that's when the Lord takes over."

Finding: Resigning to Acceptance of External Forces and Required Changes

"When they told me about the disease, I felt this isn't going to bother me. If they can fix it they will, if they can't, well they can't"

"Just knowing changes have to be made makes it less difficult for me."

Finding: Increasing Sense of Well-Being

"Rehab gets you started doing a little something again."

"This has made me feel better as we went along."

Finding: Receiving a Second Chance and Moving Forward

"I wanted to do things to give me another chance"

"Now I just try to go forward with my life."

Sintay 2011

Finding: Recovery

The participants recounted that cardiac rehabilitation coincided with the phase of recovery. Some of the participants had different opinion about the meaning of cardiac rehabilitation.

To them, it initiated a form of exercise for the heart. They perceived cardiac rehabilitation as an intervention that strengthens the functions of the heart by exercising it.

#### Finding: Behavior Modification

The second major theme of the study is behavior modification with two distinctive subthemes of personal and environmental factors.

The participants described the perceived advantages that emanated from the process of rehabilitation by initiating self-discipline within them. P4 pinpointed the facet of self-discipline as an essential part of conditioning himself.

Other key elements that originated from the psychological feature of cardiac rehabilitation were the descriptive expressions of changes in mood by the participants. The expressed feelings of the participants during cardiac rehabilitation initiated a change in their behavior. The bizarre mood of the participants changed to a feeling of being relaxed and modest during interaction or relating with other patients as described by P2. Also, participants realized the changes in their behavior. Affirmation, perception of family members and associates strengthened the belief that participants had positive mood changes after they joined in the cardiac rehabilitation program.

#### Finding: Interpersonal Relationship

The interpersonal relationships that developed among the participants were very profound and meaningful. Majority of the participants articulated the value of camaraderie in daily interaction and sharing with others. It can be gleaned from the verbatim transcription that one of the overall effects of cardiac rehabilitation for the participants was the element of companionship. Participants developed and enhanced interpersonal relationship as they underwent the process of cardiac rehabilitation.

Family support also became outstanding with the responses of the participants. They shared their outlook about the role of family members during the process of recovery. P3 and P6 highlighted instances where family support was reinforced. The involvement of family members became eminent in the theme of interpersonal relationship. The union of the family members and participants augmented the participant's condition during the process of recovery. Concerns from family members should also be expected by the health care providers and dealing with family members should be given with equal attention.

Lackey 2001

#### Finding: The Experience Trajectory

I just noticed a lump. I mean I was just washing my breast with soap and I really just kept gliding across something and it didn't feel right. I was hoping it wasn't cancer. I was just afraid because of the lump, and I know other people who have had breast cancer and have mastectomies, and different things and I was just afraid of it being cancer.

. . . I was able to realize that [it] wasn't the end for me. It wasn't a death sentence to me . . . especially when you've gone through several members of your family that have died, you'll think, oh no, I have a death sentence. But, by doctors talking to you and explaining to you and being able to understand what they are talking about, then you realize that you are not on death's door yet. It makes a difference in your life.

We all go through something. I said if I had to do it all over again, if it is going to keep me here, I'd do it. If they were to tell me that they had to take my whole breast off . . . I'd tell them they could have it and throw it away. Cause they make artificial ones, and I would get me one and wear it, cause it ain't nobody's business. Cause see, when I put my clothes on, ain't nobody got to know you ain't got but one no way.

Well, I'm gonna ask them. Sure, I'm gonna ask them cause I want (pause) I want to know as I'm cured. I really do. Cause I love me, I do. And I don't want to be walking around here knowing a something, you know, and not doing anything about it.

When the women talked specifically about their treatments, they generally discussed the anticipation of starting chemotherapy and their reactions to it. Nine of the women had known someone who actually had taken chemotherapy, heard stories about the side effects, or heard about side effects on television programs. They expected to experience these side effects. When asked for clarification about her feelings about starting chemotherapy, Yvonne said

You know, cause I had heard so much about chemo, so much about radiation, not knowing anything about either, just what I heard . . . I had heard that chemo makes you so sick, unbearable sick, lot of it sometimes makes you lose your hair and the radiation, I had heard that it makes you so tired and weak, where you just don't want to do anything, you know, just weak during the whole time. . . . Then again, I had to start thinking positive that if I am to live, I need to do whatever it takes . . . I made up my mind that I was just gonna go through with it regardless of whatever.

Not a thing. Well, only thing I knew was what I saw on TV, and they have these movies on about these women that have cancer and they'd go through chemo, and they'd be throwing up and nauseated and standing in the bathroom combing

their hair and their hair falling on the floor. That's the only thing that I knew about it . . . it would take your hair out and make you sick.

Finding:Femininity

“ . . . [my] breast was mean, they were big, true enough, but to me they were sexy, and so I said even if it is something there, I'm not gonna have my breast removed.”

“I'm going . . . from the breast being both the same size, then you're going to where one is much larger and it's a little deformity in it . . . that's a drastic change to me.”

“You don't know how comfortable that bra was. I can't wait to get it.”

“I keep this bra, this prosthesis bra, and that makes it much more comfortable and you don't have to be trying to pad it.. .you just put it on like a regular bra.”

“ . . . I thought that it would basically shed away. It came out in patches, and I had pretty long hair. And that was a problem for me . . .the way I lost it.”

I kind of had an inferiority complex when I lost all my hair. I didn't know how I was going to react to it. And back here last week, I had a big patch up in the top and it fell out. And I felt kind of funny. I said now I look like Kojak . . .on the TV . . . but I accepted it cause there's nothing I can do about it. But when I get through taking treatments, it'll grow back. But I know it will.

I did care how he felt because that was a part of him too. What I had to go through was gonna affect him too. And it concerned me how he was gonna feel . . . I said how do you feel? Are you gonna see me as half a woman, or will I no longer be able to please you physically, sexually, or whatever? He said, “Barbara, I don't even see you as that. I didn't marry you because you had two breasts.” He said, “When I first fell in love with you, I didn't know, for all I know both of your breasts could've been false. I didn't fall in love with you for that . . . .”

He was there for the surgery. Right when I came out of the surgery, he was not there. That hurt so it's like he went through a rejection for a while, so did I because I didn't want to deal with hurt. I didn't want him to touch me. . . . Then he started coming around. And he told me how he felt about it and he was scared. He was more scared than I was . . . . I was pushing away because I don't feel like a whole woman anymore.

You know that movie I'm Gonna Git You Sucka (McCarthy & Craig, 1988). It's about this man [who] picked up this woman and she was all fine looking, big boobs and everything, and when they got to the room, she started pulling off her clothes. But instead of pulling off her clothes, she started pulling . . . her fake breast, a wig, and took her wooden leg and threw it in the corner. She had one

leg. I feel like that woman in I'm Gonna Git You Sucka. At night when I pull my clothes off to take my bath and I got to pull off fake breasts, fake hair . . . the only thing [different] about it, I don't have a wooden leg to throw in the corner.

Finding: Spirituality

Sometimes you look in the mirror and you just say, God, I think I look like a freak . . . but then you think . . . hey, I'm here and that's important and about all I can say is thank you, Jesus, thank you . . . for letting me live to see another wonderful beautiful day.

I said, Lord just let me talk to you for a minute, and you show me a sign what my answer is. Shall I or shall I not have that operation [mastectomy]? And somehow or another I drifted on to sleep. And I began to dream and I do know that He talks to His children through dreams. I began to dream it was so many people around . . . these tables . . . and I looked up under the table and saw this breast hanging under the table, and I went and got somebody. I don't know who it was, but it was a lady, and I said look, somebody done left their breast under the table, and she said who's it? I said I don't know, [and] she said, well there the doctor is right there, ask him. So I goes over and grabs the doctor by his arm and I lead him back to the table and I said, doctor somebody done left their breast under the table. He looked down and he get it . . . he holds it up and I looked at it and I said, doctor is that the cancer right there, and he said, no, that's the nipple. He said, here's the cancer right here. [I said] that's the cancer? [He said] don't worry about that cause we take care of stuff like that. He said once we take that breast off, we take care of it. Sure did. I dreamed that and I went on to sleep. And when I got up the next morning, I told my husband . . . I was having my surgery.

Liu 2010

Finding: Lost in the dark woods

'lost in the dark woods and couldn't find a way out' (P #11).

.. .When my doctor told me I needed to have a below-knee amputation in order to save my life, I was very shocked and frightened. I was forced to make this decision. Other people decided my fate. I totally lost control of my condition. (P #09)

I knew I needed to make the decision as soon as possible to save my knee. However, I was so scared that this would mean I would have to lie in bed the rest of my life. I thought that if I couldn't walk by myself and have an independent

life after amputation, then I would prefer to die now. I would not be an intact person. I felt that I couldn't control my life anymore. (P #01)

I was not scared of the surgery. I was worried about my future. I didn't know what would happen to me. I didn't want to think about it because there were too many uncertainties in the future. No one gave me a clear direction that I could follow. After amputation, I was not the man I usually was. My son planned to send me to the institution because no family member could take care of me. There was no hope for the future. It was the end of my life... (P #04)

I asked my doctor to perform an amputation. I wanted relief from my suffering. I knew I could wear a prosthesis after amputation, but I was not sure how many functions I could keep. I wanted to end my suffering right away. On the other side, I was afraid that more suffering would come after amputation. (P #03)

Finding: Emotional collapse

After amputation, I couldn't believe it happened. I cried all the time. I couldn't stop my tears. I was very angry and hated myself. I thought I should have changed my doctor right away when he couldn't handle my wound. (P #01)

... Since the day I lost my leg, my nightmare began. My leg was one part of my body. It had vitality. Every time I thought about my leg, my heart was broken. The pain was endless. I could not imagine feeling 'normal' again.... (P #17)

... You people didn't understand how much I suffered every day. Only people who have experienced amputation would understand how painful this is. I feel like a little boat on a vast expanse of ocean. I felt very sad and lonely in my heart. I swallowed all the suffering by myself (crying). (P #19)

Finding: Difficulty in passing through the shadow

I felt so sorry for my family. I was unable to complete anything by myself. I wanted to be independent, but I couldn't. My son told me that he preferred to send me to the day care center. I didn't want to go there. I am 82 years old now. I am worthless and useless... (P #10)

I have just stayed at home for 3 months. I worried about the reactions from the others. I didn't want my friends to visit me. I didn't want them to pity me or feel sorry for me. The best way to avoid this was to isolate myself from the others. (P #20)

I worried about other people's judgment. I didn't like when people paid attention to my leg. It was so embarrassing for me to show my stump to the others. I thought they would not accept my appearance... (P #01)

I must go to the hospital for hemodialysis regularly. Since my amputation, it is very inconvenient to move. Transportation has become a problem. I don't know why God treats me like this. It makes my condition worse. (P #16)

Finding: Igniting a gleam of hope

I thought the God was trying to tell me something. My previous life was not healthy. I ate unhealthy food, I smoked and drank too much. I haven't considered my family at all. Amputation resembled severe warning to me. I promised my wife that I would have a new life... (P #11)

...After amputation, I thought my life was all destroyed. I lost my temper easily. I looked at the dark side of everything. But I gradually found that my pain was worse; I couldn't sleep and eat well. My children visited me less and less. One amputee reminded me that I needed to change. that I should look on the bright side of things. It was marvelous. After changing my thoughts positively, I could sleep and eat much better. My life was hopeful again. (P #11)

I still couldn't accept my loss, but I tried to change my mood and my view on life. Some are good days and some are bad days. Finally, I realised that the bad days were not really so bad. Everything I had done could be done in a different way now. Life was not going to change for me - I needed to change myself... (P #20)

One day after falling down at bathroom, I told my wife I didn't want to live any more. My wife howled and told me, 'if you died, I would die with you'. She couldn't live without me. I felt she really needed me and it was my responsibility to take care of her. Since that day, I never said I wanted to give up. I must live for my family members. (P #08)

I believed that I was the worst one. Then I saw people here (the prosthetic rehabilitation center) who were worse than me, such as those with bilateral amputations. They could walk so well. I was certainly able to do so. (P #07)

I haven't walked and gone outside for 2 months since the surgery. For most people, walking is a natural and very simple thing. But to me, it was so difficult. When I took my first step, I cried and felt so happy. I could walk again. My life was back. (P #07)

McCahill 2009

Finding: Communication with the Health Care Provider

We talked about all sorts of things. Dr. [surgeon] was really good about that and I have never felt that he has not explained something to my satisfaction. ... The



options and the scenarios and the facts and everything have been presented to me in a way that I was able to make informed decisions. It wasn't, "just go have surgery" or "just go have chemotherapy." (Participant 1)

He doesn't talk to you in great big words. He explains it for you to understand. If I looked like I was confused to him, he'd draw it for me. He never made me feel like I had to hurry up. He's always got time for you. My oncologist and surgeon have worked hand-in-hand. He [surgeon] took the time to do that and gave me the attention I needed. (Participant 4)

I wasn't making any decisions or anything. So she [oncologist] did come in, but I thought she was awful forceful. She sits down and she told me, she said I think you've got extensive coverage of the liver with cancer. ... She wanted to get going on chemo already, to set it up. ... So I didn't say anything. ... I kind of doubted her word when she said extensive coverage, not that, but extensive spread. I didn't think she had enough facts in front of her to make a decision like that without no biopsies and nothing on the liver part. (Participant 9)

#### Finding: Support from Others

It was probably just as well that my wife had the summer off because somebody had to drag me to chemotherapy and drag me back kicking and screaming because I didn't want to go at all. At one point, I almost quit. (Participant 1)

My husband is very positive that everything will work out fine. I don't know what his inner thoughts were. ... I was very lucky to have a lot of people around me who were encouraging. ... My tennis group every week would send me cards after I'd come back from chemo. People kept track of me and said they were praying for me. ... My daughter, who is a physician, called almost every week. I knew ... she was thinking about it and checking up on what was going on.... Encouraging, yes. Perhaps being overzealous as far as I was concerned because she wanted me to be sure to check on what was being injected and whatever, so nobody was making mistakes because she said it was possible. (Participant 3)

Yeah, it just gives you that extra push to go on, when it's just like, God I don't want to go for another chemo treatment but you've got two kids, that you've got to go, you've got to give it your all. Yeah, you're sick, you're tired, but you just can't give up. (Participant 7)

#### Finding: The Patient's Own Attitude

You go through all this stuff and then you get cancer or you find out you have it and it is like ... most of all that other stuff is really not that meaningful. The job isn't that meaningful. Politics is not that meaningful.... You've just got to get your mind in the right place and just say I am dealing with this. (Participant 1)

I think for anybody who has got to deal with surgery or cancer in general, I guess the first thing you've got to do is have your mindset. It is all in your head. You can be sick or whatever else, but if you've got your mindset, this is okay. ... I know it is not for everybody, but for me, my faith in God and a little bit of time praying first before you make those decisions is really important. (Participant 4)

Unwavering? Belief that you're strong enough you can recover. It's the optimistic view of life that even facing some pretty challenging health care procedures, I personally will persevere and get out in record time. I figured out early on if you want to get out of the hospital, you have to walk out. Good health is really a state of mind. A very positive attitude about staying well is how you stay well. (Participant 6)

#### Finding:Cure Uncertainty

Well, I think that depends on the person. I think that for me, I don't know that I could have too much information. I think maybe Dr. [colorectal surgeon] or the radiologist saw something on some of those first CTs. They saw a spot. They didn't know what it was and they weren't necessarily going to say, "Oh boy that could be cancer," ... but in some respects, how much do you tell a patient that you may be unsure about something and want to really figure something out. How much do you tell the patient and get them worried? So, there is that factor. Some people would sit around wringing their hands for months until they got to the next CT to see if it was 1 mm bigger or smaller or whatever it was. That is a tough thing I think. (Participant 1)

I just feel Dr. [oncologist] is going do another CT scan in November. I sometimes kind of wish that he would do it sooner or that because if anything shows up I want it taken care of right away I don't want to give it a chance to do anything that we don't know about. (Participant 2)

I think the hardest part is the waiting for the results and then to turn around waiting for the PET scan to come back, finding out that was cancer in your liver, but now there is something else in your pelvis. Then, it was back to waiting again to get the biopsy done. Then the day before the biopsy, they called and said it was normal ovarian function and I was, like, wait a minute. Who are you? How do I know you know anything about it?" ... I was glad that was nothing, but that is the toughest is the waiting. Once you know, you can deal with it. It is the not knowing. (Participant 4)

#### Finding:Coping Strategies

If you had come last week, there were a few days when I felt really depressed and wondered if this was a natural thing when you have been struggling along and then all of a sudden, it is all sort of over and kind of post-partum depression here.

We've had a nice four or five days, so that has gone away. ... Weepy. That is about it. It comes to a head and you sort of just cry a little and it goes away. (Participant 3)

I try to turn it around and remember the fact that the blessings that we have throughout the day, ... my grandchildren, my children, all those little things; you look at them and you realize that they are all a gift. Everything is a gift. Every day is a gift. Once you realize that and you know that the worst thing that is going to happen and can happen to me today is I might die and pray to God in his mercy I would go to heaven. Once you know that and that is reality every day, cancer can't hurt you. (Participant 4)

#### Finding: Hospital Care Concerns

Sometimes I got the feeling they didn't even know what you were in the hospital for, but do all the nurses who are working with you in the hospital or around you, do they all know what surgery you had or whatever? ... I guess it is that feeling that you don't know who is who and of course, part of it up here at this hospital where it is a learning hospital and there are all these extra people, that you are introduced to maybe once and they do come back and sometimes and it is hard to keep track of who everybody is. That bothers me a little." (Participant 3)

I felt that the questions of care to me revolved around inadequate staffing. I really felt that the numbers of nurses were inadequate. They keep them busy enough that they are forced to do those medications that require the degree and knowledge. The other support care is kind of tough to get. (Participant 6)

Then they wanted to get in my port, but it wasn't healed really. ... I said, "You can get blood anywhere. I am easy to get. Leave the port alone." I said, "Furthermore, you better come back with someone big because you are not touching it. That was the end of it." (Participant 9)

#### Finding: Internet Information

I think back in 2001, my husband got on the Internet and he was very, very concerned. Very concerned ... that I was in stage IV ... I'm not sure, six months (to live) maybe. My husband was very upset and concerned, as well as my daughters.... I would say that they should listen to their physician and go by what they say and do what they say. Don't pay attention to other people or even ... well, in my case the Internet was kind of, I don't know if you can call it false information, but it certainly didn't help my husband. It was considered stage IV cancer. (Participant 2)

Well, you know the things that could have gone wrong during the surgery, which, you know, I didn't go into it with my eyes closed. I researched everything on the

Internet to find out how often.... I went through WebMD for a lot of it and just read what the risks of surgeries would be. (Participant 7)

I've read survivor stories and they've been very en-couraging from what I've read from these people who have chosen to submit stories, but the clinical stuff, the technical stuff, I read it and I just get so depressed that I end up sitting there crying.... There were places where people could submit their chat room comments, bad experiences with an original chemo drug that they were prescribed and having to switch.... And I'm thinking, holy cow, let's just hope he hits on the right combination the first time because to stop this and then to try something else ... (Participant 10)

Wall 2011

Finding: Perceiving individual health perspective and onward movement

Erm well, one day when I was working, well I actually worked out and about with my job, and it was one of my customers, who was actually a doctor's receptionist, said, 'What have you done to your neck?' I felt this big lump in my neck. Now, I don't remember seeing it there in the morning when I shaved.

Well, at the time I was working in secondary schools and then I started to have a series of seemingly unrelated problems - various things ....urinary infection, erm migraines, but worse, far worse. You know, a whole variety of things, over probably two or three years.

and it was so bad; I actually used to sleep on the quilt, because it was painful. I couldn't sleep on my side because (pause) my spleen was double the size.

I used to have a lot of worries with my husband and I used to think, 'I can't worry about that tonight, I'll have to have a right good worry at it in the morning, but I need my sleep tonight.' So I'd empty my mind, I'd go to sleep and I'd wake up in the morning and half of the worries had stopped anyway.

Christmas came and we went to my mum's. He (husband) managed to get four days off and we went down for Christmas. Then my legs started itching at night. I thought, 'Gosh, I wonder if my mum's using different soap powder?'

I think up to July I was reasonably fit and healthy, but in July I can remember feeling a bit unwell, and then during August I did have a couple of night sweats, well perhaps more than a couple, but I just put it down to the hot weather really, because it was very warm then.

Well you know yourself, there are so many, every magazine there's always things on cancer. Now there's a hundred and one different types, but it was the first thing that crossed my mind.

In the morning, I was getting ready to go to work, and I felt warm. Quite hot. I panicked and start to think, 'Oh it may be breast cancer'.

It was all a bit puzzling really... I wasn't unduly concerned really because it was just that, I didn't quite know what it was. Even before I got the pain in my chest I sort of went through March, from January, feeling there was something strange, not knowing what it was.

Then what triggered me going to the doctor was that we had a church barbeque, and I went along to the barbeque and I was talking to this chap, he was a doctor, a GP. I was talking to him and he said, 'Erm excuse me, I hope you don't mind me saying this, but I can see this lump here on your neck, and I'm a GP and if I were you I would go to your own GP and get it checked out'.

So December it started (breast swelling). But I didn't really start seeing anybody until the March... It was just a general thing for something else. For tablets or something, and I thought I'd mention this.

Finding: Penetrating communication processes and investigations

So he (GP) said that I should be seen by the oral surgery people as a matter of urgency, and so he rang there and then.

It wasn't painful (referring to breast swelling), and that was on the Monday, and he (GP) phoned the doctor at the hospital. On the Tuesday there was a phone call, and I went up there on the Wednesday, and they said they'd do a syringe biopsy.

The only thing is that it could have been diagnosed earlier. I mean, going for 12 months (to GP) and having the same symptoms for 12 months. (Gastrointestinal problems and weight loss)

Oh that was funny. I don't think the person who took the ultrasound had a sense of humour like me. I was lying on the bed, you know, with the stuff on (meaning gel on abdomen). I said to the fellah, 'I don't want to know when I will have the baby, I just want to know how many'. (Male patient)

I am able to protect myself from things. I am able to deal with things in a very sort of remote way. That's the way I dealt with it. (Referring to scan)

Well, she was talking (the sister) and she was explaining about the blood and the lymph nodes, and I understand now, and the lymphatic fluid, because I have read all about that. She was very, very good.

Some of the things, the initial consultant that I saw, I asked her if there was anything in my diet that I could change, and she said, 'No, no, just go away and live your life normally' So...I thought, 'I don't believe you. So I went away and I researched diets, vitamin supplements and exercise on the Internet and found that there were hundreds of things on the subject.

Finding: Advancing towards focusing on the non-Hodgkin lymphoma diagnosis

And he said (hospital doctor) 'Well, the bad news is, it might be lymphoma,' cancer of the lymphatics. Well lymphoma I think he said, or cancer of the lymphatic system. But then straight away he said, 'But the good news is that if you're going to get cancer, it's the best one'.

It was high grade. (Name of consultant) did actually tell me that it was actually better to have the high grade because it is easier to treat. So I had never even heard of non-Hodgkin lymphoma.

I mean, it was such a shock, a complete shock, it was a terrible existence for about the next 4-5 weeks, because you hear different things. People tell you different things.

You have got to look at the funny side of things, or you start looking at the down-side of things. Well I've had a few down days, I get my down days now, but my aim is to be the longest living lymphoma cancer patient ever.

Ward-Smith 1997

Finding: Willingness to Undergo Treatment Again

"there is no comparison to the pain or unpleasantness of other treatments."

"no feeling after treatment"

no "grogginess like there was with chemotherapy."

the treatment "couldn't do anything but help."

treatment "pinpointed the tumor, which is better than regular radiation."

"was an opportunity you can't pass up, and needs to be done before the tumor gets too big." "there was nothing to be scared about with this treatment ... A piece of cake compared to other things."

Finding: Becoming a Gamma Knife Candidate

"...I remember asking the doctor if I couldn't be one for the Gamma Knife and he said no because it was too large. So when he told me this time that we're going to

use the Gamma Knife I was thrilled to death. I thought well now we don't have to do another surgery, we can do this."

"It wasn't an opportunity for me when I first started with my treatment and that was really a let down. I was excited when they said I had the chance to get in there and try it out."

Finding:Self-Education Regarding the Gamma Knife

"I read all of the literature very, very carefully and then heard so much about it from other people ... The doctors I've talked to, they are personal friends of mine in South Dakota, are the ones that have gone to Houston and everybody says how lucky you are to have that in your area."

"...I mean I had already heard about it before you guys ever talked to us about it. My sister-in-law, as soon as she found out I had a tumor, she looked it up for me."

Finding:Awareness of Diagnosis

"... I started reading about this type of tumor and obviously I need to get everything I can to help me with it.... I'm for anything that will help."

"Well, you got to look at where you're standing, though, ... you have to put your faith in something."

"... it's the uncertainty that you have no control over, and no one can tell you anything is going to be 100%. Everything is an unknown - what my tumor will do - if this treatment will help - everything."

Finding:Lack of Discomfort During Treatment

"... I've already been through a lot and when you get to that stage, at least I had, with the radiation and chemo I figured it can't be any worse than what I've been through....

"you're a little bit apprehensive, a little scared. But I must say there was nothing to be scared about this treatment.... I've been through things a lot worse than this. It didn't hurt at all, no pain. ... When the doctor came in and said we're all through, I said you've got to be kidding. It's like that song that Peggy Lee used to sing 'Is That All There Is ?' because I had myself all worked up."

Wiederhold 2011

Finding:Weighing Dialysis Against Transplantation

At first, I didn't know what to say when he [the doctor] told me everything. That I shall take it [the kidney] was clear from the beginning; I should not have had to register for that [registration for transplantation]

Finding: Experience of Positive Changes

What can I say, I feel better, there is energy, you feel it in your body, there is a change in the body itself again... Feels energetic, feel ready to take on anything [patient very euphoric: author's note].

Finding: Dealing with the Organ

I think it would be better if you asked for it [the experience after a kidney transplant] in half a year, when everything has settled because I think it is still too new to say something. You can't really deal with the situation right now. That's all going to come with daily routine (F 367-372).

Finding: Experience of Impairments And Worries

Well, the greatest fear is, I think, that of any kind of rejection, in the near future or later and then maybe...if you're told, and be it in 15 years, that machine is your best friend again. I think that will be a very bitter moment (B 130-135).

Finding: Experience of Self-Confidence

And what else is supposed to happen to me? And I don't intend not to treat the gift that has been entrusted to me carefully, but I will guard it with my life, and if I decide to do something like this, I will do this (A 572-576).

Finding: Experience the Need For Support

I have to think about getting well, how my life is going to go on.. .that is the next question, but before I can do that I'll see what they tell me what can I still do, what may I still do (E 113-118).

Backstrom 2006

Finding: The quality of the contact

'I contacted the hospital in order to postpone my admission a few weeks, and I am very pleased that they granted my wish'.

'I waited and waited ... and then my daughter said I should phone the hospital and ask ... although I don't want to nag . but then I did . and they scheduled me for an operation in short time'.



‘They did everything to make me eat . They cooked the food that I wanted and served me with their nicest china. They did everything for me . they were like angels’.

‘I remember that I was taken into the wrong OR ... then they took me out again ... the anaesthes- iologist - a very nice man - explained everything and it turned out just fine’.

‘At least an hour should be reserved for the operating surgeon to inform you before you leave the hospital. There are so many questions, and the next of kin should also be present, I think this is very important’.

‘The surgeon was doing his rounds and he was in a foul mood. I understood it was all about another patient, who had got drunk the day before. He took it out on the rest of us. I understand that doctors can have a bad day, but I felt that he was a little unprofessional’.

‘We were four grown men in one room and we were quite lively ... and I understood that the nurses divided the ward between them, and that they fought a little to get our room’.

‘Some are more reserved . they don’t dare ask for help. I helped a man - he was quite thin - get a different meal. The nurses helped so he got what he wanted, and then he ate it all. We have to look out for each other’.

‘My wife was with me when the doctor informed, and that was very good, because we both heard the same’.

‘Relatives don’t get enough information. They need to know that things aren’t that bad, so that they don’t stop you from exercising’.

‘I asked for a shower ... it was difficult, since I had a lot of dressings on, or so they said. I almost didn’t feel like I was their patient’.

‘I had a syringe in my throat. It wasn’t needed any more and it bothered me. They had trouble taking it out, but then a grown nurse with lots of experience came and took it out . and seven or eight staff watched her’.

#### Finding:Coping

‘Then you feel insecure, especially about what your body can take. You feel ... I for one had my share of crying’.

‘Follow-up is very important, I think. I would prefer having a phone number with direct access to the ward, then I could have contacted them directly, and I would feel safer. After all, that’s where they did the operation and where they know how things are done’.

‘And then the doctor phoned me to hear how I was doing. I’ve never experienced anything like that before. And she said I could phone her any time, it was very comforting’.

‘I was in (name of facility), it was the best! Everyone who has been through heart-surgery should go there, it should be compulsory’!

‘Because I dared push myself, to see what I managed. And I did it! I am so happy for that today’.

Bernstein 2000

Finding: anticipation of pain

Two of the participants expressed a fear of pain while the rest minimized their perception of it, although the anticipation of pain was present. In this study, all of the participants stated that they felt no pain from the needle insertion and described the experience of the insertion as one causing the sensation of a “pinch or prick.” This perception was expressed as relief, and the participants in this study emphasized that the acupuncture needles did not induce pain.

Finding: apprehension toward newness

Although each participant volunteered to accept acupuncture as an optional treatment available for substance dependence, approaching the unknown created apprehension and anxiety. After receiving the treatment, the participants described a change of their emotional and psychological states to feeling subdued and having revitalized energy. In this study, the participants were apprehensive and preoccupied with interpersonal conflicts, including social and family issues existing before acupuncture treatment was started.

Finding: mood elevation

With acupuncture, the participants reported a reduction of apprehension along with a clearing of thought processes, peacefulness, self-confidence, decisiveness, and motivation for their recovery.

Another indescribable aspect of the experience was the affective component of mood elevation.

Finding: indescribability of the experience

Each participant in this study expressed both physical and affective experiences that were unique and unfamiliar. These experiences could be attributed to the participants’ first exposure to acupuncture for substance dependence. The indescribability of the experience pertained to the unfamiliar physical sensations and the unexpected feelings of mood elevation.

Finding: physical sensation

Participants expressed the movement or flow of physical sensation from the acupuncture site to other areas of the body: pressure-like, headache-like, tingling, soothing, and warming sensations. These sensations were reported by the participants as unfamiliar, strange, subtle, and difficult to describe accurately.

Finding: relaxation

Relaxation was the strongest of all the themes reported by participants. Participants described feelings of both emotional and physical relaxation, of calm and serene feelings, accompanied by sleepiness, then followed by revitalized and balanced energy. All participants used the terminology “relaxation” as the experience with acupuncture. Each participant described the experience of relaxation in various forms: numb and floating sensations, feeling “high,” sleepiness, and tranquility. The participants said that they were able to achieve physical relaxation followed by clearer thinking and relief of their emotional turmoil. The participants’ descriptions of the experience of relaxation in this study revealed alleviation of tension and anxiety, rebound energy, ability to sleep, and diminished physical discomfort. These experiences associated with relaxation gave the participants a positive impression of acupuncture. Following the treatment, the participants expressed a desire to further explore acupuncture treatment for substance dependence.

Finding: the effect of acupuncture on sleep

The last theme resulting from this study was the effect of acupuncture on sleep. This effect was an unexpected result of the acupuncture, and one that the participants did not anticipate as a benefit. Inability to sleep, even with the assistance of a sleeping pill, is a common problem among substance abusers when they abstain from substances during their recovery phase. One participant, interviewed immediately following the acupuncture, did not have a chance to experience the effect of acupuncture on his sleep. All other participants described the benefit of better sleep from acupuncture. They emphasized that sleep disturbance was a serious problem during the period of abstinence from substance use.

Billhult 2009

Finding: The experience of being relaxed in body and mind

“I feel relaxed and harmonious. Both in body and mind.”

“And then I became very relaxed. I have never felt anything like this in my whole life”.

“When I leave it feels like I have been to a pedicure, I feel like I float. (Float?) Yes, I think it feels great”.

“It is very comfortable, like being on a beach and just being there. I think it is cosy to feel the warmth of the sun and to be close to the water”.

“I can get these sensations from childhood. It feels wonderful. they are moments when I have felt very well, before all of this [the anxiety] happened”.

“Not even a bomb falling beside me would have made me move”. Relaxation was a sign of comfort and something experienced by the patients as providing energy.

“I had a very positive experience [of the massage] as I became more calm, got rid of tension and things like that.”

“I feel a calmness and harmony that I almost never feel otherwise.”

Finding: The experience of unconditional attention

”I don’t need to perform to get this [the massage].”

“I feel relaxed, since I don’t feel any demands on me.”

”Somebody is doing something for me.”: “Then I might have to be sociable. Nice and funny. I don’t have to be like that here [in the massage room]. I just lie down on the massage table, I just feel great there.”

“In receiving massage I become valuable as a human being. I get so close to the other person that I almost become the other person. That's how I feel.”

Finding: The experience of reduced anxiety

”After the massage I experience another kind of calm. This is inside of me. No heart beats or pressure. In general I feel more relaxed both in body and mind. “

“Something has happened after all, I think that the anxiety has faded somewhat.”

" Yes, it [the massage] helps me in relationships with other people, which is something that I experience as difficult. I am tense and then it is difficult."

“Immediately after the first session, I did not feel worried, neither afterwards nor in the long run.”

“It was when I was here on a Thursday. I was very sad but then it was just like everything changed. I felt well all weekend.”

Finding: The experience of increased self-confidence

“Me being more relaxed results in better functioning in what I do.”

“I have noted that when I was cooking dinner, I relaxed more in my body. Everything worked out better, I got all the right ingredients, and everything simply worked out better.”

“And now I even clean the house, take walks and cook dinner. I am out of bed practically all day now.”

“Because then I have more strength and power.”

“One day I thought: I'm going to take the bus into town as I have been thinking of doing for such a long time. So I did, just to see some people. I really thought that I did a good thing for myself by doing that.”

“I sometimes think negative thoughts, but then I try to think in another way, to counter my own thoughts.”

“ Yes I have less negative thoughts and consider more what really happened.”

“The anxiety automatically decreases because I don't focus on myself, how I look, how I sit and how I stand, because I feel well.”

Herlin 2010

Finding: A sense of fear

In the beginning I could not sleep the night before because I knew that they would canalize my fistula the next morning it was terrible.. (3).

I get so irritated, especially with women that who shout out loudly, just like a child. I wish someone would tell her that it is not alright.if she has anxiety or whatever it is.that we all have .I think about it a lot. what is wrong with her.? (2).

It is so very hard to see other patients around that look very ill, that I can feel, they look so tired.I think: what is wrong with them? They just lie there and sleep. But they are probably tired (7).

Finding: Dependence on caregivers

The personal chemistry must work for me ...otherwise they are not allowed to canalise my fistula....[laughs]. I must have faith in that person, faith is very important. (3). I get so nervous when there are new nurses that are supposed to learn.they really don't know how to do it, so they talk to themselves to remember, and then you get nervous yourself. Then I start to think: do they really put the tubing right? So then I get a little bit worried (5). It was different. some of the

nurses could take my fears of dying - they were very understanding - but some did not understand at all (8). Now when I understand the machine, what the machine really does, I can go in and change the parameter. that makes me feel like I am contributing to my treatment (6).

Finding: Time lost in dialysis

When I got sick, and started with hemodialysis, I felt that I had to use the time. I started to study and therefore I have a life outside the dialysis. Now the dialysis is just a little part of my whole life and the other is with my studies, that is the real me. The dialysis is just something that I do in between (7). You have to go away to the ward and arrive on time, and after the treatment the day is almost over. Those days are not fun. I feel too stressed in the mornings to do something before I leave home (4). It feels like a regular work from 7 to 5, there is no option, I just have to do it, even if it is Christmas Eve, New Year's Eve, it doesn't matter. it is just something that I have to do (6).

Finding: Feelings of loneliness

It is nothing you talk about in the lunchroom: 'I'm having HD treatment!' It is not so fun to say. and then if you meet someone at the pub. I'm alone so that can happen, how do you say it? Should you say it at once? 'I'm going in HD treatment and waiting for a new kidney!' Or should you say it after a week, or a month? (7). To work is something I think is very important. it is the social side. that you get out. otherwise it would have been hard. if I had no work to go to. (1). To work means everything to me. I have to get out and meet people, my colleagues and the social thing. otherwise I do not function. (6).

Finding: Being on a waiting list for a kidney transplantation

To be transplanted means that I have to get through another complicated surgery. and after that it is not for sure that it will work out. that I don't know. And I have understood that there are a lot of medications afterwards (4). Of course I think of the future. The future for me is a transplantation that I am waiting for, and then I hope that everything will work out fine so that I can go back to work full time (3).

Jonsson 2011

Finding: Experiences of symptoms and difficulties

Terribly negative . . . psychologically extremely hard, very hard . . . not once more ... it ran in every possible direction ... it smelled like hell and lying everywhere in that damn mess.

I thought I would have much much more pain.

Finding: Emotional experiences

The worst part is yet to come, if there is anything more now, so that I have to have chemotherapy and of course . . . I'm not looking forward to that . . . but you put that part aside when lying up there, then it catches up with you when you are about to be discharged from hospital.

As I say you always have to get over a barrier before you get used to it, I knew all the time that I and I know I have to get used to it, I know all that and and that's the way it would be . . . but it always takes a couple of days before you on the whole, well this is, this is the way it looks like, but as soon as I started with it so to speak and got past this barrier so to speak and look at it ... I think and its not bothering me anymore.

That was what I feared, because I thought I couldn't live with it . . . I'm not young anymore, I'm of that age and why should I live and have such a thing, such a thing on my abdomen, no I couldn't imagine that.

This fear made you . . . felt worse than you really were I thought and afterwards I can say that a lot was dependent on me being so afraid of rupture, how is it inside now ... I was about to go to the toilet and my stomach function came rather fast . . . there I thought how is this going to be, will it rupture inside and everything come out.

Finding: Influences of the caring environment

There is a lot of movement then . . . that is of the sort of think I think about . . . when night staff come some of them don't speak quietly, some think . . . that it is their dayshift or so to speak, forget that others are sleeping.

Sleeping away from home isn't so very easy, even if you are well. . . there is always some sound ... a fellow patient beside me had a lot of pain and was up every other hour ... I didn't get much sleep, but I slept half an hour at a time and was awake one hour or so, but that's the way it is . . . that's the way it is when there is more than one in the room, that is not possible if you don't have a single-room ... if there is to be peace and quiet but that's a utopia that it would work like that.

Finding: Experiences of being taken care of

One assistant nurse really saw me . . . gave me a down quilt when I said I was cold ... to do such things means a lot as a patient.

It is these three things which I say; thoughtfulness, reflection, what am I doing, it becomes so mechanical, very mechanical.

I could have understood it myself . . . but I might have missed that information.

And next day when she came to work and I felt happy to see her . . . nice to see you . . . and after that a good connection the whole time . . . you feel greater trust in that person.

Finding: Factors influencing postoperative

The eye felt more hunger than the stomach, when you started to eat oh how nice it would be with food . . . but in the end . . . you did not manage to eat so much.

Krohne 2011

Finding: Assigning meaning to the screening experience

P3M: (I remember it) vaguely - I've really experienced so much weird whilst being here - so much out of the ordinary. What I want to say is... so I haven't really got a clear idea about everything.

Finding: Completing the screening test

P14M: It wasn't that it couldn't be done, but at my age. I got tired - this is a weariness I carry with me everywhere (and it kicks in every time) I'm exposed to something complicated.

P4F: I got the impression that I passed the test. Yes. Or you could say it was examination questions, right? KK: You got sort of a school feeling?

P4F: Yes. I didn't pass on all of it - and I really want to be that person who passes...

Finding: Assessing own performance

KK: Is this something you thought about afterwards that you didn't. (manage all)?

P4K: Yes, yes - it's very. yes, I didn't like it. Train, rabbit. no, let's see it was train, rabbit. No, it was house, train. hmmm, let's see; I think it must be house, rabbit, and train.

KK: Yes, you've got it!

P4K: Yes, I have - but it still annoys me. I have to admit

P11M: No, that's something I just close my eyes to and forget - elegantly.

KK: Right.



P11M: That's something I'll suppress.

KK: What do you mean you suppress? Stuff you don't manage or these screenings?

P11M: Nooo, not the screening. Stuff I can't manage, that's what I'll elegantly suppress. .I'm not bothered enough to let it annoy me.

P5M: I think it went well up to a certain point - and then I was finished!

KK: You were finished? Where did you come to a stop?

P4M: It was that subtraction task.

KK: Is this something you've thought about afterwards?

P4M: Some.

KK: What have you been thinking?

P4M: That, by Jove, I'll get even!

P1F: Yes, (I've done it) once before - and things might have been a little clearer for me then. And now I'm not able to write, so just writing my name is a problem.

Finding: What do 'they' do with the cognitive screening test results?

'It is probably to do a little bit of research on what we remember, and...if our heads are where they are supposed to be.' (P1F).

'It's okay to be screened 'cause then [the occupational therapist] gets to see what I really need help to do' (P10F).

Kwok-wei So 2007

Finding: Isolation versus social intercourse

The experience [of receiving internal radiation] was very difficult and painful. It was as if I were in hell. (P1)

I felt it [internal radiation treatment] was like a punishment'. (P4)

[I] stayed there [in the isolation room] for more than 30 hours. I felt as if I was being punished. I would prefer to be in a coma and unconscious.. .lying there [in bed] was quite unbearable. (P4)

I was in the room. The door was very thick, like a wall, and was very heavy - like a few thousand tons. (P1)

The nurses and healthcare workers were quite good. but I did not know how to ask them to help. I mean, the biggest problem was I could not move, right? (P4)

My sister is a Christian. She said they [her sister and friends from the church] would pray for me. Sometimes, friends from the church visited me. That made me feel more comfortable. (P4)

A nurse visited me and chatted with me. I really felt thankful. It made a great difference when a nurse was present and chatted with me when I was facing problems. I told her that I was in great pain. Then she chatted with me. I had forgotten my pain when I chatted with her. I felt very comfortable. I thanked the nurse a lot. (P5)

The nurse helped me to arrange the setting that was convenient to me. This helped me a lot because I could reach things easily...I remembered that the first few hours after the treatment was started I had some discomfort in my abdomen.the nurse comforted me. I think it was very good. (P2)

[My children] told me something about home and let me know what they were doing at that time. I felt I was at home. They told me about their happiness and unhappiness. I felt [as if] they were by my side.(P3)

my first day of treatment was the second day for that woman. She was with me. When we chatted together, my emotions were better. I did not feel nervous - and I could relax during the treatment.(P3)

Finding:Unbearable symptom distress versus endurance and coping

My back felt uncomfortable. Yes, it [back pain] started after 16 hours [in bed]. This type of pain was even worse than death. I felt that my back, vertebrae and pelvis were extremely painful. (P7)

There was more than 30 hours.after the instrument [applicator for the radioactive substance] was put into the body when you could not move and needed to stay totally still. [During the treatment], I had diarrhoea after eating, and so I did not eat. Finally, I did not eat anything and only drank some rice water. (P5).

If I moved, I could feel that the tubes were inserted inside the lower part of my body. At that time, I was afraid that even just a slight movement would cause pain. If I moved, I felt the tube was in my body and then I noticed that I could not move anymore. (P4)

I thought [the effect of radiation] must be very severe. No one wanted to come close to me. There were few doors [in the isolation room] and people came in and

out quickly. Normal people behaved like this. We are the patients who have problems [with a radioactive applicator inserted] in the lower part .what do you think about the effect of radiation on me? I was really worried. I did not know if I would have adverse effects later. (P7)

We comforted each other and said [the treatment] would be finished shortly. After the treatment, we could go back home. Both of us had the common goal that the disease should be treated as soon as possible and we would go back home soon. (P3)

Finding:Growth from the experience

I had to go for internal radiation which lasted for over 30 hours, and this was what worried me most. I had to [go] under anaesthesia as well. I told the physician that I could not bear it anymore. I told my sister that I would die this time. I did not know whether or not I could bear it [the treatment]. (P5)

After I had undergone the internal radiation treatment, I recalled the therapies I had received before. That pain was not a big deal. Those were just little things. It was as simple as a cut. (P1)

Logan 2006

Finding:Creating a Focused Isolation

“While I was in diagnosis, as I say, I almost pulled myself back from anything that I felt was going to interfere with me getting on with what I had to do.”

spirituality “helped me through, well, this whole issue of cancer, and varied dealings with relation-ships with the family.”

“I know when I was having my core biopsy, I think the girls thought that I was . . . because I was doing inner-self and really talking to myself and really shutting them out.”

“Definitely while I was in the process, I wouldn’t have felt comfortable sharing. I was too emotional. Much too emotional; I needed my strength.”

Finding:Seeking Connections

“I never really got a chance to go down enough [get depressed] before I was pulled up again . . . because I have support around me. My husband to start with, who is always with me, and then my sisters. I am not alone, not alone in this.”

“So he was worried, you know, if anything happened to me, what is he going to do with the children?”

“Oh, well, I go around talking to God all day.”

“Prayer is an ongoing thing. And you’re not praying for the same things that you would normally pray for. I guess it’s being rather selfish actually. You’re praying for yourself and that everything is going to be alright.”

“So many people are saying, ‘Well, we’re praying for you,’ and I know they are. And it’s a comfort to me.”

“Oh, well I prayed a lot, and I figured, you know, why should I be saved when somebody else isn’t? Why? So I prayed, but with that sort of ambiguity there.”

“Sometimes I don’t know how to pray, so sometimes you stumble around prayer.” Some participants felt a spiritual connection not associated with religion.

“[God] is for other people. I can’t believe in that sort of thing.”

“Because people here are all very loving and caring. It’s the whole atmosphere; it’s just functional. It has a soothing effect.”

“it was when I could first cry and start to talk about it with someone other than someone who was suffering with me.”

“Someone needs to ask the questions.”

Notter 2006

Finding: Pain and shock

‘I knew it was a big operation but afterwards I was just so weak and the pain was terrible... I had no idea, I thought I’d be tired but this was different. and it took me so long to get over it... I just felt like a wet rag, and I know I looked terrible... I didn’t want anyone to see me I knew they’d be shocked . all those drips and drains and things’

‘my mind just couldn’t let go . every time I moved or breathed it couldn’t be ignored . I’ll never forget it . it’s not like childbirth [this participant had previously had two children] fading as soon as it’s over . I’ll never forget it never .’

‘the reality was something else . I lay there and thought ‘what have I done’ . I’d thought I’d be able to cope with it, after all women are used to pain, with periods and childbirth and so on .’

‘after the pain of childbirth there is such joy . you forget how awful the pain was . with this it goes on and on . there’s nothing [to look forward to]. so you keep wondering will it ever end . I think that’s it you know . labour pains stop once the

baby's born . there's no guarantees with this . no one can tell you when it will stop'

Finding:Body image and sexuality

'he [husband] looked aghast . he went white . I couldn't help I was so weak I cried and that made it worse for him . it's terrible they [families] should be counselled or warned . '

'it was awful . they'd explained it but I just wasn't prepared for the mess I saw . all scars and

'I felt less feminine . I thought look at me who'd want to touch that . my smooth skin had gone, my stomach looked awful . how could I ever lie on a beach again, what would my husband think, would he still want me'

'less of a woman . my husband's wonderful . he really tried but I just knew I wasn't the same . the bag was noisy and it felt odd'

'my husband thinks it is disgusting . we don't mention it . he never saw my stoma I had to keep it covered and he wouldn't talk about it . the whole subject is taboo . I don't think he touched me at all while I had the ileostomy, and he wouldn't let me keep anything in the bathroom, I had to keep it all out of sight . hidden away'

Finding:The loop ileostomy

'I never looked at it . not once . my mother had to change the bag I wouldn't even do it in hospital they thought I get over it but I didn't, I lived with my parents and if it leaked or anything I'd just call mum . she did it for the whole time I had it . '

'spreading across my stomach repulsive.it isn't normal.it smelt .I couldn't seem to get the smell off me no matter how much I washed'

I hated it, they wanted me to wait three months but I made such a fuss they took me back in after six weeks ... they said I wasn't really ready but I didn't care I said I would cope with anything just to get rid of it [the ileostomy] . '

'it's demeaning ... I mean you have to dispose of the bag . it's not like babies nappies, . this is different you can't just bin them, so everyone knows you're different, that you have problems how would you feel having to have special bags . you've got no privacy left . '

'it's as if I'd got something catching . something awful.. I just knew people were talking . I mean how would you feel . I couldn't look any of them in the face'

‘I hadn’t though about it before . but I just didn’t know what to do . I just stood there, I mean it was one of those toilets with walls that stop part way down, anyone next door would have seen what I was doing . I wanted to cry . I just rushed home and waited to get rid of it [the ileostomy]’

‘I can’t ever go out without being all padded up . nothing seems to work . I spend most of my time at home . it’s easier . I keep going back . he [the surgeon] and his staff are very good but nothing changes . but I’m determined to keep the pouch,,, I feel normal now . I go to the toilet like everyone else . I felt mutilated enough by the surgery, having to have a bag that I couldn’t control was dreadful .’

‘I was so relieved that I didn’t have to have one [ileostomy], I really don’t like the idea’

‘I don’t know how I would have coped . my husband would have hated it’

Finding:Role of the general and specialist stoma care or pouch care nurses

‘she [stoma care nurse] was excellent . when she was there I was fine . ’

Persson 2002

## RESULTS

Finding:Alienation from the body

Patient D said, "It looks like a piece of raw meat. The worst of it was when the staff told me to change the appliance myself—to wipe and change it."

One woman described difficulty understanding how the stoma functioned and its unpredictability: "In the morning I saw spots of feces on the bath-room rug. I thought, who is responsible for that? It can't be me."

Finding:Altered Body Image

One woman described emotional shock when looking at the pouch for the first time. One of the women who had lost weight was satisfied with her body and appreciated that she was able to tuck her blouse into her skirt or trousers when the pouch was empty, something she had not been able to do preoperatively.

Finding:Influence on Sexual Life

A woman (patient B) had bought a beautiful long blouse to cover the stoma and the pouch to feel more attractive when she had sex, but she said that "Sex is just not so much fun with the stoma."

Finding:Uncertainty about living with the stoma

One woman (patient H) believed that the pouch was sometimes visible to others, except when she wore a special pair of trousers. A man (patient G) stated, "When I put my trousers on I momentarily think it can be seen but then I do not care." Fears of injuring the stoma also were expressed. Patient A said, "When I lean forward to hammer a board with nails, the stoma will not function." Some of the patients were also anxious that the pouch would come loose during showering.

Finding:Influence on Social Life

Patient C said, "It can be a topic of conversation for people who have no business discussing it!" Patient H said, "I don't like parties and meetings now, I prefer to be alone" because of the fear of flatus incontinence. Patient G said, "I look and wonder if there is any other person like me." Two women who, preoperatively, had experienced frequent and urgent bowel movements, described the enormous relief of planned toilet visits: "Being able to go out shopping without fear of needing the toilet is a huge relief, and life is much more relaxed than before the operation." Relatives were also involved, and subjects shared their concerns with their loved ones.

Finding:Influences on Participation in Sports and Leisure Activities

"I won't take a sauna together with my friends. They will probably think, My Lord, he has a big bag dangling on his stomach. Or maybe I am being too sensitive?"

Finding:Physical Problems Related to the Stoma

Patient B said, "I wake up every morning with a huge balloon on my tummy."

Stephens 2005

Finding:Change on various levels

I'm not the same person because of the..., what I have been through and I am not the same person on every level, spiritual, psychological and physical. and so I can't return to something because if I did it wouldn't be who I am now. It would be to deny something

.... the treatment is so invasive. I never imagined, when I started, that the treatment would leave me feeling the way it did.

Finding:Fear

You have this feeling constantly, you know, it may not be in the forefront of your mind, but it's always there that this disease can come back and grab you.

Because we all know we are going to die but to confront it intensely and in the short space of time was what was really quite demanding.

Finding: Isolation

I think it's (the sense of isolation) more from the transplant actually, I think it's related to that. There are two things that go one. One of them is that, there are not that many other people that have been, there is no one who's been through the identical experience but there aren't that many people that you can talk with that have been through that experience. That's isolating in itself.

Finding: Concern about others' well being and coping skills

Some people have asked me, about it, an' I said it affected (husband's name) more than me I think.'

As a patient, you have not got a choice really, your only choice is whether you just fight or whether you just cope, but as a member of the family or a very close friend, they are just there and they don't ask for, well you don't as a patient, but they're your support and who's helping them.

Finding: Adaptation, adjustment and recovery

you do recover, you can lead a normal life, but I think you have to ... you have to ... gauge yourself as to how far you go, because I found, if I overdid it, for 2 or 3 days after I would suffer for it, you know, and this is after perhaps 9 months to a year.

I think I would be it at about, be at about 40% (of previous energy levels) Sometimes I put it at 30% of what, you know I would normally feel comfortable in doing and mostly that's because I just feel very uncomfortable and nauseated in the mornings and things like that.

I am quite protective of myself now, if I see a kid with a cold I think I must pop over here you know. Or if I am tired then I will say, you know, its 7.30 I am going to bed if I'm tired, if I feel tired in the afternoon I'll have a rest.

the lack of energy was dreadfully frustrating to start with. As time went on I still made big mistakes with it but ... It was during that time, that I had to say to myself, what am I trying to do, am I trying to replicate what I was doing before. I'm certainly not listening to what my body can do now.

Finding: Changes in values, outlook and priorities



'an' it seems to bring things into perspective. What are important and what's just a lot of nonsense

I suppose in a way looking out there at the building opposite one of the analogies that I used for myself its like if I could suddenly see what held the bricks together. I'd seen a building before

Finding:Transplant is a separate and discrete experience from diagnosis and initial treatment

So I feel that these are two very clear points, one was the diagnosis as such when things just obviously changed but over which there was no measurement, no control, no . nothing I could do about it really. Then from the bone marrow transplant afterwards, once I had made up my mind to do that.

Finding:New life

it was like being reborn. What am I going to do with it, am I going to screw it up again and go home .. but I am going to take it and use it properly

Finding:Bereavement

there is a grief aspect, I mean,. uhm ... there is definitely a bereavement because you, . my own experience that I have lost my, lost my life as it was. There is no question and . uhm . I have found something different but certainly I have lost, uhm, what I was doing as well as what I was being and living. So yes there is an enormous bereavement and I think it is parallel.

Therkleson 2010

Finding:Meditative-like stillness and relaxation of thoughts

I am sure many times when the nurse came in I just didn't want to come back into the world, you know, you just wanted to stay there where your body was so lovely and comfy; it was perfect.

It was cosy and warm and I felt like I was floating on a cloud.

From the rushing in and everything being so outwardly alert and living on nerves, I came to a much more peaceful, relaxing situation.

Finding:Constant penetrating body warmth throughout the body

I haven't experienced that warmth before, you sort of feel penetrating warmth that was getting into your bones; it wasn't surface warmth. You know how you

stand in front of a fire and get warm and as soon as you move away it's gone, well this is constant.

It did just seem to spread; my back got warm then it was sort of as if my whole nervous system was saying, 'This is really nice, I'll have some as well'. It spread down both legs and arms, that lovely warmth was so good.

You are relaxed and if you are relaxed it doesn't matter what you are doing you just get on with it and don't think about it. If you are in pain and you can't get up from sitting down or anything the brain takes over and tells you there is an obstruction. I felt a greater freedom once I got off the table and was warmed up.

Finding: Positive change in outlook

Thoughts at the start were all the external things that I have to think about in the day; these quickly disappeared. I could align my thoughts in whatever way I wanted to in daydreaming.

I experienced OA as a disability; like having to get by with a broken part, yet 7 years ago I could hardly keep my feet on the ground and I would run everywhere.

My father died at my age, crippled with OA; in fact my mother became confused and thought I was her husband at one stage.

Some of my family members, they probably didn't know the extent of my disability. Because there is nothing much you can do about it if you keep going on about it. I wasn't actually hiding it; I was just not sharing with anyone. Now I have done a lot of talking to friends and people I have met.

Finding: Increased energy and interest in the world

This week I feel things are flowing, I am going back to a creative style that I thought I had lost in my work; there is more movement in my head and thinking.

After the compress I wake up feeling awesome, awake and alive. I get on with the day and find my thinking is wide awake. It's like a buzz and I am off to work sparking.

After the week's course I spread my wings free and remained flying for about 4 days. I still have increased energy in my thinking and I feel positive.

Finding: Deeply relaxed state that progressed to a gradual shift in pain and increased interest in others

Every day as I lay down the right side of the back became quite tense. I didn't have a sore back when I lay down; it was like the experience of an old pain or

tension. The warmth of the GKC infiltrated and penetrated the body, activating a sense of opening and relaxing, with a gradual release of tension and pain:

It's the warmth that goes through the body from those compresses that causes the relaxation. Whatever the ginger does from then on, when you are relaxed it is able to do its thing.

I was totally relaxed with the GKC; a time free of pain, great.

I came home and my wife ran a mile - not really!

Now I just say 'yes please'. I haven't been good at asking for help and accepting the fact that people are now opening doors for me.

Finding: Increased suppleness within the body

I am not inclined to be self aware of my foot and stuff like that; people will see me limping around but I am so busy I am not aware whether it is hurting or whether I am cold or hot, basically I am just too busy to be aware.

My whole leg is freer, I can get in and out of the car easily, I don't have to lift my leg. When I get out of bed I can walk straight away without a pause and I think I am beginning to stand more evenly.

Now I am standing up straight without even thinking about it. My posture has improved definitely. Also I can't get over that breathing last night, I thought my breathing was so easy; I took a deep breath in and out and found it was a real flow, where before it was very shallow.

By the end of the second compress I did think something was happening. I walked up the road to my friend. It doesn't sound far three doors up the road- but when you have a problem like this it is like a mile.

Finding: More comfortable and flexible joint mobility

I felt the warmth in my hands and there was more movement in the hands; the warmth sort of feeds through the arms.

Having warmed up you are relaxed and moving freer; there is no question about that.

There are certain movements in a cultural performance that means I have to swivel and now I am swivelling without even thinking about it, which I couldn't do before. I have more flexibility and mobility in my hip.

I felt as though I was slightly rejuvenated, with more energy; this continued through to going to bed.

Therkleson and Sherwood 2004

Finding: Patients experience warmth in the body as increasing in intensity and radiating outwards

After a while it got really hot, like a hot water bottle. If it had been as hot as it felt you would have had to take it away. It was quite a tolerable, intense heat ... I actually did put my hand underneath to feel the heat but there was none. That was a real surprise - - to realise the heat was inside me . I asked the nurse to have a look, can you look if it is red? She said no there is nothing to be seen there ... Because it is such an intense, you have to say, heat, it is not warmth, and it is heat. Quite mysterious how it would come from this compress.

The ginger was definitely warming as the ginger worked, definitely warming. Not warmth because of the water but because of the actual plant itself ... at one stage it was quite intense, not uncomfortable, but you definitely noticed more and really felt it and really knew it was not because of the water but real heat from the ginger . definitely more of a chemical reaction sort of heat than a thermal heat from water.

really warming, a definite feeling, a sort of fuzzy sort of warm ... when the compress was taken off, I still felt that warmth. Sort of around the compress area but also it moved down my legs and my feet and up my back. So I could actually feel it was making an effect internally . I actually noticed that my joints felt warmer, particularly in my ankles and knees more than elbows. My peripheral joints, they felt the warmth there.

Finding: Patients experience stimulation of internal activity within their body

I had the sense that I could quickly engage again and get on with it. It seemed I could more easily choose one thing and just do it ... I could do that, then came back and did the next thing and the next thing.

I came home last night and gosh, I felt extremely good ... I stayed up late and vacuumed and cleaned and had a lot of energy. I really felt wonderful.

Finding: Patients experience changes in thought-life, sensory perception and bodily tension

During the compress I had reoccurring incidents from the past which relate to a court hearing I have coming up next week, that I haven't thought about for a long time . it felt like the thoughts were quite persistent playing on this track during the compress and the rest time.

I was actually quite reflective. Then found, as the compress was on, my thoughts came more to present and future, more sort of thinking about what was coming next rather than what had been.

I was aware of my thoughts flying around, it took a while just to come to rest, stillness... I had the sense that they were flying around in an anticlockwise direction a metre above my body. I could see and hear the thoughts.

I had a very disturbed nights sleep afterwards. I do have disturbed nights sleeps for some reason or rather depending occasionally but last night was almost as though I had taken something home with me and hadn't got rid of it ... which I try not to do.

I got tingling in my hands, my hands felt heavy . I had a bit of tingling in my feet . I suppose it was almost like a pressure tingling. The tingling sensation seemed to come from within and cause a sense of pressure, as if there was an internal activation of the dermis.

A strange experience around my fingertips . quite a real pressing, similar as if from the inside when you press on a piano key but it was coming the other way.

Finding:Patients experience centredness within themselves and a greater sense of personal boundary in relation to the world

‘A sense of containment, a grounding, very good. It was definitely not an out there experience, like I couldn’t get out’. Jane continued ‘I felt really incarnated and part of my body and present . centred is the word that keeps coming up because I felt contained in my soul-responses to things and not drawn out’.

‘A shift in how I am in my body . a feeling of being awake and aware through my whole body. I felt just as present in my lower limbs as in my belly, shoulders, arms, everywhere I felt aware of my whole body’.

‘If I would have to put it in a nutshell, calm would be the word I put there, yes, it is a certain stillness, calmness’.

Velji 2001

Finding:Women’s experiences with brachytherapy were embedded within the complete context in which treatment was given, shaped by personal, environmental, and treatment-related factors

. . . . but some of the nurses were exceptionally good. They really were . . . about trying to make me as com-fortable as possible in bed, and the same with washing me for the two days . . . they were really nice with that. And there’s one nurse on

in the afternoon that was exceptionally kind . . . nothing seemed to faze her as far as that goes . . . Well, I could say she was motherly, but that sounds kind of silly at my age because she certainly . . . she was an older woman compared to some of the other young girls. I think she had been a nurse for quite a few years and had a lot of experience and seemed to understand more, especially when my nerves broke down as they did a few times.

One thing, when they say they will come back in, you know, 5, 10 minutes . . . I mean, if it's not going to be for an hour, say an hour . . . that's one thing . . . You know, to me, I thought to myself, you know, well, I'm not a child. If you're not going to be back for an hour, just say it. Don't leave me in this position and say you'll be back . . . or we'll be back to change over in five minutes and you're still kind of holding onto the railings and an hour later . . . I mean, I understood that they were busy . . . don't treat me like a child. If you're not going to be here, tell me an hour. I can take it.

I found that the knowledge of the actual machine was very, very limited. Only a couple of people on a shift actually knew what they were doing. So, that was very frustrating because you're lying in bed and you can hear somebody out there asking somebody questions . . . "Well, what do you do?" and "How do you do this?" and then they'd be pushing different things and you're thinking, "My God, why are they even touching it? Go away."

I personally think if they explained exactly how uncomfortable you are and how much pain you're in, it would have prepared you mentally a little better . . . mechanically, they tell you what it's going to be like, they show you what it's going to be like, but they don't actually know how much discomfort and awful it is . . .

I could see her, you know, laying there in that room and when that throbbing was starting, this is it, this is what I've got to go through for three days, and maybe it'll get worse, you know. I don't know, when I woke up the pain wasn't there any more. I thought, oh, goodness, maybe they're doing something better now. But that's what was in my mind. If Cheryl hadn't died and told me all those horror stories, well, I might have listened more carefully [to the teaching provided].

One thing that I didn't like or at least upset me to a point: they told me I was going down for one o'clock to the operating room . . . by this time, it was two o'clock, but it would have helped my nerves a whole lot if somebody had said, "Well, we're backed up today, and you're not going down quite soon."

. . . but it was uncomfortable, especially when you have to lie on plastic. You know, plastic pillows, plastic sheets, plastic pads, everything . . . so that alone makes you perspire. And I can't seem to lie on plastic too much, so I knew I was

in for a problem even before I went into that bed. But anyway, I found the room was warm, and I got the girls finally to shut the heat off in it, and from then on it was tolerable. For me, that was the difference.

. . . but there's only one thing that's wrong . . . if they would just change the [green] color of those cups they bring you the tea and the soups . . . well, it just made me feel like if I was going to throw up. If they just had a nice white cup . . . nice white . . . I don't know about everybody, but white to me is clean, it's clean, but that green.

Finding: The discomfort women experienced during brachytherapy was perceived as a totality of symptoms, including but not limited to pain

. . . to turn around or to keep lying in one position for a while, that really made you [uncomfortable], and it gave me a pain in my back. My back would kill me . . . I had pain in my lower back. I had a bad back before, so lying that flat . . . yes, all through the treatment. And I guess most of it was I had to be taking a pill for keeping me from going to the washroom, and I think that [made] a lot of discomfort in the stomach, that makes your stomach feel [bloated].

I was on painkillers every three hours, on acetaminophen #3, because my back was just breaking in half. After the first 24 hours, the nurses didn't come in to move you. You had to move yourself. Well, there were two . . . two pains . . . the first pain was from being on your back. So, there was that pain, and then, after the radiation had started, after I had the treatment for probably six to eight hours, then the actual radiation pain on my lower back kicked in . . . like a burning, paining sensation.

I feel that if they gave the patient a pain pump similar to what they do after major surgery, it would be much more advantageous because then you could regulate when you want to move and also when you're sore because there is some pain with the radiation as well. And what helped it was, I finally received acetaminophen-3, and when they were administered every three hours, it really relieved it.

That definitely would be helpful if you were moved every three or four hours, and the second thing that would be most helpful would be if you received a back rub at least every night or at least once a day if not twice a day.

It's funny, I would go upstairs to have a bowel movement and then by time I finished the bowel movement,

I would go in and lay down and to . . . I would go to sleep. I'd be that exhausted from it. That hasn't happened today, I stayed awake. So, I'm feeling much stronger each day, but I feel that I have a long way to go to have even a part of the energy I had. I haven't felt up to going anywhere. I am amazed . . . like

everybody said you will be tired . . . you will be fatigued. And I said, “Yes,” but I’m amazed at the degree of tiredness and I’ve never felt this way before in my life. Just, you know, as I say, the effort of having a bowel movement would put me to bed.

Finding: The brachytherapy experience was characterized by an intense focus on time and tensions embedded in issues related to time

. . . fifty-one hours . . . the machine was scheduled for it. And I kept tabs on that . . . You looked at the clock a lot, and you kept tab of the time that was passing . . . so when they would come in, you know, [you’d] ask, “How much time is left on [the] machine?” you know, so then they laughed and told me. They knew how anxious I was to get it over with. ‘Cause it does seem like a long time, you know, when you think 51 hours, my goodness. And then when it hits 24, you think, oh, good, it’s coming down . . . and how’s the other half, how’s the next half going to be.

. . . one thing that really bothered me, you know, you sit there and think of what they’re doing to you, and you have how many hours you’re going to get of radiation and that. So, you’re looking . . . and mine was 58. And you’re looking at 58, and you’ve got this set in your mind, and you want to get it down, and you want to get it over with. And one thing that really bothered me was every half-hour somebody coming into the room and the minute somebody comes into the room, the machine is shut off, you know. And I got really peeved one night at one of the nurses, and I said, “Why don’t you guys co-ordinate instead of one person coming in and taking my temperature and my blood pressure and then half an hour later somebody else comes in and gives me some pills. I don’t want people to keep interrupting and shutting my machine off.” . . . that’s the biggest thing that bothered me is the amount of time that people walked in. It drove me nuts.

I also found that there was a disrespect for the time because you were on the pulsar. I found that people pulsed off the machine at their convenience rather than waiting . . . for the time off on the machine. There didn’t seem to be a respect for the time off . . . that this is when they should be coming in to do your vitals and to check on you and everything else.

I had heard that it’s not an easy process and, through the booklets and what people explained to me, that you can have company, but every time company comes to visit you, it shuts down the machine and is that much longer that you’re on it. So, I had requested that everybody just stay away. Let me just do my time and just get out of there as fast as possible.

. . . the other thing was looking at the clock and seeing how much time I had left. Another thing I do is visual imaging,



I guess you'd call it. Killing the cancer cells . . . and I took the song "A Hundred Bottles of Beer on the Wall" and I changed it. And I changed it to "A Hundred Cancer Cells on the Wall," take one down, stab, kill it. So I would sing that. I would go through that, and I'd sing it.

. . . if they invent something that you could put a book up on, like a bed tray with a slant on it or something with a ledge that you could put, so you could just lay there and . . . you can't hold your arms . . . lay flat on your back and hold your . . . and try to read. I took letters, ad-dresses, ready to write letters, and I couldn't write. I thought, well, I'll just sleep, I guess. And watch the news.

Worster 2008

Finding: I couldn't believe it

"I was numb, really, numb. If someone had slapped me in the stomach, I wouldn't have felt it. I just couldn't believe it was that. I had no pain, only the discomfort of keep wanting to go to the toilet. I was frightened." (6)

Finding: Being alone

".. because no one else can do anything about my body apart from doctors ... So it was my problem, however much anyone sympathised it was my problem ... that is a lonely position to be in." (13)

"I felt alone because it is my battle and nobody else's. There is nothing anybody can do for you. They can help but you have to fight it ... Nobody else can do it for you so I felt alone ... I mean my children and my husband were very supportive but at the end of the day it is your battle not theirs and I felt very alone." (15)

Finding: Informational needs

".. stacks of it. It was wonderful. It was given to me by the colo-rectal nurse. She loaded me up with so much information it was unbelievable. I found it helpful." (16)

"All the books and instructions they gave me ... I haven't read a thing ..." (9)

"Well the trouble is .. I'm not very well up with medical things. I just don't take an interest in anything like that, so when they said a tumour (it) didn't mean anything to me. It wasn't until after-wards when they said tumour usually means cancer .. It didn't register with me in the least .." (9)

“.. and I said will you hurry up and tell me something please because you’re frightening me and he said we have found a mass. Well I didn’t know what a mass was but I said oh, well, what could I say?”(19)

“I was given lots of leaflets which I read ... right up to about the week before I was going into hospital, I really didn’t think about anything. I didn’t think about it much, but the week before I read and started to get frightened” (6)

“I always repeat what the consultant has said, so that they understand and can question .. we do it in stages. They always want to know what happens next and when and we talk about that. I’m always very honest .. about the wait for certain scans. That brings a lot of agitation because they generally want their

Finding:Protecting family

"... we didn’t tell them until about three days before the operation. They didn’t have an idea so it was a bit of a shock We kept it from them because we all went out at Easter and I thought what is the point in telling them . it’s going to ruin everybody’s Easter. Leave it until as late as possible. So I phoned them ... They were very taken aback, but thought I’d done the right thing. I said, have I hurt you, have I offended you that I didn’t tell you and they said no, because we know that you did it because you were looking out for us, you didn’t want us to worry so they were ok ...” (15)

“my main problem really was that we asked whether my wife could come in before the operation . and visiting times didn't start until 11 o'clock. So we asked, would it be possible for her to come in prior to that because we thought by 11 o'clock I would probably be in theatre, and I knew that it would help her if she had a chance to see me on the day. But they wouldn't let her ... it was deemed that it was just not possible and I thought that that was harsh and unfeeling really. But the chaplain came ... and said that my wife was downstairs in the chapel . . I was wired up to this drip and everything else at that stage, waiting to go down, and I just called the nurse over and said look I would just like to pop down to the chapel for a minute or two, taking my trolley with me, can I do that, and they said yes but don't be long... That is my only criticism I think of the whole of my treatment ...it was harsh and unfeeling.” (2)

Finding:Unexpected consequences of investigations

“.. the worse nightmare of all was when I had this camera job (colonoscopy) done . not a very nice experience. I don’t mean physically, I mean mentally, because you are going through a very nasty place, people working, things going on. There were two doctors who put this camera up and informed me with great glee that they had found the problem. They said look . you must look, and I didn’t want to look. I wanted to put my hands over my eyes and let them do what

they've got to do and somebody tell me a result at a later date ... They were telling me what they had found and would I look. That is stuck in my memory. That was horrible ... It was as though they were pleased they had found something.. to me it was a nightmare. I didn't want something to be found. I certainly didn't want to look at it, and that comes to my mind more than anything . you have got to know in the end I agree, but there must be more subtle ways ...” (14)

“I went for my sigmoidoscopy and I was very tense when they put this little thing up and the nurse said, if you don't relax this is going to be uncomfortable. But all of a sudden I looked up at this screen and there was the inside of my bottom and I was absolutely entranced, which took my mind off what they were doing ...” (8)

“.. nine times out of ten patients will lead you into what they want to know . patients seem to be much happier these days in saying what they want. Some say I don't want to know any of that just tell me when am I coming in, how long the operation going to be and how long am I going to be in hospital. Others will want all the t's crossed . there is a checklist in that there are things we must address ...So there is certain essential information but generally, it is tailored to the individual, because the surgery and circumstances are different. A young man of thirty is very different than someone of 80 ..”(CNS)

Such support was not available in the absence of the CNS, as evidenced below:  
“.. he told me when he was going to do the operation and they had done a scan of some sort . he just said that I have got a tumour, and went on to explain . they found these bits that had escaped into the liver. So that was that because I didn't see him again until the morning of the op when he came and stuck his head in the door and said 'good morning', and he went ...I was devastated, so was my husband, we cried and cried. It was a very lonely time” (11)

“One of them is that pipe they pass down through the nose into the stomach ... That really is pretty unpleasant and . the first time they got the tube in they made a bit of a fist of it. Then . the doctor, whoever, decided they hadn't got the right tube anyway, so they went through the whole thing again. That was not very pleasant ...” (18)

Finding:Loss of control

“I did feel under pressure but I knew they were right. I was just so scared” (3)

“I had the most complete and fully innocent faith in the doctors and nurses that looked after me because I had no real idea what their abilities were. There was nowhere else I could go, nothing else I could do. Well I could have refused to have the operation, to sign the form, so I had a choice. But it did involve utter

reliance upon a group of complete strangers and their professional, fully professional business. But I rationalised that, well I had to do this, I had to have the operation, the only place I could have an operation is in a place like this with a group of people like this. What are you going to do? Are you going to worry about them? Are you going to check their credentials and qualifications or are you going to accept that you have no control over this part of it, they do.’ (13)

“I was scared absolutely witless to the point... when they came to get me I was saying that I’m just not going to have it done. I want to go home. I don’t have to have it done, I’ve got to go home. They still didn’t know whether it was cancerous or not and I was just so scared. I perhaps didn’t really want to know ...I couldn’t phone my husband because he was at work . . . So I phoned my mum . and just said ‘I can’t have it done’, so she said ‘I’ll come in’.

They told me I was going down at 1.00 and my mum got there about 10.00 just as the man came and got me. I said ‘no it is not me’, he said ‘oh yes it is’, I said ‘no it’s not me I’m not going till one’ and my mum said I’ll come with you and ... came through to the anaesthetic room but on the way there, I just basically climbed off the trolley ...I said ‘I know my rights’ and I was being really silly and pathetic ...I was just so scared. I didn’t want to go ... So anyway mum said ‘Please, have this done, have it done for mum because you have come all this way and you have been really good so please have it done’. I said ‘No!’ They went and got the anaesthetist ... basically I just gave in I think in the end.’ (3)

“I wasn’t at all prepared mentally for that operation. I had almost gone into the theatre quite light-hearted. People have often said, ‘Oh you’re so brave’ ...I had no idea of the enormity of a big operation ...” (8)

“Tuesday came, which was the day of the operation, and then I started to be a bit anxious about what was going to go on, not knowing what to expect really ...” (2)

Bryar 1997

Finding: The Hardest Thing We Ever Did

I couldn’t even have imagined. Until you’ve had the experience you don’t even know how badly things can go wrong.

I made the mistake of asking her if everything looked okay, and she didn’t answer. She said, well, there are a few things I want the doctor to look at. So at this point I become almost hysterical because something’s wrong and she knows it.

The sonographer was chat chat chat; then she just stopped talking to me. And I thought, okay this is bad.

I could never have envisioned how bad it was.

It was pretty bad. Went from just walking around crying to the first night, I didn't sleep at all. There were all sorts of things just running through my head, partly, I think, because you didn't know that much about the disease.

I think I kept grasping. If there's a chance for it to work out or go away, and in a nice way she was kind of saying no. So we both of us just walked out of there really shell-shocked. . . .

They said we could just arrange to have the D&E and I was like, wait, wait, no, no. You know, this has been like 20 hours or something. I never imagined myself making these decisions, and I sure don't imagine myself making them in 10 minutes.

It was real surprising to me how strongly I felt that I didn't want to end the pregnancy. When I think of people ending their pregnancies, I thought it was a real black and white issue.

That's the decision we had made, that if something was wrong we were going to terminate the pregnancy. It wasn't, "Oh my God, there's something wrong." It was, "Oh my God, I'm going to have to kill my baby." I'm Catholic, I've been programmed to think like this. I truly believed that I would go to hell for doing this, and I haven't been a practicing Catholic for a very, very, very long time.

I guess I thought a lot about quality of life and is it fair to the baby, a baby that was going to have so many difficulties. We thought, too, of all the kids you could adopt, a child that needed a home. To bring in a baby that was going to have so many difficulties, you know, is that right? It wouldn't have been fair to us. It wouldn't have been fair to the other kids. It wouldn't have been fair to this kid. On a family that's pretty much strained already, it would've been just too much.

Our mantra has become, what are we going to get out of this? You just saw all these babies and you really looked at them as a miracle.

The initial finding out and dealing with it was such a growing-together experience. You just look at each other and say, "If we can live through this, arguing about taking out the garbage ceases to be important."

We decided to go ahead and allow that (research on the fetal ovaries) because it feels like some good comes out of what happened and maybe it would help somebody else.

I keep telling her I want to feel normal again. My normal has changed, and I'm going to have to look very hard to realize when I'm feeling normal again. Your normal isn't like it used to be. Your perspective has changed. Your everything has changed. Facing the fear describes a new vulnerability that women

experienced as they were forced to realize that any pregnancy can be abnormal, even if they do all the “right” things.

You end up living with this lie that you tell people. You tell them you had a miscarriage. It’s a pretty sad and devastating thing, but it’s not something you initiate. It’s just kind of God’s will. It happens and then you just try again.

... the days that I’m fine in the morning, and by noon I’m in the pits and then by 3 I’m okay again. Or the whole day that I go on and I’m okay, and then all of the sudden that night I feel guilty because I haven’t felt sad during the day.

It’s a real smack in the face, I mean, that threw me for a good couple of days, it was just like I’m really, really not pregnant. It’s sort of like, okay, my body’s healthy again, when is my mind going to catch up? You know then that your hormones are sort of getting back to normal, so you can’t blame your roller coaster on your hormones.

Finding: Saying Hello and Goodbye

I thought this didn’t count. It was only 4 1/2 months, you know? It wasn’t a full-blown thing. It was devastating.

We had read their advice on holding the baby and naming the baby, and both of us had wanted nothing to do with that. We wanted not to feel very connected to the baby, didn’t want to know the sex of the baby.

We came to the conclusion that the baby had a heart-beat, and the reason she had a heartbeat was because I was her lifeline. This was a baby on life support, basically, and I was her life support, and that was a turning point in our decision. If we’re in a horrible accident and a machine is pumping our blood and making us breathe and doing everything for us, we don’t want to live like that. If it’s good enough for us, why isn’t it good enough for this baby?

We just spent the day getting acquainted with our baby and cried on and off. We packed up our stuff, and I didn’t want to leave [the hospital]. He [husband] wanted to bring her home and bury her on the property. He didn’t want to leave her there.

Making memories is really important, too. If I could see her or if I could, you know, all I have is my imagination. I want to remember her the way I think she would look as opposed to the way she really did look. I went into the hospital pregnant, and I come out of the hospital not pregnant and I have nothing. I have nothing.

Forsberg 2000

#### Finding: Facing the inevitable

The hardest thing for me in spite of all was the fact that I was 60 years old. There are so many young people who haven't lived as long as I have and who might need this liver, this organ more than me. Why should I be so fortunate to receive this? This was the final obstacle for me when I was facing the fact.

#### Finding: Recapturing the body

I remember it was so hard because I couldn't sleep. The wound was leaking and I had to go up and put towels on it. I was cold and wet. I was terribly tired and worn out. The body needs energy and to rest. It's an enormous bodily strain. You want to feel well and cannot accept that it takes time. The pain after the surgery was hideous. I had unbearable, terrible pain in my back. They had no idea how much pain I had.

I haven't felt the slightest bit interest in sex. Hugging but no more. It has been gone since the operation but now its back at last. It has been a great problem and I have felt uncomfortable over all. Touching was OK but at a certain point I hid behind my shelter. It's a maturity thing. It takes about a year. It's easier now, not 100%, but we try. My husband has been very supportive. I haven't discussed this with anyone but I don't think I'm the only one in this situation. I felt very broken inside, with the intestine and all that. It didn't work. You felt like a wound, an open wound only healed on the surface. Then you are not ready for intimacy. You want to protect yourself.

#### Finding: Emotional chaos

Mentally I feel different than usual. I view life in a new perspective. I am grateful to have received a new life. Sometimes I feel born again. Sometimes I am very depressed, sometimes I enjoy life.

I experienced attacks of anxiety, fear of death, ordinary attacks of anxiety. Everything you can imagine. I ran out in the corridors totally wrecked. I couldn't find me. Who am I? Where do I come from? I was completely dizzy. It was like the familiar me but the safety I had felt was no longer there. Instead there was a new person. The whole identity, you became new, a new person, sort. The expression in my eyes looks different and everything, my skin, hair and nails, everything is affected.

#### Finding: Leaving the experts

When I came to my local hospital I had a depression so to speak. I felt abandoned in some way when I came there. You have more time to share here [at the transplantation unit] than they have. I got my own little room and when you stepped out into the corridor there was nobody with the same experience. Here

there are other patients who have been in the same situation. So it was hard. I felt lonely.

So I went home. It was a separation. It was final. In Gothenburg the treatment is so intense in everything, blood tests, blood pressure, temperature and all those things, and suddenly nothing. In some way the theoretical bit is a precondition for the liver functioning. Then you are left alone. What will happen now? You imagine that you can go to bed healthy and the next day you are half dead. Deep inside I guess is the fear of not making it. You have come so far and you can see that you will get well. Then you don't want to take a chance. The tests themselves are not a guarantee of the complete well functioning liver, but somehow that is what you believe.

Finding: Family and friends

It seems like people are afraid of inviting me to their homes. Now when I don't drink anymore they dare not invite me to their parties because maybe they want to have a drink themselves. So they don't want to tempt me into trying to drink again. I am always alone. No one ever keeps in touch, suggesting going out or inviting me to someone. My sister has been strange. She hasn't spoken to me since I was in hospital. She said: 'You have yourself to blame'. I called her once after the transplantation and then she said: 'I don't want to talk to you. I give you one year maximum'. 'I don't want anything from you', I said. The rest of the friends, well, they talk to me on the phone, but they never invite me. It hasn't happened one single time, but I manage.

Finding: The threat of graft rejection

You feel betrayed. You can't trust your own body. In spite of all it hasn't become a part of me. You don't feel sick when the liver test results are high. Then I try to convince myself that it's good to find out early and attend to it, but you are disappointed. You don't trust your body, but I guess it's because it's a threat. Is this the beginning of the end? I thought a lot. I actually did. Will it become worse and worse? How long time do I have left? I thought a lot about that.

The feeling is there every time I visit the out-patient clinic. I am very scared of it all, I really am, but it's something I have to learn to live with. As long as I take my medicines I'm not supposed to have this feeling, but it's constantly there in the back of my mind. It's hard, the test results have been stable and then I've become more calm, but the fear of rejection will never go away. That is what I believe.

When I had those rejection episodes I was more fixed to them every time. I saw a pattern as well as what was changing every time there was a possible rejection. I partly could read the signs by myself. So I was terribly nervous when I was on



my way to the lab. Not to mention when I was waiting for the results. That was worse than anything. I was doing very well the first 3 months and then I had three rejection episodes the following 3 months. Each time it became more traumatic. I doubted that I would ever be better. How could this go on? The liver tests wouldn't stabilize and suddenly every tiny change made a difference.

Finding: Honouring the donor

I am thinking about the poor person who died and then I got the chance to survive. From what I have understood it's a man because I've found out that it must be a man donating to another man. I have thought a lot about the depth of gratitude you owe that person who lost his life to save mine.

We gave this liver a name. We called it Jansson. Why we called it so, I don't know. It just happened. In the beginning it was something unfamiliar which was left to me to take care. I walked around holding it like when I was pregnant. I was surrounding the liver with my hands the way you hold your stomach during pregnancy. As time went on it was more like a gift which ought to be treasured. It came very strong to me when they were planning a liver biopsy due to a rejection episode. I didn't like it but I knew it wouldn't hurt. Suddenly I found out what brought my concern. I had received this liver and it was mine. I disliked touching it. After that, it has grown to be a part of me and the feelings of carrying another person's liver disappeared rather quickly. I feel grateful for someone giving it to me. I have decided to be grateful, but most of all I will keep it safe and treasure it.

Jonsen 1998

Finding: Going downhill

Life went only backwards and quickly downhill.

Life went straight downhill and to hell.

I had no life.

Finding: Defence and denial

How unfair that this disease should hit me.

I wonder, why just me? I don't think it's fair. Others denied that they had the disease or repressed it. Statements highlighting this included:

I'm ill, but I have repressed it

I concentrated and worked harder so I had no time to think about the disease

Finding: A chance of surviving

Hope to be better.

Hope that it will not get worse.

Hope to stop the disease.

From no chance to some chance.

A feeling of help.

Finding: The decision — no choice

There was no alternative, I saw the outcome of my mother.

If there had been any other treatment, I should have chosen that.

My first thought was: no, taking out my liver, never.

I was afraid of the operation, I was uncertain about the outcome. Things I don't know about scare me. They had told me that they were not sure about the outcome.

Finding: Waiting powerless and uncertain

It was the longest months of my whole life.

Finding: The first few steps after surgery

It's over now.

Waking up alive.

Having made it.

A very good and peaceful time.

Feel safe now.

Even feelings of euphoria were mentioned:

After the operation it was being high on junk, everything was plain sailing.

I was very unprepared, shocked and sad, when they removed the drain and my gall bladder was destroyed. This experience was worse than the operation.

Poor physical condition was also described as a common unexpected result:

Completely exhausted.

Had no power.

Shabby.

Half-dead.

Feelings like insecurity and lack of control were mentioned. These feelings made some of the informants reflect upon death and relapse into their disease, which threatened both their hope and their future. Behavioural changes were also experienced by some informants, for instance increased self-centredness and sentimentality, less tolerance and confused identity. Many informants reported hypochondria, illustrated by the following statements: I watched my body very carefully, I thought I was ill the first half-year, I was uncertain if I was in a safe haven.

I watch my body more carefully than a healthy person does.

Finding: Freed from the death sentence — the bright side

I am not going downhill now, I'm slowly on my way up. I can see the possibilities of life now.

This filled the informants with joy, relief, power and hope. Accordingly, they experienced greater quality of life:

A more worthy life now.

A new life.

Psychologically better.

Life is easier.

A more positive life.

Can see a future.

Finding: Still disabled — the dark side

It's hard for me today, because I cannot do what I want to do with my hands and feet; things I want to do but can't do.

The fact that my feet and legs are out of order affects my every-day life.

It has been hard to accept and learn to cope with the fact that my hands haven't become any better and that I can't do any more now than before the transplantation.

I feel inferior, because I cannot fix the things I could fix before.

Finding: Mastering up strength to recover

I fight for my children. Having a father like they had before is important to them.

Training is important, coping with everyday life.

I have been so anxious to train. It keeps me going, that's why I am so well as I am today.

The physiotherapy group has supported me a lot. It made me feel less alone. A person needs to know that she isn't alone.

I long for a suitable job.

I dream about water and about feeling it — to take a swim in the ocean and feel the water.

Finding: Need for support and help

My journey home was poorly planned. They helped me out from the hospital, then I had to manage on my own.

They should have told me that when I come home my next hell will start and I will have no bell to ring.

It has been easier for me than for my wife.

## References

Archer J., Hayter M.. Screening men for prostate cancer in general practice: experience of men receiving an equivocal PSA (prostate specific antigen) test result. *Primary Health Care Research and Development*.2006; 7( 1): 124-134.

Altender R.R., Kenner C., Greene D., Pohorecki S. The Lived Experience of Women Who Undergo Prenatal Diagnostic Testing Due to Elevated Serum Alpha-Fetoprotein Screening. *MCN The American Journal of Maternal/Child Nursing*.1998; 23( 4): 180-186.

Backstrom S, Wynn R, Sorlie T. Coronary bypass surgery patients' experiences with treatment and perioperative care - a qualitative interview-based study. *Journal of Nursing Management*.2006; 14( 1): 140-147.

Beck CT. The Lived Experience of Postpartum Depression: A Phenomenological Study. *Nursing Research*. 1992;41(3):166-70.

Bernstein K.S. The Experience of Acupuncture for Treatment of Substance Dependence. *Journal of Nursing Scholarship*.2000; 32( 3): 267-272.

Billhult A., Maatta S. Light pressure massage for patients with severe anxiety. *Complementary Therapies in Clinical Practice* .2009; 15 (1): 96-101.

Bondas-Salonen T. New mothers' experiences of postpartum care – a phenomenological follow-up study. *Journal of Clinical Nursing*. 1998;7:165–74.

Bryant R, Young A, Cesario S, Binder B. Transition of Chronically Ill Youth to Adult Health Care: Experience of Youth With Hemoglobinopathy. *J Pediatr Health Care* 2011;25:275-83.

Bryar S.H.. One Day You're Pregnant and One Day You're Not: Pregnancy Interruption for Fetal Anomalies. JOGNN.1997; 26( 1): 559-566.

Buckley RP. Edmund Husserl. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. Encyclopedia of Phenomenology. Dordrecht: Kluwer Academic Publishers; 1997. p. 326-33.

Cerbone DR. Understanding Phenomenology. Durham UK: Acumen 2006.

Cohen MZ, Omery A. Schools of Phenomenology: Implications for Research. In: Morse JM, editor. Critical Issues in Qualitative Research Methods. Thousand Oaks California: Sage; 1994. p. 136-56.

Colaizzi PF. Psychological Research as the Phenomenologist Views It. In: Valle RS, King M, editors. Existential-Phenomenological Alternatives for Psychology. New York: Oxford University Press; 1978. p. 48-71.

Crotty M. Phenomenology and Nursing Research. Melbourne: Churchill Livingstone; 1996.

Davidson L. Phenomenological research in schizophrenia: From philosophical anthropology to empirical science. Journal of Phenomenological Psychology. 1994;25(1):104-30.

Dudley T., Chaplin D., Clifford C., Mutimer D.J. Quality of life after liver transplantation for hepatitis C infection. Qual Life Res.2007; 16( 1): 1299-1308.

Dreyfus HL, Wrathall MA, editors. A Companion to Phenomenology and Existentialism. Oxford UK: Blackwell Publishing; 2006.

Esbensen BA, Swane CE, Hallberg IR, Thome B. Being given a cancer diagnosis in old age: A phenomenological study. *International Journal of Nursing Studies* 2008;45:393–405.

Embree L. *Reflective Analysis. A First Introduction into Phenomenological Investigation*. Second Edition. Bucharest: Zeta Books, 2011.

Embree L. Constitutive phenomenology of the natural attitude. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. *Encyclopedia of Phenomenology*. Dordrecht: Kluwer Academic Publishers; 1997. p. 114-6.

Finlay L. *Phenomenology for Therapists. Researching the Lived World*. Oxford: Wiley-Blackwell; 2011.

Forsberg A., Backman L., Moller A.. Experiencing liver transplantation: a phenomenological approach. *Journal of Advanced Nursing*.2000; 32( 2): 327-334.

Giorgi A. *The Descriptive Phenomenological Method in Psychology. A Modified Husserlian Approach*. Pittsburgh, Pennsylvania: Duquesne University Press; 2009.

Giorgi A, editor. *Phenomenology and Psychological Research*. Pittsburgh PA: Duquesne University Press; 1985.

Giorgi A. Sketch of a Psychological Phenomenological Method. In: Giorgi A, editor. *Phenomenology and Psychological Research*. Pittsburgh PA: Duquesne University Press; 1985. p. 8-22.

Herlin C, Wann-Hansson C. The experience of being 30–45 years of age and depending on haemodialysis treatment: a phenomenological study. *Scand J Caring Sci*. 2010;24:693–9.

Hershberger PE, Kavanaugh K. Enhancing pregnant, donor oocyte recipient women's health in the infertility clinic and beyond: a phenomenological investigation of caring behaviour. *Journal of Clinical Nursing*. 2008;17:2820–8.

Husserl E. The thesis of the natural standpoint and its suspension. In: Kockelmans JJ, editor. *Phenomenology: The Philosophy of Edmund Husserl and Its Interpretation*. New York: Doubleday & Company Inc; 1967.

Husserl E. On Eidetic Reduction. In: Kockelmans JJ, editor. *Phenomenology The Philosophy of Edmund Husserl and Its Interpretation*. New York: Doubleday & Company Inc; 1967.

Husserl E. *The Idea of Phenomenology. A Translation of Die Idee der Phanomenologie Husserliana II*. Translation and Introduction by Lee Hardy. Dordrecht: Kluwer Academic Publishers; 1999.

Husserl E. *Ideas: General Introduction to Pure Phenomenology*. Translated by W. R. Boyce Gibson. London: George Allen & Unwin Ltd; 1931.

Husserl E. *Cartesian Meditations. An Introduction to Phenomenology*. Translated by Dorion Cairns. The Hague: Martinus Nijhoff Publishers; 1960.

Husserl E. *Phenomenology and the Crisis of Philosophy. (Philosophy as Rigorous Science and Philosophy and the Crisis of European Man)* Translated with Notes and Introduction by Quentin Lauer. New York: Harper & Row; 1965.

Husserl E. *The Crisis of European Sciences and Transcendental Phenomenology. An Introduction to Phenomenological Philosophy*. Translated by David Carr. Evanston: Northwestern University Press; 1970.



Husserl E. Phenomenology and The Foundations of the Sciences. Third Book. Ideas Pertaining To a Pure Phenomenology and To A Phenomenological Philosophy. Translated by Ted E. Klein and William E. Pohl. The Hague: Martinus Nijhoff Publishers; 1980.

Husserl E. Ideas Pertaining To A Pure Phenomenology and To A Phenomenological Philosophy. First Book. General Introduction To A Pure Phenomenology. Translated by F. Kersten. The Hague: Martinus Nijhoff Publishers; 1983.

Husserl E. Ideas Pertaining to A Pure Phenomenology and To A Phenomenological Philosophy. Second Book. Studies in the Phenomenology of Constitution. Translated by Richard Rojcewicz and Andre Schuwer. Dordrecht: Kluwer Academic Publishers; 1989.

Husserl E. The Basic Problems of Phenomenology. From The Lectures, Winter Semester, 1910-1911. Translated by Ingo Farin and James G. Hart. Dordrecht: Springer; 2006.

Iaquinta ML, Larrabee JH. Phenomenological Lived Experience of Patients With Rheumatoid Arthritis. Nurs Care Qual. 2004;19(3):280-9.

Jaromahum J, Fowler S. Lived Experiences of Eating After Esophagectomy: A Phenomenological Study. MedSurg Nursing 2010;19(2):96-100.

Jonsen E., Athlin E., Suhr O.. Familial amyloidotic patients' experience of the disease and of liver transplantation. Journal of Advanced Nursing. 1998; 27( 1): 52-58.

Jonsson C.A., Stenberg A., Frisman G.H.. The lived experience of the early postoperative period after colorectal cancer surgery. European Journal of Cancer Care. 2011; 20( 1): 248-256.

Keaton K.A., Pierce L.L.. Cardiac Therapy for Men with Coronary Artery Disease: The Lived Experience. *Journal of Holistic Nursing*.2000; 18( 1): 63-85.

Kersten F. Intentionality. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. *Encyclopedia of Phenomenology*. Dordrecht: Kluwer Academic Publishers; 1997. p. 350-5.

Kisiel T. Husserl and Heidegger. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. *Encyclopedia of Phenomenology*. Dordrecht: Kluwer Academic Publishers; 1997. p. 333-9.

Kockelmans JJ, editor. *Phenomenology. The Philosophy of Edmund Husserl and Its Interpretation*. New York: Anchor Books Doubleday & Company Inc; 1967.

Kockelmans JJ. Some fundamental themes of Husserl's Phenomenology. In: Kockelmans JJ, editor. *Phenomenology The Philosophy of Edmund Husserl and Its Interpretation*. New York: Anchor Books Doubleday & Company Inc; 1967.

Kockelmans JJ. *Edmund Husserl's Phenomenology*. West Lafayette, Indiana, USA: Purdue University Press; 1994.

Kersten F. Constitutive Phenomenology. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. *Encyclopedia of Phenomenology*. Dordrecht: Kluwer Academic Publishers; 1997. p. 110-4.

Krohne K., Slettebo A., Bergland A.. Cognitive screening tests as experienced by older hospitalised patients: a qualitative study. *Scandinavian Journal of Caring Studies*.2011; 25( 1): 679-687.

Kwok-wei W., Chui Y-y.. Women's experience of internal radiation treatment for uterine cervical cancer. *Journal of Advanced Nursing*.2007; 60( 2): 154-161.

Lackey N.R., Gates M.F., Brown G.. African American Women's Experiences With the Initial Discovery, Diagnosis, and Treatment of Breast Cancer. *ONF*.2001; 28( 3): 519-527.

Liu F, Williams R.M., Liu H-E, Chien N-H. The lived experience of persons with lower extremity amputation. *Journal of Clinical Nursing*.2010; 19( 1): 2152-2161.

Logan J., Hackbusch-Pinto R., De Grasse C.E.. Women Undergoing Breast Diagnostics: The Lived Experience of Spirituality. *Oncology Nursing Forum*.2006; 33( 1): 121-126.

Levinas E. Intuition of Essences. In: Kockelmans JJ, editor. *Phenomenology The Philosophy of Edmund Husserl and Its Interpretation*. New York: Anchor Books Doubleday & Company Inc; 1967.

Lauer JQ. *The Triumph of Subjectivity. An Introduction to Transcendental Phenomenology*. New York: Fordham University Press; 1958.

Logan J, Hackbusch-Pinto R, De Grasse CE. Women Undergoing Breast Diagnostics: The Lived Experience of Spirituality. *Oncology Nursing Forum*. 2006;33(1):121-6.

McCahill L.E., Hamel-Bissell B.P.. The patient lived experience for surgical treatment of colorectal liver metastases: A phenomenological study. *Palliative and Supportive Care*.2009; 7( 01): 65-73.

Moran D. *Introduction to Phenomenology*. New York: Routledge; 2000.

Moran D. *Edmund Husserl Founder of Phenomenology*. Cambridge UK: Polity Press; 2005.

Macann C. *Four Phenomenological Philosophers: Husserl, Heidegger, Sartre, Merleau-Ponty*. London: Routledge; 1993.

McKeown F. The experiences of older people on discharge from hospital following assessment by the public health nurse. *Journal of Clinical Nursing*. 2007;16:469–76.

Mitchell T, Turton P. „Chemobrain“: concentration and memory effects in people receiving chemotherapy – a descriptive phenomenological study. *European Journal of Cancer Care* 2011;20:539–48.

McKenna WR. *Epoche and Reduction*. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. *Encyclopedia of Phenomenology*. Dordrecht: Kluwer Academic Publishers; 1997. p. 177-80.

Mohanty JN. *Meaning*. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. *Encyclopedia of Phenomenology*. Dordrecht: Kluwer Academic Publishers; 1997. p. 443-6.

Natanson M, editor. *Phenomenology and the Social Sciences*. Evanston: Northwestern University Press; 1973.

Norlyk A, Harder I. What Makes a Phenomenological Study Phenomenological? An Analysis of Peer-Reviewed Empirical Nursing Studies. *Qualitative Health Research*. 2010;20(3):420–31.

Notter J, Burnard P. Preparing for loop ileostomy surgery: Women’s accounts from a qualitative study. *International Journal of Nursing Studies* 2006;43:147-59.

Paley P. Husserl, phenomenology and nursing. *Journal of Advanced Nursing* 1997;26:187–93.

Paley P. Phenomenology as rhetoric. *Nursing Inquiry* 2005;12:106–16.

Pearson A. Evidence about clients' experience and concerns. In: Hoffmann T, Bennett S, Del Mar C, editors. *Evidence-Based Practice Across The Health Professions*. Sydney: Churchill Livingstone Elsevier; 2010.

Pearson A, Field J, Jordan Z. *Evidence-Based Clinical Practice in Nursing and Health Care. Assimilating Research, Experience and Expertise*. Oxford UK: Blackwell Publishing; 2007.

Pearson A, Robertson-Malt S, Rittenmeyer L. *Synthesizing Qualitative Evidence*. Philadelphia, PA: Lippincott Williams & Wilkins Wolters Kluwer; 2011.

Pearson A, Weeks S, Stern C. *Translation Science and the JBI Model of Evidence-Based Healthcare*. Philadelphia, PA: Lippincott Williams & Wilkins Wolters Kluwer; 2011.

Persson E., Hellstrom A-L.. Experiences of Swedish Men and Women 6 to 12 Weeks after Ostomy Surgery. *JWOCN*.2002; 29( 1): 103-8.

Polkinghorne DE. Phenomenological Research Methods. In: Valle RS, Halling S, editors. *Existential-Phenomenological Perspectives in Psychology: Exploring the Breadth of Human Experience*. New York: Plenum Press; 1989. p. 41-60.

Ray MA. The Richness of Phenomenology: Philosophic, Theoretic, and Methodologic Concerns. In: Morse JM, editor. *Critical Issues in Qualitative Research Methods*. Thousand Oaks California: Sage 1994. p. 117-33.

Reeder HP. *The Theory and Practice of Husserl's Phenomenology*. Second Edition. Bucharest: Zeta Books, 2010.

Scanlon J. Eidetic Method. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. Encyclopedia of Phenomenology. Dordrecht: Kluwer Academic Publishers; 1997. p. 168-71.

Sintay R.K.M.. Lived experiences of patients undergoing cardiac rehabilitation. Asian Journal of Health.2011; 1( 1): 58-65.

Schmitt R. Husserl's transcendental-phenomenological reduction. In: Kockelmans JJ, editor. Phenomenology The Philosophy of Edmund Husserl and Its Interpretation. New York: Anchor Books Doubleday & Company Inc; 1967.

Smith B. Realistic Phenomenology. In: Embree L, Behnke EA, Carr D, Evans JC, Huertas-Jourda J, Kockelmans JJ, et al., editors. Encyclopedia of Phenomenology. Dordrecht: Kluwer Academic Publishers; 1997. p. 586-90.

Spiegelberg H. The Context of Phenomenological Movement. The Hague: Martinus Nijhoff; 1981.

Spiegelberg H. Doing Phenomenology: Essays On and In Phenomenology. The Hague: Martinus Nijhoff; 1975.

Spiegelberg H. The Phenomenological Movement: A Historical Introduction. Third revised and enlarged ed. The Hague: Martinus Nijhoff Publishers; 1982.

Stephens M.. The lived experience post-autologous haematopoietic stem cell transplant (HSCT): a phenomenological study. European Journal of Oncology Nursing.2005; 9( 1): 204-215.

Svenaesus F. The Hermeneutics of Medicine and the Phenomenology of Health. Steps Towards a Philosophy of Medical Practice. Dordrecht: Kluwer Academic Publishers; 2010.

Svenaesus F. The Phenomenology of Health and Illness. In: Toombs SK, editor. Handbook of phenomenology and medicine. Dordrecht: Kluwer Academic Publishers; 2001. p. 87-108.

Therkleson T. Ginger compress therapy for adults with osteoarthritis. Journal of Advanced Nursing.2010; 66( 10): 2225-2233.

Therkleson T., Sherwood P.. Patients' Experience of the External Therapeutic Application of Ginger by Anthroposophically Trained Nurses. Indo-Pacific Journal of Phenomenology.2004; 4( 1): 1-11.

Toombs SK. The Meaning of Illness. A Phenomenological Account of the Different Perspectives of Physician and Patient. Boston: Kluwer Academic Publishers; 1993.

Toombs SK. Introduction: Phenomenology and Medicine. In: Toombs SK, editor. Handbook of phenomenology and medicine. Dordrecht: Kluwer Academic publishers; 2001. p. 1-26.

Van Manen M. Researching Lived Experience. Human Science For An Action Sensitive Pedagogy. New York: State University of New York, 1990.

Velji K., Fitch M.. The Experience of Women Receiving Brachytherapy for Gynecologic Cancer. ONF.2001; 28( 4): 743-751.

Wall C., Glenn S., Poole H.. Experiences prior to diagnosis of non-Hodgkin lymphoma: a phenomenological study. Journal of Advanced Nursing.2011; 67( 11): 2363-2372.

Ward-Smith P.. Stereotactic radiosurgery for malignant brain tumors: the patient's perspective. Journal of Neuroscience Nursing.1997; 29( 2): 117-124.

Wiederhold D., Langer G., Landenberg M.. Ambivalent Lived Experience and Instruction Need of Patients in the Early Period After Kidney Transplantation: A Phenomenological Study. *Nephrology Nursing Journal*.2011; 38( 5): 417-423.

Woodruff Smith D. Husserl. Milton Park, Abingdon, Oxon UK: Routledge; 2007.

Worster B., Holmes S. The preoperative experience of patients undergoing surgery for colorectal cancer: A phenomenological study. *European Journal of Oncology Nursing*.2008; 12( 1): 418-424.

Yegdich T. In the name of Husserl: nursing in pursuit of the things-in-themselves. *Nursing Inquiry* 2000;7:29–40.