

# Patient Education Materials from a person-centred perspective

– *Coping and co-design in colorectal  
cancer care*

Frida Smith

Institute of Health and Care Sciences at  
Sahlgrenska Academy  
University of Gothenburg

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frida.smith@vgregion.se

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*Till mamma*



# Abstract

To cope with possible stressful events after colorectal cancer surgery, patients need to be prepared for the early postoperative phase. Complementary written information is often used, but requires improvement. The overall aim for this thesis was to describe patient reported stressful events and coping strategies and with a person-centred approach characterize existing and co-design new patient education materials for patients undergoing colorectal cancer surgery.

Situational coping reported by 105 patients 4-6 weeks after colorectal cancer surgery were described in study I by using the Daily coping assessment instrument. Self reported stressful events along with coping strategies used and if considered helpful or not were analysed from 523 diary entries. In study II, 125 Patient Education Materials from 27 hospitals in Sweden were examined for readability, suitability and comprehensibility with a mixed method design. Using a validated instrument revealed that 44 % of the discharge information was not suitable. Language technology measures showed that up to 29 % of materials were difficult to understand. Analysis of five focus groups with 15 patients revealed additional areas to be included in new materials. A new Patient Education Material was developed with stakeholders (patients, professionals and researchers) using a participatory methodology design. In study III, negotiations derived by areas of tensions were reflected on and presented. Main tensions were related to power structures. Parallel to this, in study IV, principles on how to design Patient Education Materials by combining the dimensions of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> person described in Action research as voice and in Ricoeur's philosophy as self were developed from a theoretical analysis.

As a whole, the thesis is built upon the principles of first, second and third person perspective used as a philosophical and theoretical basis to present a workable example in a practical setting. The results can benefit both patients and other relevant stakeholders in the healthcare system in developing written patient education materials.

## Keywords

Person-centred care, colorectal cancer, coping, written information, patient education materials, participatory co-design.



# Sammanfattning på svenska

För att kunna återhämta sig på ett bra sätt efter ett stort kirurgiskt ingrepp behöver man som patient vara så förberedd som möjligt. Postoperativ återhämtning innebär en återgång till den nivå av oberoende eller beroende personen hade före det kirurgiska ingreppet. Genom att återta kontroll över fysiska, psykiska och sociala funktioner kan personen tackla de stressfulla händelser som kan uppstå på ett mer adekvat sätt. Ett begrepp som betecknar hur personen tacklar och hanterar stressfyllda händelser ur ett relativt medvetet perspektiv är coping. Alla människor har olika strategier för coping och dessa kan vara mer eller mindre framgångsrika och utgår ofta från känslor kopplade till tidigare händelser i livet. Kolorektal cancer (KRC) är den tredje mest vanliga cancerdiagnosen i Europa och innebär i nuläget kirurgi som primär behandling när bot är möjlig. Återhämtning efter KRC-kirurgi innefattar både generella och specifika symptom, såsom smärta, illamående, förändrade avföringsvanor, sårläkning och i vissa fall anpassning till ett liv med stomi. För att åstadkomma en snabb återhämtning enligt evidensbaserade kriterier behöver patienten vara delaktig och motiverad. Patienter efterfrågar skriftlig information som ett komplement till muntlig men uppger ofta att informationen inte varit tillräcklig för att kunna förbereda sig och återhämta sig som de önskat. Hälsolitteracitet innebär den förmåga en person har för att kunna ta till sig och använda information om sin hälsa, men hur hälsolitterat en person är kan variera och påverkas av yttre förhållanden som stress och oro. Vårdpersonal behöver ha ett holistiskt perspektiv på postoperativ återhämtning, där fler aspekter än de enbart fysiska får uppmärksamhet. Att arbeta utifrån personcentrerade principer innebär att man ser personen som en tillfällig patient med unik expertkunskap om sig själv. Denna kunskap ska tas tillvara på samma sätt som annan kunskap och patienten ska vara en självklar medlem av vårdteamet. All vård ska ske i ett partnerskap som också ska dokumenteras och utvärderas. Denna avhandling undersöker hur ett personcentrerat förhållningssätt kan appliceras på skriftligt informationsmaterial för patienter diagnostiserade med kolorektal cancer som ska genomgå elektiv (planerad) kirurgi.

Delstudie ett undersökte vilka stressfyllda händelser som rapporterades fem dagar i rad av 105 patienter 4-6 veckor efter kirurgi för KRC, vilka copingstrategier som användes och om de ansåg som framgångsrika eller

inte. Analysen av 523 ifyllda formulär visade att även om många inte upplever några stressfyllda händelser alls, så var flertalet påverkade av händelser kopplade både till operationen och till livet i allmänhet. Värst upplevdes händelser kopplade till smärta och illamående och flest använde acceptans eller direkt agerande (gjorde något åt saken) som copingstrategi. Hur framgångsrik en copingstrategi var gick inte att koppla till en specifik grupp händelser och kan därför inte generaliseras. Coping är individuellt och måste utgå från personens berättelse om tidigare händelser i livet.

I delstudie två undersöktes läsbarhet, förståelighet och lämplighet i 125 skriftliga informationsmaterial från 27 svenska sjukhus med tre metoder; ett validerat instrument, språkteknologi och fokusgruppsintervjuer. Analyserna visade att även om de flesta materialen blev bedömda som lämpliga, så brast de i interaktion och motivation till läsning. Bland de som enbart berörde utskrivning bedömdes 44 % som undermåliga. Nära 30 % bedömdes ha ett för svårt språk utifrån språkteknologiska bedömningskriterier. De fem fokusgruppernas 15 deltagare uttryckte en avsaknad av områden som inte blev bedömda eller framkom med de andra metoderna.

Utifrån resultaten av delstudie ett och två utvecklades ett nytt skriftligt informations- och samtalsstöd. Detta gjordes i en strukturerad co-design metod, där tidigare patienter och vårdpersonal var med från början i designen tillsammans med forskare och andra experter. Under arbetsprocessen analyserades hur forskarna hanterade de intressekonflikter som uppstod och hur de lyckades balansera spänningar så att allas kunskap och åsikter togs tillvara. Mönster som tydde på hierarkiska maktstrukturer framkom, framför allt när det gällde vem som till slut bestämde vad som ansågs som validerad och värdefull kunskap. Det blev tydligt att det var ovan för vårdpersonal och svårt för forskare att se patienter som kompetenta deltagare i utvecklingsarbete.

Parallellt med delstudie tre gjordes en teoretisk analys där principer för första, andra och tredje person som utgick från aktionsforskning och Ricouers filosofi jämfördes och slogs samman till en modell för framtagande av skriftlig information utifrån ett personcentrerat förhållningssätt.

Avhandlingens fyra delarbeten kan läsas separat, men utgör tillsammans ett bidrag till ett växande forskningsfält, personcentrerad vård, och visar hur filosofi och teori kan användas i ett praktiskt exempel, vilket också svarar an på patientcentrerade kriterier i den nationella cancerstrategin och den nya patientlagens del om information till patienter.

# List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Smith, F., Öhlén, J., Persson, L-O., Carlsson, E.  
*Daily Assessment of Coping in early postoperative recovery after colorectal cancer surgery*  
Manuscript, 2016.
- II. Smith, F., Carlsson, E., Kokkinakis, D., Forsberg, M., Kodeda, K., Sawatzky, R., Friberg, F., Öhlén, J.  
*Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: A mixed method design*  
Patient Education & Counselling 2014; 94(2): 202–209.
- III. Smith, F., Wallengren, C., Öhlén, J.  
*Participatory design in education materials in a healthcare context*  
Action Research, 2016. Doi 10.1177/1476750316646832
- IV. Smith, F., Carlsson, E., Wallengren, C., Öhlén, J.  
*Principles on how to design and develop patient education materials to function as tools in person-centered care – a synthesis of Action Research and Person philosophy*  
Submitted.



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# Abbreviation

AR	Action research
CRC	Colorectal cancer
DCA	Daily Coping Assessment instrument
IRR	Inter rater reliability
PCC	Person-centred care
PEM	Patient education materials
RN	Registered Nurse
SAM+CAM	Suitability and Comprehensibility Assessment of Materials



# Preface

My journey as a researcher started rather reluctantly. I had been working at the colorectal surgery clinic at Sahlgrenska University Hospital/Östra since I graduated as a registered nurse in 2003, both at the ward and at the outpatient clinic. Apart from my daily work, which consisted mostly in working as a contact nurse for patients diagnosed with colorectal cancer (CRC), I was also the chairman of the regional network for nurses working with this diagnosis. This work entailed writing regional and national care-programs with help and support from the Oncological Centre, later Regional Cancer Centre west. During the work of preparing, writing, presenting and trying to implement the care-programs I learned a lot about cancer care from perspectives previously unknown to me. I also learned about quality improvement work and became keen to use my knowledge “at home”. When asking the head of surgery department if I could do such work part time at the clinic, I was told that I could, but only if it was done as research, something I had not considered and thought time-consuming and somewhat ineffective. However, the academic world had always been tempting to me, and I had already finished my specialist nurse education in cancer care, which meant I was allowed to become a PhD-student.

Simultaneously, the Centre for Person-centred Care (GPCC) was formed at Gothenburg University, and research about CRC and learning from patients in palliative care was already on going at the oncological clinic. There was also excellent research performed at the stoma-care department at Östra, and a new research team was formed to develop and work with a larger program: Person-centred Information and Communication in Colorectal Cancer Care – PINCORE. The PINCORE program became one of the core-programs of GPCC in which I became the PhD-student. The studies in this thesis are a part of this complex intervention program aiming at increasing the preparedness for patients diagnosed with CRC and scheduled to undergo elective surgery. Three Swedish hospitals were included in both the PINCORE-project and the thesis studies; one university hospital in Gothenburg, one more rural regional hospital and one smaller private non-profit hospital placed in a large city.

An intervention concept for communication was developed and tested together with the new Patient Education Material (PEM) from study III. Workshops with staff at all three sites were performed, where the principles of person-centred care were presented and a model for communication and the new PEM

were introduced. Pre- and post intervention data was collected. Included patients filled in questionnaires at five time points: after given information about surgery, but before admission to hospital, at submission from hospital, 4-6 weeks after surgery, 3-months after surgery and finally 6 months after surgery. Instruments used were EORTC-QLQC-30, the Distress-thermometer, Sense of Coherence, Daily Coping Assessment and Preparedness, a new instrument developed and validated within the program.

Parallel to my PhD-studies, I was working at the Regional Cancer Centre west as a quality manager. My main tasks involved, and still does, the facilitation for development and implementation of contact nurses for all cancer-patients together with the development work of an individual, written care plan; "My care plan". Part of the work entailed developing an education for contact nurses both regionally and nationally.

As a clinical nurse, I had found communication and dialogue particularly interesting and wanted to share and develop my knowledge in this area. The two tracks in which I was involved shared the belief of a capable person behind the patient and someone who's knowledge needed to be better used and paid attention to. Therefore, the studies included in this thesis can be seen as a parallel process to the practical work I have done and still perform structurally in cancer care, and likewise the research contributes with knowledge to the structural work to improve cancer care from the patients' perspective.

# 1. Introduction

When exposed to stressful events, people react differently depending on situation, context and other traits that can be referred to as personality or having previous experiences (1). Often people try to regain control over a chaotic situation by seeking more knowledge about what is going on, what will happen and what I can do myself to affect the outcome. If the stressful event is related to being diagnosed with cancer and exposed to treatment such as surgery or chemotherapy, there might also be a fear of death with existential questions arising (2). The person might have lost loved ones to cancer, worry about children and other family members, be in great pain or suffer from other symptoms such as fatigue or nausea. At the same time, the person needs to gather strength and courage to deal with postoperative recovery and possible side effects of treatment. All this can affect how information is interpreted and how the person can be prepared and cope with the inextricable situation that has been forced upon oneself. Most people can recognize a lack of cognitive ability to comprehend and incorporate information given in a stressful encounter, health related or not, as well as people working within health care often consider how to best present the information for it to be useful. Both patients and nurses can often recall situations when the information provided couldn't be used as knowledge to act upon after the word cancer had been spoken, even if repeated and complemented as written information.

This thesis uses a person-centred approach as an ethics to research in collaboration with stakeholders. It also puts the approach in the practical setting of written patient education materials (PEM) in colorectal cancer (CRC) surgery by first examining what stressful events patients experience during early recovery and how they cope with these events. Secondly, the quality of existing PEM from both a textual and a patient's perspective point of view was examined. Using the knowledge from these two studies, an Action Research approach was used in the development of a new PEM and finally the knowledge gained from these three studies was theorized.

As a whole, the thesis is built upon the principles of first, second and third person perspective used as a philosophical and theoretical basis to present a workable example in a practical setting.



## 2. Background

### 2.1. Person-Centred Care

Person-centred Care (PCC) is a way to look at the patient as a partner in care, and a member of the care team. Biomedical research and positivistic research have made enormous impact on survival rate and treatment options, but at a possible price of seeing patients as objects in specialized units (3). In today's society, there is a call for a more person-centred approach in healthcare. In Sweden, most professional and societal organizations such as the Swedish Society of Nursing, the Swedish Association of Local Authorities and Regions (SKL) and regional political governments have decided to work towards such approaches. Even if the statements of the necessity to work in such a way are strong, with evidence becoming more substantial, there is still a lack in the knowledge in how to do it and make it sustainable.

Historically, the start of modern health care research did not occur until the mid 1800's, and the big breakthrough came as late as after the Second World War. In two parallel processes, medicine and care have somewhat struggled to understand, use and interrelate to each other's field of knowledge. Medicine became more and more specialized, and the separation between the body as an object or a subject became more obvious. Phenomenologists have shown an interest in the dualistic way of looking at somebody with an illness: the objective, distanced look of medical science and the experiences of a lived body from a person who is suffering (4). Person-centred care tries to incorporate both views, but putting the subject first, i.e. the person. It can be explained as the difference between a "what" and a "who", or describing a patient and telling the narrative of a person. The difference between the two can also be seen as a reversible something (a patient) and an irreversible someone (a person), in the sense that being a patient is a role amongst many other roles a person has, but whatever present role, the person you are remains. You cannot be a patient without also being a person, but you are always a person even when you are not a patient.

Person-centred care can be seen as an attempt to make a change in the attitudes of seeing the patient as a passive object with a specific disease to an active partner with experience, context, history, family and loved ones, individual strengths and weaknesses (3, 5, 6). All these attributes can be used to provide

better care in a partnership between patients and providers, and form true dialog and democracy in decision –making.

To ensure that PCC is systematically and consistently practiced, a three-step model to establish routines that initiate, integrate, and safeguard PCC in daily clinical practice, has been developed by the University of Gothenburg Centre for Person-centred care (3). It involves three routines; first initiating the partnership through using patient narratives, then working the partnership as shared decision making and last safeguarding the partnership in documenting the narrative. A narrative in this sense means that the staff actively asks the patient to share personal experiences and thus enables the person to appear, i.e. experiences, capacities, wishes and needs that can be related to how the person will handle the disease, and not just be exposed to treatment options. If a care-plan is discussed and planned together with the patient as a true member of the team, it is believed that that person will have a better chance of achieving the goals of treatment, than if he or she had just been “involved” in a later stage when the plan is in fact just presented to be accepted or not. By also documenting the partnership and the decisions made together with the patient, it is ensured that the narrative and partnership can be incorporated and evaluated alongside medical bio-marks (3, 7-9).

## 2.2. Surgery as treatment in colorectal cancer care

Cancer treatment is often thought of as chemotherapy and radiotherapy, but for many diagnoses, surgery is primary and only curable treatment. Colorectal cancer, being the third most common type of cancer in the world as a whole (10), but also in Europe (11) has surgery as primary treatment, often combined with chemotherapy or radiotherapy. Surgery can be performed as either open or laparoscopic; with no difference on survival rate (11) but with less symptoms and possibly higher quality of life if laparoscopic surgery is possible (12). Evidence of best treatment guidelines has been produced by the ERAS society (13, 14) to enhance recovery after surgery. In Sweden, a national care-program was launched in 2016 (15), and this program recommends adherence to the ERAS guidelines. In short, the guidelines contain several pre- peri- and postoperative factors to minimize risks, nausea and pain and hence enable the patient a fast-track program with a short hospital stay. Since the ERAS-guidelines put new demands on patient participation in preparing and rehabilitation, information and counselling is considered crucial for it’s success.

Depending on the location of the tumour, a resection of the colon or upper rectum is performed. The tumour and adherent lymph nodes are removed and sent for pathological staging and the ends of the intestine are sewn together, cre-

ating an anastomosis. If the tumour is located in the lower parts of the rectum, an abdominoperianal resection including sphincter resection is performed, resulting in a permanent stoma. Results from the pathological staging determine whether the patient will be offered adjuvant chemotherapy for six months or not. Evidence of the usefulness of this treatment is somewhat incoherent (16, 17), but since there is a possibility to promote recurrence (particularly for stage III tumours), the Swedish national care program recommend this utilization (15). Radio- and chemotherapy can also be offered to the patients pre-surgery, again depending on location and staging of the tumour. Apart from general knowledge about the postoperative recovery, such as wound care and pain management (18), CRC-surgery provides risks of specific symptoms during early rehabilitation that need to be addressed. These include diarrhoea, stomach pain, nausea, vomiting, feeling bloated and having difficulty eating (19, 20). Health-related quality of life may drop as a consequence from having pain, experiencing fatigue and worry about limitations in life in the case of a stoma being performed (21). Additionally, patients have reported existential concerns when returning home after CRC-surgery (2) and the information need about the surgery and how to handle symptoms at home not being coherent with the information provided (22, 23).

### 2.2.1. Postoperative recovery

Postoperative recovery has been defined theoretically through a concept analysis (24) as “an energy-requiring process of returning to normality and wholeness as defined by comparative standards, achieved by regaining control over physical, psychological, social, and habitual functions, which results in returning to pre-operative levels of independence/dependence in activities of daily living and an optimum level of psychological well-being”. This means that postoperative recovery is complex and includes different turning points where the person is returning to normality and wholeness. Allvin et al (24, 25) state the importance for health care staff to embrace the holistic definition of postoperative recovery as something that exists beyond discharge and does not solemnly involve the lack of bodily symptoms. By having such a holistic perspective, health care professionals can help the patient to return to preoperative levels of independence and dependency. This definition also responds well to a person-centred approach where the person’s resources are enhanced and encouraged and the patient is seen as a partner in the care team. The findings of using a person-centred approach leading to an improved discharge process (26) might be relevant for CRC-surgery as well, and thereby respond to the demands of the patients’ being

a vital part of their own rehabilitation stated in the protocols for best care (13, 14).

## 2.3. Written Patient Education Materials

Written information is often delivered as a complement to oral information before or after a medical procedure (27). Used as Patient Education Materials (PEM) they provide information, advice and/or counselling about the procedures and care the intended reader is about to undertake (28), and is often asked for by the patients (29). There are many things to consider on how to design the PEM to enhance the readability and comprehensibility (28, 30-32). From a review by Hoffman and Worrall (30), supported by others, (28, 31, 33) the main recommendations for designing effective written health education materials are to involve all key stakeholders, including patients, in the development and testing of the written material, and especially try to obtain the following characteristics in the design of PEM:

### Content

- Clearly state the purpose of the material
- Focus on providing information that is behaviour-focussed
- Ensure that the content is accurate, up-to-date, evidence-based and sources appropriately referenced

### Language

- Avoid judgemental or patronising language
- Aim for low reading level
- Use short sentences, expressing only one idea per sentence
- Use short words, preferably one to two syllables, where possible
- Use common words wherever possible. Avoid the use of jargon or abbreviations. Include a glossary if necessary
- Write in the active voice and in a conversational style
- Write in the second person (you instead of the patient)
- Structure sentences so that the context or old information is presented before new information (To lower your risk of stroke (context), you will need to make changes to what you eat (new information))

#### Organization

- Sequence the information so that the information that patients most want is at the beginning
- Use subheadings
- Present the information using bulleted lists where possible
- Group related information into lists, no more than 5 points in each list, and label each list descriptively
- Keep paragraphs short and express only one idea per paragraph
- Summarize the main points, either at the end of sections or end of the material

#### Layout and typography

- Use a minimum 12 point font size
- Avoid the use of italics and all capitals
- Only use bold type to emphasize key words or paragraphs
- Ensure good contrast between the font colour and the background

#### Illustrations

- Only use illustrations if they will enhance the reader's understanding
- Use simple-line drawings that are likely to be familiar to the reader
- Use an explanatory caption with each illustration

#### Learning and motivation

- Incorporate features that actively engage the reader (blank space for questions, short quiz, list 3 things you should do) (30)p. 1171

### 2.3.1. Written information production and patient participation

Written information is said to be only effective if it can be read, understood and used by the intended reader (30). Despite the evidence of the importance of design and production, many PEM are internally produced by clinicians (34) and hence possibly diminishing the chances of producing excellent materials. Only following guidelines and toolkits on how to best present text in health care context might not cover aspects from a patients' perspective, something that was

found by McCarthy et al (35). Apart from this, there is evidence that PEM became more relevant, readable and understandable if patients were involved in the development process (36-38). Buckley et al (39) found that having a patient perspective when developing discharge instructions provided meaningful guidance that would have been missed if only following guidelines.

## 2.4. Patient and public participation in research

Patient and public participation or involvement in research is becoming increasingly more common, due to an international interest and demand of involving the stakeholders in the matters that concern themselves (40). Having patient participation in research have shown beneficial in all stages of the research process, but can also be challenging from particularly power and ethical points of view (41). It can also cause validity problems, where the academic dissemination is proceeded and is found to be time consuming and costly. The quality of this kind of research is however considered not completely sufficient to standard requirements, and more rigorous evidence is desirable (42). Persons with a cancer diagnosis involved in research must be seen as a valuable resource with explicit knowledge. Health care professionals are used to do things for patients, but need to be encouraged to do things with them (43, 44), and this applies to patients as well (42, 45).

## 2.5. Policies related to the thesis

In relation to the ambition to contribute to the development of theory in the field of PEM development, particularly in the early postoperative recovery phase of CRC, this thesis builds upon two policies: the national cancer strategy and the updated Swedish patient law.

In Sweden a national cancer strategy was launched in 2009 (46). This was an attempt from the government to provide an equal cancer care of high quality, since there were significant regional differences in both treatment and care. From this, six regional cancer-centres were formed with ten criteria to work from. One of these criteria was “the patients position” where it was specified that an individual care plan was to be developed and used. This plan should be different from the normal medical care plan in that it would be written from the patients’ view, with different questions asked and addressed. Cancer rehabilitation should also be included. From the work of a group consisting of both patients and staff, a template for what was named “My care-plan” was created. The

key-question from which the plan evolves is “What is most important for you today” complemented with a timeline of planned actions. The plan does not need to be incorporated in the patient’s chart, but any care action provided must be able to be found according to documentation standards. The care-plan should be owned by the patient and is not for healthcare staff to use for communicating between themselves, even if it is desirable to be able to read what has been communicated earlier. The work of developing such plans is under progress, both as e-support and as printed products, but not in full use to this date. Further research of both development and use has been suggested to be needed, but was not incorporated in the assignment to the RCC or in the development work of the template.

In 2015, there was a new law launched in Sweden (2014:821). This was really an enhancement from already existing laws, but putting more of a patient perspective on the responsibilities from the health care providers. In the section about information, it is stated that, “the patient should be given individually adapted information about his or her health condition, methods for investigation, care and treatment.... The information should be adapted to the receiver’s age, maturity, experience, linguistic background and individual conditions. The person giving the information must, as far as possible, make sure that the receiver has understood the content and meaning of the information provided. Information should be written...” The writings of this new law thereby put more demand on the health care professionals to take active measures to ensure the information has been received and understood by the patient. It also relates well to the description of “My care-plan”. However, the description of information in these policies is still relatively one-dimensional, with a sender and a receiver of static information, and does not clarify assimilation and learning from a patient’s perspective. This calls for a different attitude to which person-centred care can respond.



## 3. Theoretical perspectives

Throughout the work of the four included studies, person-centeredness has been an approach and used as an orientation to care, although the thesis does not include studies that are designed to implement or evaluate PCC per se. Theoretical perspectives that share a similar epistemology to PCC, that is that knowledge should be created in partnership, have been used together with methodologies that respond to the research aim. Person-centredness, coping and health literacy are first introduced and later put in the perspective of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> person.

### 3.1. Philosophical orientation: Person-centredness

The French philosopher Paul Ricoeur (47), talks about two different identity concepts; the substantial identity of an object –*idem* - which relates to what something is, and the identity of a reflecting self - *ipse* – relating to who somebody is. Talking about personal identity, you have to start with *ipse*, otherwise there will be no possible way to reach the perspectives of a person. This cannot be solitude, but must be mediated through interaction with other people, where **who** I am is anchored in the many roles of **what** I am. A narrative identity can, according to Ricoeur, oscillate between a lower point, where *ipse* and *idem* are at risk of being mixed, and a higher point where *ipse* might exist without *idem*. Translated into a medical discourse, this can be recognised as only seeing the patient without the person's attributes, or not acknowledging the benefits of medical science and/or treatment. Hence, having the perspective of *ipse* being superior, presupposes a complementary between person and patient, and could in this perspective be considered a prerequisite for person-centred care (4). Further, Ricoeur talks about an asymmetrical reciprocity, which might be seen as a challenge to the often-hierarchical structures of healthcare. In this perspective, several elements both enhance and correct each other. First; the reversibility of having the role as a patient, secondly; the irreplaceability of being a person, and thirdly; the equality and similarity between people, that in a PCC-context corresponds to partnership.

## 3.2. Coping

Coping as a concept has been used extensively in health care research. It focuses on how a person handles a stressful event, in all everyday situations as well as illness related. Lazarus and Folkman's (48) traditional definition of coping as "constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of a person" (p. 141), means that coping is process-oriented and something the individual (consciously) uses to deal with threatening situations, rather than relying on habitual, automatized behaviour. If coping is ineffective, it can have negative consequence on health, morale and social interactions, just as the opposite is true for successful coping, where stress is likely to remain under control. Lazarus also defined stress as a relation between the person and the world around her, where the person perceives a threat as to demanding to deal with, according to the ability the person sees herself possesses to handle the event and also to the emotions triggered and the meaning given by the person. This, according to Lazarus, is why people react differently to a seemingly similar stressful event. Coping strategies are then the active, cognitive response to these events, i.e. what the person does to endure, reduce or tolerate what has happened. When measuring coping and coping strategies two major functions emerged in research: problem-focused or emotion-focused coping. This polarised way of seeing coping was however not something that Lazarus (1) agreed with in later years, where he stated that seeing these (as he refers them to) functions as independent types of coping is a serious mistake, as they actually complement each other in stressful situations.

It is also pointed out that the process of coping with a specific threat, varies depending on the context, and the adaptational significance and requirements of these threats must be specified and treated separately rather than focusing on the overall illness (49). This means that even if many stressful events are similar to patients post CRC-surgery, the experience, reaction and coping might differ depending on time of the event, personality and capability. Experiencing the same symptom can trigger different emotions depending on what personal experiences the person have. If having gone through other types of surgery for instance, with good or bad results or experiences, can give the person a preconception that will affect the emotions, the meaning and also the coping of the stressful event. Lazarus (1) clearly marked in later years that the coping process cannot be separated from the person doing the coping in a specific situational context: "Knowing adequately those who cope – that is, describing them as persons in a particular environment.." (p. 21). He also developed his theory to include four interacting processes: appraising, coping, the flow of actions and reactions, and relational

meaning. This theory even more stresses the importance of knowing the background, i.e. why somebody reacts in a certain way to a specific event has to do with emotions gained and triggered from previous situations and that the reaction/action as a whole might be greater than the sum of the parts. Similar thoughts are described by Smith (50) as emergence, and can relate to the concept of narrative used in person-centred care literature (3, 6). Finding out more about coping mechanism is thereby a difficult task, balancing between generalizable knowledge to be individually adapted in a health care encounter such as CRC care and rehabilitation.

### 3.3. Health literacy

Health literacy is the ability of a person to acquire, understand and use information about one's health, including cognitive and social functions (51). Health literacy can be considered as a polarized phenomenon (you have or you have not), or as a complex phenomenon (52). It can be seen as something: a) *functional* relating to reading skills and education level, b) *interactive* where the cognitive skills are combined with social skills to extract information and derive information from different sources and in different situations, and c) *critical*, which is an even more advanced cognitive skill to evaluate the importance of the information provided (53). Mårtensson and Hensing (52) however promote the idea of health literacy also being something dynamic, which might fluctuate depending on the state of the individual, the situation, the culture or the environment. Put in the context of this thesis, it means that a person in a threatening context can have difficulty assimilating information to knowledge guiding to actions and hence be less prepared to cope with stressful events during the recovery phase. Preparedness is described by Friberg et al (54) as a cognitive-emotive-existential state and should be related to how the nurse needs to view the patient as a learning person. There might be a discrepancy between what is perceived as being said or heard or handed out as written information. Exposed to a stressful event at home can thereby be harder to cope with if health literacy was or still is affected negatively due to a possibly threatening situation. Finding and following the correct advice on how to act might be a difficult task to overcome.

### 3.3.1. Assimilation of text

The relationship between a writer and a reader of text and particularly how text can or should be interpreted has involved many fields of thoughts, including philosophy. Ricoeur (55) has taken the philosophical idea of the death of the writer as soon as the text is produced one step further. When a text is produced, the writer becomes a reader amongst others, independent on his or her intents with the text. The text now belongs to the reader to interpret, but for a reader to be able to interpret and utilize meaning of the text, there has to be, according to Ricoeur, a complementary act of more existential character. Here, the reader must endeavour to assimilate the text into his or her own world and life. This means that the text cannot solely be projected to the self, but the self has to be expanded through meeting the new world that the text is suggesting. By assimilating the text, the reader gives “the world in front of the text” a meaning that changes a situation into a world where the expanded self now lives and acts. In a cancer context, this can be seen as the difference of reading and cognitively understanding information when it does not actually concern you, to when the information forces you as a person to deal with a new life-threatening world of examinations, treatment and recovery. The self has to be expanded for the person to understand the text from a new perspective and hence assimilate and give the words a meaning.

### 3.3.2. Co-construction of knowledge

One of the research approaches to involve the public as participants and co-constructors of knowledge is action research (AR). Action Research has many definitions, but the key-components are a will to make improvement and change together with the persons involved and an attempt to describe the processes of change and learning from a scientific point of view (56-59). Brydon-Miller et al describe the set of shared beliefs of AR as “a respect for people and for the knowledge and experience they bring to the research process, a belief in the ability of democratic processes to achieve positive social change, and a commitment to action” (60) (p.15). It aims to increase the ability to control one’s own destiny and develop skills to improving the capacity of people, all in a sustainable and just environment (57). In short, it means doing research with people instead of on people, something also in congruence with ethical considerations stressed when co-constructive learning, collaboration and participation are discussed (41, 43, 61). The power of AR rests, according to Brydon-Miller and Coghlan on “its ability to take on complex systems and multifaceted problems without expecting simple answers but with a commitment to honouring the knowledge and experi-

ence of others and working together to bring about positive change” (62) (p 227).

### 3.4. First, second and third person

*Returning to Ricoeur* and “Oneself as another”, Kristensson-Uggla has developed this hermeneutics of the self into first, second and third person personalism (4). This attempt to incorporate the different perspectives in an updated view on personal identity, offers a more structured way to meet the challenges in today's health care. A person cannot be understood as somebody existing only in first person singularise, simply because already here there is a relation between me and I, myself, and then himself into ourselves. The sentence “I have decided to...” (svenska: jag har bestämt mig) reveals evidence of a discussion or reflection within that person. Language presupposes interaction with other humans, as do human actions. There has to be an “I” that interact with others in an institutional context. Ricoeur himself concludes this ethical intention as “Aiming at the good life with and for others in just institutions”(63). Put in health care context, this can be interpreted as a need to both give and get help from both individuals and the larger community/institution such as health care processes. Kristensson-Uggla (4) defines this as a “complex dynamic of first, second and third person personalism, where relations with oneself, dialogic relations and institutional relations are intertwined in a discontinuous continuity”. The three dimensions on person can further be related to foundations of AR, coping and health literacy.

*In action research, three voices can be heard:* first, second and third person's voice. In traditional research, only third person's voice is presented, when researchers are doing research on persons, presenting it to other third persons in reports and manuscripts (56, 64). Using a first person voice means that the researcher inquires his or her behaviour, assumptions and desires both in the world in general, and in the research project specifically. Second-person inquiry focuses on how the research is performed in a face-to-face dialogue in a collaborative and democratic process.

*Coping can also be seen from* a first, second and third person perspective, where I as a person must find strategies to cope with something threatening happening to me. This is the core of coping where, as described above, how I react to a stressor depends on both my personality and on previous experiences. This intrapersonal appraisal of the threat is then transferred into an action or reaction that is displayed in an interpersonal relationship where a relational meaning is constructed (1). How the person experiencing the threat is then appraising the situation again determines the emotions to a possible new threat or as a helpful

encounter. In the context of healthcare, the third person perspective can be seen as the organization in which the care should take place, and where the first person perspective will be exposed to several second person encounters that delivers both threats and provides support.

*Finally, also health literacy can be seen from the three dimensions of person.* The third person here is the provider of the generic health information to be delivered and can refer to official evidence-based documents such as published research, guidelines, care-programs and legislations. Other less validated information on Internet or in the daily press that people search for or are provided with can also be considered as a 3<sup>rd</sup> person provider of information. There is no interaction between a sender and a receiver and the encounter is one-dimensional. When a person is being informed about a health related matter in a 2<sup>nd</sup> person encounter, and possibly provided with a PEM, this information should become knowledge to be gained through interaction and dialogue. How this knowledge is transferred and received depends upon factors related to readability, suitability and comprehensibility, all related to who the person behind the patient is. The 1<sup>st</sup> person perspective is when this knowledge is assimilated in an expanded self and can relate to the dynamic features of health literacy in a complex situation, such as being diagnosed with cancer.

## 4. Rationale

Many processes start when a person is diagnosed with cancer, both within the person and also in the care and actions to treat the condition. Treatments for CRC with a curable attempt always involve surgery and hence a postoperative recovery phase for the person. Since current best evidence protocols plead for short hospital stays and significant involvement from the patient to recover at home, there are new demands needing a different approach from both patients and health care for the recovery to succeed. Thus, in order to be more prepared, patients need more knowledge about possible stressful events they might need to cope with. In addition, a person-centred approach where the patient is seen as a competent member of the team is crucial to enhance preparedness for the person behind the patient.

It is well known that patients in most medical treatment processes complain about not getting enough or insufficient information in order to cope with and be prepared for symptoms and side effects as well as other stressful events when recovering at home. It might be characterized as a paradox in today's information society, that lack of information is still something experienced by patients. It might also be the case that the healthcare settings, when striving to adhere to this, focus too much on the form (websites, apps, prints) and miss the most prominent way of communication; i.e. listening to another person's narrative. Having a person-centred approach in care actions means that the person behind the temporary "patient" is predominant, with recourses, needs, preconceptions and experiences. Likewise, having a person-centred approach in research can entail using patients as knowledgeable partners in a co-constructive learning process.

Written information is frequently used and also asked for by patients and healthcare staff. Laws and national documents demand information providers to enable patients' involvement and understanding in care. There is much research on how to best present and write text, but less about how the text can be transformed into knowledge assimilated by the intended reader, here the patient. Finding out the requests for improvement of patient education materials entail scrutinizing existing material and asking stakeholders to share their experience on what constitutes valuable content and design. New approaches on the production of information text applied to general and specific needs related to the medical condition and the intended reader is needed.



# 5. Aim

## 5.1. Overall aim

The overall aim for this thesis was to describe patient reported stressful events and coping strategies and with a person-centred approach characterize existing and co-design new patient education materials for patients undergoing colorectal cancer surgery.

## 5.2. Specific aims

*Study I* aimed to describe the most stressful events and coping strategies used by patients with colorectal cancer 4-6 weeks after surgery and whether the coping strategies were considered helpful or not.

*Study II* aimed to characterize PEM provided to patients undergoing surgery for colorectal cancer to gain a better understanding of how to design readable, suitable and comprehensible PEM.

*Study III* aimed to present present the negotiations derived by areas of tension when stakeholders were involved as co-designers in the process of developing patient education materials.

*Study IV* aimed to develop principles on how to design and develop patient education materials to function as tools in person-centred care.



## 6. Ethical considerations

The work presented in this thesis rely upon the World Medicine Associations Declaration of Helsinki (65) to ensure that human subjects involved in research are met with: respect for the individual, beneficence and justice. Respect refers to the respect for the autonomy and/or protection of those with diminished autonomy. Beneficence aims to ensure the maximization of benefits and minimization of harm and justice means that the participants should not have a greater burden than benefit by participating in research. The research project was approved by the Regional Ethical Review Board in Gothenburg (Ref. No. 545-10 and 536-12) and the participants gave their informed consent before participating.

The patients participating in study I were also included in a larger research program involving several questionnaires to be answered during a six-months period. They were informed about the amount of questionnaires before surgery and that they had the right to resign from the study without it affecting their care.

For study II, it was the participants involved in the focus groups that were informed and gave their informed consent. As described in the methods section (see page 45), great care was taken to create homogeneous groups to enable an environment in which the participants could feel safe and trust each other. After each session, the group leader and assistant remained and responded to any eventual reactions or feelings from the meeting. If necessary, adequate healthcare staff was contacted for help or information for the participants.

Study III and IV demanded a somewhat different ethical approach, since the participants were also invited as co-designers. They were thereby, apart from general information to which they gave their informed consent, also informed about their role and what their contribution would expect from them. The risk of harm was thereby not only considered by a board of ethics, but also by the participants themselves. Ethics in this form of participatory research focuses on the individuals and how they define a set of values formed in democratic dialogue (66) and complex ethical issues can be confronted where the researcher will have to take a personal value stance to defend his or her research. The underlying ethics of all studies in this thesis was the person-centred approach, where everybody's knowledge must be incorporated in a democratic team and in partnership.



# 7. Methodology

## 7.1. Methodological viewpoints

How knowledge is created has different traditions in different academic paradigms. The intensified use of mixed methods can be seen as a response to widening the paradigm to find the optimal answer to a research question from pragmatic points of view. Action Research rejects, according to Greenwood and Levin (57), the superiority of professional researcher knowledge over practical knowledge from the persons it concerns, i.e. the stakeholders. Instead, all knowledge should be constructed in processes identified as scientific knowledge generation. Further, AR focuses on the ideas that theory and action cannot be separated, and that the validity of a theory is how it actually works in a real-life situation; the workability. Theoretical and practical knowledge, defined as mode 1 and mode 2 knowledge (67), both need to be engaged in an AR-intervention study, with emphasis on mode 2 and the researcher being a change agent (59). The practice of Action Research (AR) is commonly seen as a cycle of action and reflection (62).

There are tendencies of a rising conflict of creation of knowledge in the nursing society, where some propose an elitism from the nursing society to claim abstract knowledge as better than practical knowledge (68). These authors make a call for nurses to use AR methodologies in order to “actively work to transform the underlying abstract epistemology into a relational, inclusive epistemology, where all forms of knowledge and theory are valued and understood as contributing to new traditions of knowledge” (p. 150). Dick (69) proposes a combination of emergent data-driven methodologies such as AR and grounded theory to complement the more theory-driven ones, in which the complexity of people might be underestimated. By not complementing the approaches, there is a risk of research leading too easily to theory driving evidence, which will in turn drive practice: *theory - evidence - practice*. If instead using emergent methodologies as a balance, there can be a shift to practice-based evidence: *practice -evidence - theory*. Scientific knowledge, procedural (to do with skills) and personal (tacit/intuitive) are all needed and should be integrated in nursing, and Kitson et al (70) talk about defining the fundamentals of care as something still not agreed upon in the nursing society. This discussion also involves how nurses and other

health care professionals perceive their role in a therapeutic encounter from evidence-based clinical knowledge to promote person-centred care.

Power and knowledge and how they relate can be seen from at least three views, firstly: knowledge as resources owned by the powerful experts and transformed to the powerless as the truth yielded by objective research; secondly: knowledge as controlled by the powerful, where the powerless are sometimes invited to produce and act upon the set agenda of knowledge creation; and thirdly: emphasis on shaping consciousness of the agenda where participation in knowledge production in itself builds greater awareness and self-consciousness of capacities for action (71). If a person is seen as capable as a partner in care (3, 4), he or she should be seen as capable of being a partner in developing the care through research in a co-design environment. This is where AR-methodologies could possibly help bridging the old paradigm of nursing to one that involves knowledge-creation in a partnership. Considering power and knowledge creation, this thesis strives to use the knowledge from all stakeholders to develop theory, instead of only asking stakeholders for opinions about matters already decided as the truth. Table 1 provides an overview of the studies conducted in this thesis.

*Table 1. Overview of studies.*

	Study 1	Study 2	Study 3	Study 4
<b>Focus</b>	Exploration of stressful events perceived by patients. Frequency, level of stress, anticipation, coping strategy and helpfulness of coping strategies.	Characterization of education materials provided to patients. Readability, suitability and comprehensibility from manual analysis, automated analysis and patient experience.	Description of the co-design process of developing a patient education. What tensions arose and how were they dealt with?	Analysis of similarities between person-centred care and action research. Can the two approaches be synthesised and used in the development of patient education materials?
<b>Design</b>	Cross sectional	Mixed methods	Action research	Action research
<b>Data collection</b>	The Daily Coping Assessment questionnaire	Existing PEM (n=125) Focus groups (n=5)	Process groups, Meetings, interviews, e-mails, field notes	Group reflection parallel to study 3
<b>Participants/providers of data</b>	Patients' diary entries (n=523)	Patients in focus groups (n=15) Hospitals sending in PEM (n=27) Stoma care companies (n=4)	Patients (n=3+8), professionals (n=2), scientific reference group (n=8) Research group (n=3) Patients (n=3+8), professionals (n=2), scientific reference group (n=8) Research group (n=3)	
<b>Setting</b>	1 University hospital 1 Public hospital 1 Privat non-profit hospital	1 University hospital PEM from 27 Swedish hospitals	1 University hospital	
<b>Data analysis</b>	Descriptive statistics	Manual analysis with SAM+CAM instrument  Automated analysis with Language technology  Deductive and inductive descriptive analysis of focus group interviews	Participatory Design/Elwyn process protocol  Constant comparative analysis.	Constant comparative analysis.

## 7.2. Study participants

The study participants of the studies were asked to participate by the research assistants at the three study hospitals (Study I) and by the first author (Studies II-IV).

### 7.2.1 Study I

At the preoperative consultation, 259 patients were included in a larger research program (see pages 17-18) in which the questionnaire the Daily Coping Assessment (DCA) used in study I was included at the third of totally five data collections during six months. This time point was 4-6 weeks post surgery, when patients had returned home, and had not yet had their postoperative consultation with the surgeon and did not yet know all results from the pathology analysis from the surgery. The result from this would determine whether they would be offered an additional adjuvant chemotherapy treatment for six months or not. Patients were included through consecutive sampling at three hospitals in Sweden (one public university hospital, one public regional hospital and one private non-profit hospital with no emergency patients) Inclusion criteria (for both the larger study and the present one) were: diagnosed with CRC and scheduled for elective surgery. Excluded from the study were: patients receiving pre-operative chemotherapy or long-term preoperative radiation, those with spread cancer disease at inclusion, those undergoing emergency surgery, patients with cognitive failure and patients unable to understand the Swedish language.

### 7.2.2 Study II

*Patient education materials.* Hospitals with more than 35 CRC registrations in the national registers of CRC in 2008 were asked to send all the PEM used in 2010. Externally produced PEM from four stoma care companies used by most hospitals were also included, resulting in 217 PEM items. PEM that provided information, advice or counselling about procedures and activities during the CRC surgery process were included for analysis (n = 125). Excluded PEM were: welcome letter/notification letter, declaration of health, maps and directions, business cards, ERAS diary with no information, oncological treatment and other material not specifically related to CRC surgery (n = 92).

*Focus group participants.* Six women and nine men participated in five focus groups at a university hospital. Since discussing sensitive matters, homogeneity was considered valuable and this was taken into account when determining group composition, i.e. older and younger people with or without a stoma. Each group comprised three participants who had undergone CRC surgery with curable intent within the last year and represented a variety of social backgrounds, reading habits and levels of computer literacy.

### 7.2.3 Study III

Results from the focus groups in study II was used in the first step of the analysis. The process groups were formed at a University hospital according to the protocol followed (72). First, a project management group was formed, consisting of the PhD-student a Post-doc researcher, both registered nurses, and a colorectal surgeon. Secondly, an advisory group was formed. This group consisted of three former patients (two women and one man), who had been operated for CRC and expressed an interest for written information previously and two registered nurses (one working at the ward and one at the out-patient clinic). Thirdly, a scientific reference group was formed, the eight members of this group having been invited because of special interests or expertise, or because they represented key relevant organizations. Last eight consecutive patients were consulted about the text and pictures before the final draft was made.

### 7.2.4 Study IV

This study was based on the process of Study III, and the participants were therefore the same as in that study. The analysis did however not include any participation of the different group members, apart from the two researchers from the project management group and two researchers from the scientific reference group.

## 7.3. Designs and methods for the individual studies

### 7.3.1 Study I

*The Daily Coping Assessment instrument.* For the investigation of situational coping, an exploratory design was used. The Daily Coping Assessment (DCA) (73) measures the number and types of predefined coping strategies used during the day to handle what the person perceives as the most bothersome event, illness related or not. The instrument consists of 4 parts, where the first part encourages the participant to describe the event or problem considered the most bothersome of the day. Part two is an estimation of how bothersome the event was on a scale between 1-7, where 1 is not bothersome at all and 7 extremely bothersome. If no bothersome event has occurred, the person leaves the rest of the questionnaire blank. In part three, the person is asked to evaluate whether the event was anticipated or not and whether he or she felt in control and could influence the event. Lastly, the person chooses from eight predetermined coping strategies that were used to handle the event. The strategies were: Distraction (thought of something else), Situation redefinition (looked at the problem in a different way), Direct action (did something about it), Catharsis (expressed emotions), Acceptance (accepted the problem), Seeking social support (sought support from others), Relaxation (relaxed) and Religion (sought spiritual support). More than one strategy could be used for each event. To find out if the strategy used by the participant was helpful or not, an additional question was added in the questionnaire for the original instrument: "Did you find the coping strategy helpful?" (Yes/no). Since it was desirable to examine stressful events and coping from a situational rather than an individual point-of view, the included patients were instructed to fill in the DCA each day during a five-day period (73). In line with the exploratory design, each diary entry was treated as a unit for analysis and there was no consideration to the individuals coping over the five days of measuring in this study.

*Analysis of open question.* The reported bothersome event from the diaries entries were first deductively sorted using the 14 areas covered by the EORTC QLQ-C30 (74) as codes. This cancer specific health related quality of life instrument is well established and validated and covers several aspects that a person affected by a cancer diagnosis can be influenced by. When analysing and sorting the diary entries, several of the reported stressful events did not fit the

EORTC QLQ-C30 areas and were then, as a second step, inductively coded. This resulted in eleven new created areas, leaving 25 areas. Since the frequency of diary entries in some of these areas was too low or non-existent, a new analysis was performed, resulting in 12 areas where some were merged and one area was excluded (cognitive functioning). Still, some areas included too few diary entries to perform a statistical analysis, and therefore a final analysis took place, where the 12 areas were merged into 10. The final areas with citations to exemplify the meaning of the areas are presented in table 2. In the cases where more than one stressful event was reported; the first one mentioned was used in the analysis.

*Table 2. Domains and categories of stressful events exemplified with citations extracted from the diary entries*

Domains	Stressful events - Citations
<b>Physical -, role- and social function</b>	<ul style="list-style-type: none"> <li>• “Needing my husband’s help when buying groceries, due to lifting restrictions for heavy bags.”</li> <li>• “Since I have a large social life, I know a lot of people. It’s hard to handle all nice ”how are you, what’s happened, what is wrong” in the wrong situations, like in the supermarket, in large groups etc.”</li> <li>• “Started training again. Felt lost in the changing room, how can I dare to get changed in this environment?”</li> </ul>
<b>Emotional function</b>	<ul style="list-style-type: none"> <li>• “Worried about how I’m going to make it. I felt weak, low and sad.”</li> <li>• “Very worried about having cancer also in my lungs.”</li> <li>• “Not being able to pee, crap or feel any kind of sexual desire is making me crazy”</li> </ul>
<b>Nausea/vomiting</b>	<ul style="list-style-type: none"> <li>• “Felt sick.”</li> <li>• “Vomited, felt sick and had to go back to hospital and be readmitted.”</li> <li>• “Was sick all night after eating scrambled eggs.”</li> </ul>
<b>Pain</b>	<ul style="list-style-type: none"> <li>• “Came home - pain!”</li> <li>• “Pain, took a tablet.”</li> <li>• “Stomach-ache.”</li> </ul>
<b>Fatigue/Sleep</b>	<ul style="list-style-type: none"> <li>• “Felt very tired, just wanted to sleep.”</li> <li>• “Couldn’t sleep last night, had pins and needles in my whole body.”</li> </ul>
<b>Nutrition</b>	<ul style="list-style-type: none"> <li>• “Lost weight, bad appetite.”</li> <li>• “Had no appetite what so ever.”</li> <li>• “Find it hard to eat nice food without getting stomach problems.”</li> </ul>
<b>Bowel related problems</b>	<ul style="list-style-type: none"> <li>• “Needing to be close to a toilet. Got no control over defecation.”</li> <li>• “Constipated, very little faeces.”</li> </ul>
<b>Stoma related problems</b>	<ul style="list-style-type: none"> <li>• “The stoma made a very loud sound at the GP’s reception.”</li> <li>• “I was careless when putting the bag on and it leaked.”</li> <li>• “The colostomy bag leaked when visiting friends.”</li> </ul>

*(Continued) Table 2. Domains and categories of stressful events exemplified with citations extracted from the diary entries*

Domains	Stressful events - Citations
<b>Surgery or treatment related problems</b>	<ul style="list-style-type: none"> <li>• “Discovered an infection in the wound. Have to go every day to have it rinsed.”</li> <li>• “Difficulty emptying the bladder.”</li> </ul>
<b>Problems unrelated to cancer or treatment</b>	<ul style="list-style-type: none"> <li>• “My husband’s illness.”</li> <li>• “Worst problem is a pain in my foot and ankle, which makes me walk badly. Can’t take walks like I would like to. Had this before cancer surgery as well.”</li> <li>• “Fitting a new water pump in the tractor. Freezing outside!”</li> <li>• “Selling the house.”</li> </ul>

### 7.3.2 Study II

*Mixed methods.* A mixed method design (75) was used, i.e. the application of deductive quantitative analysis of PEM using a validated instrument, supplemented by language technology analysis, as well as deductive and inductive analysis of data from focus group meetings involving former CRC patients.

*Suitability and comprehensibility assessment, the SAM+CAM instrument* The 125 included PEM were divided into subgroups: Information about the whole surgery process (brochures or leaflets), dietary advice, Stoma care brochures, post-op advice leaflets and discharge brochures. To evaluate the quality of the collected PEM, the Suitability and Comprehensibility Assessment of Materials (SAM+CAM) (28) was used. This instrument was developed from the Suitability Assessment of Materials instrument (SAM)(76), one of only a few validated instruments for the evaluation of PEM. The SAM has been used in different health contexts (77-83), including cancer care. It has also been used to evaluate web-based PEM on CRC screening (84). No further studies using the SAM+CAM instrument was found at the time of print of this thesis.

The SAM+CAM instrument comprises six categories (C) and measures 22 variables (v): Content (C1-v1-4), Literacy Demand (C2-v1-5), Numeracy (C3-v1-2), Graphic Material (C4-v1-2), Layout & Typography (C5-v1-3) and Learning, Stimulation, Motivation (C6-v1-6). According to the instrument protocol, raters score 0 points per variable for a 'not suitable' rating, one point for 'adequate' and two points for 'superior'. The maximum score is 44. Variables that do not apply are rated N/A and are deducted from the maximum score. The total score divided by the maximum score is given as a percentage. In the overall evaluation of PEM, 0-39% is considered 'not suitable', 40-69% is 'adequate' and  $\geq 70\%$  is 'superior'.

Two raters used the SAM+ CAM instrument on the included 125 PEM. A translation to Swedish was performed by the raters using the instrument, but not as a completed validated translation to be used by others. Both raters were registered nurses who had worked in the CRC-surgery field for several years, and hence had a good understanding of the process and were also used to providing pre- and postoperative information to patients. The raters took good care into practicing using the instrument and being in agreement on how to do the rating, and the ratings were examined for inter rater reliability.

To assess the homogeneity and consensus between the two raters using the SAM + CAM instrument, an inter rater reliability (IRR) calculation was performed. This calculation reveals if a particular scale is appropriate for measuring a particular variable, where a too low IRR might indicate that it is not coherent enough for standardized use, or that the raters are not in agreement on how to use the instrument properly. There are different ways to control the IRR, but for the SAM + CAM instrument it was examined by computing Krippendorff's alpha coefficient (85, 86) at the subscale-level and at the item-level based on the responses of the two raters. All of the 31 brochures that were in the category "Information about the whole surgery process" together with 11 random samples from the other categories were included in the IRR. Krippendorff suggests that reliability values greater than 0.800 indicate adequate reliability and that reliability values between 0.667 and 0.800 suggest a need for caution (86). The mean values of the subscale- and the total-scores were evaluated and standardized mean differences were computed to ascertain the magnitudes any observed differences between the raters. Responses to items with discrepant ratings were reviewed by both raters to achieve consensus. The remaining PEM's were subsequently evaluated by only one of the raters

*Language technology analysis.* Automated analysis of natural written language offers the advantage of reliably and consistently measuring linguistic factors that characterize PEM's. There are several ways to approach the task of examining their content, e.g. by using a number of standard linguistic features (e.g., word count, terminology load), in combination with results provided by readability tests and other statistical means. A common approach to readability assessment is the use of various readability formulas that measure certain textual characteristics that are quantifiable with simple mathematical equations, and yield an estimate of a text's difficulty, usually, in terms of grade levels. However, surface-level features of texts can be insufficient for determining the degree of adaptation required for highly heterogeneous groups of readers. Therefore, additional parameters have been considered when aiming at tailored text production, such as features mirroring the vocabulary load and sentence structure (87). Despite

certain shortcomings (88), readability formulas are useful, practical and objective predictors of text difficulty, particularly if these are used not in isolation but in conjunction with other tests and measures.

Automated language technology analysis was used to determine the readability level of the PEMs and to investigate possible correlations between the examined measures and the SAM+CAM scores on the category Literacy demand. A small set of the several existing surface oriented linguistic features and readability measures were selected (89) for further investigation and for their comparison with the manually assigned SAM+CAM scores (table 3 and 4). Prior to the analysis, all documents were automatically tokenized (i.e., determining word boundaries) and segmented into sentences. For some of the measures (e.g. Full Nominal Ratio) the texts were also annotated with a Swedish part-of-speech tagger (e.g., nouns, verbs, prepositions).

**Table 3.** *LIX scores for PEM used in colorectal cancer care*

LIX value	<25	25-30	30-40	40-50	50-60	>60
Description	Easy-to-read children's books	Easy, fiction	Moderate, newspaper	Difficult, official texts	Very difficult, bureaucratic	Dissertations
n (of 125)	1	8	106	10	0	0
%	0.8	6.4	84.8	8.0	0	0

Table 4. Readability analysis scores

Type of analysis	Explanation	Easy	% of total n = 125	Medium	% of total n = 125	Difficult	% of total n = 125
Average Sentence Length (ASL)	Short sentences (7-14 words) imply easy to read text while long sentences usually have a negative impact on readability.	<12	12 % n = 15	>12 <16	67.2% n = 84	>16	20.8% n = 26
Percentage of Long Words (LW)	Words >6 characters.	<20	32 % n = 40	>20 <25	59.2% n = 74	>25	8.8% n = 11
Percentage of Very Long Words (VLW)	Words > 13 characters, i.e. the vocabulary load.	< 1	12 % n = 15	>1 <3	59.2% n = 74	>3	28.8% n = 36
Word Variation Index (OVIX)	Measures the ratio of unique tokens in a text, i.e. the idea density. The higher the OVIX value, the more difficult the text is assumed to be as it is wordier and more varied in style.	<50	5.6% n = 7	>50 <60	69.6% n = 87	>60	24.8% n = 31
Full Nominal Ratio (FNR)	The ratio of nouns, prepositions and adjectives/participles to the number of pronouns, adverbs and verbs. A higher figure indicates a more professional and stylistically developed text, while a lower figure indicates simpler, informal language.	<1	67.2% n = 84	>1 <1.2	22.4% n = 28	>1.2	10.4% n = 13

*Focus group interviews* Focus groups were used as a method (90) to gather data through group interaction about a predefined subject; thoughts and preferences about patient education materials. Since it has been suggested (91, 92) that it is preferable with homogeneity within the group, but heterogeneity between the groups, the groups were formed from age, gender and type of surgery performed (table 5). Five groups were formed with three participants in each. Each focus group lasted two hours and was audio- or video recorded and later transcribed verbatim. A small set of PEM was used as stimuli materials. These PEM had already been analyzed by automated language technology and the sample brought to the focus groups included PEM from the three categories “easy, medium and difficult”. The participants were not informed of these ratings. In addition, the PEM used at the clinic where the participants had had their care and treatment was included, as well as stoma care PEM when relevant. Questions about the use of PEM, preference of PEM and pictures in PEM were introduced and discussed between the participants. When necessary, the leader of the focus group tried to make sure everybody’s voice was heard by addressing persons that were not as dominant or did not contribute to the discussion (90, 91).

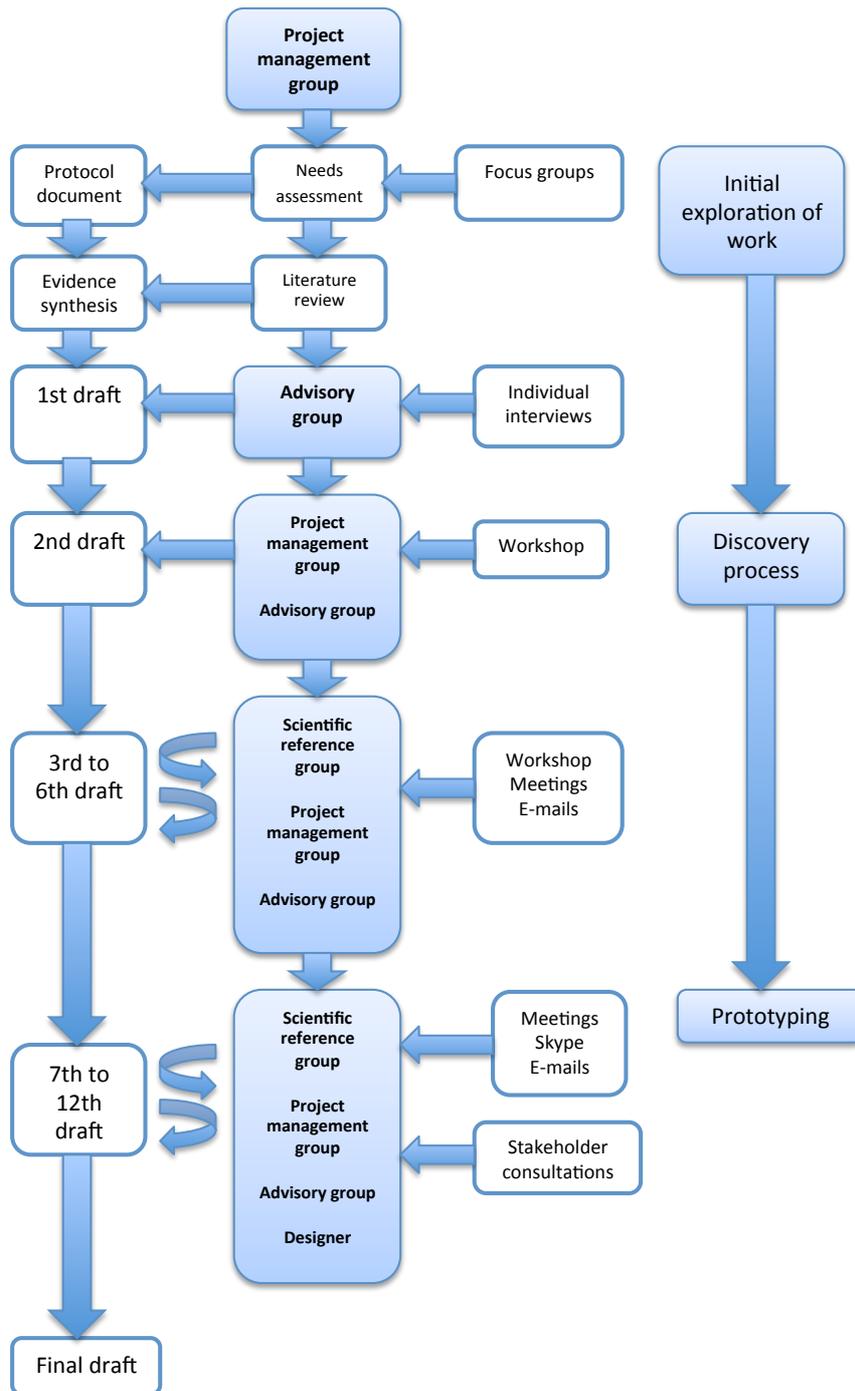
**Table 5.** *Focus group participants*

<b>Focus group composition</b>	<b>Male/Female</b>	<b>Age</b>
Group 1: Older patients without a stoma	M	73
	F	81
	F	89
Group 2: Female with a stoma	F	61
	F	68
	F	75
Group 3: Male with a stoma	M	75
	M	69
	M	57
Group 4: Younger patients with or without a stoma	M	37
	F	40
	M	47
Group 5: Older patients without a stoma	M	71
	M	75
	M	70

### 7.3.3 Method Study III and IV

*Participatory design.* In study III, a new PEM was designed and developed together with the relevant stakeholders; patients, clinicians, researchers and designer. The action research methodology Participatory Design (93) was chosen, since the outcome of this AR-method is often consisting of a designed artefact, which has been designed in an iterative partnership between the researchers and the concerned stakeholders. “My care-plan” was used as a framework to develop the PEM from. Alongside the actual design and development of the artefact, the method focuses on the researchers ability to deal with conflicting interests and negotiate between the stakeholders to reach the desired goal. During the process, the tensions and negotiations with particular focus on the researchers ability to cope with conflicting interests and sources of knowledge were described, reflected upon and analysed. Working in heterogeneous and complex context is said to give more detailed insight to problems, give room to ideas and creating solutions and hence generate innovative working environments (43). How knowledge is shared and conflict is negotiated and used as a source of development by the researcher, is what constitutes the scientific presentation of the study (94). Three basic steps are followed; Initial exploration of work, Discovery process and Prototyping. Throughout the whole process, the cooperation, curiosity, creativity, empowerment and reflexivity of the stakeholders should be reflected upon by the researchers (94). Working in collaborative-participatory design invites the stakeholders to become partners.

*Process framework.* To work in co-design with patients can be complex, costly and time consuming. Using a well-defined process model is recommended for collaborative working, such as co-design (43), and can avoid a project to culminate in unnecessary complex results by trying to apply everybody’s considerations. A process framework by Elwyn et al (72), originally to develop web-based decision support interventions was followed after adaptation to fit the process of developing PEM. In this process map, a set of documents and tasks, along with definitions of groups involved are defined. A *project management group* was formed consisting of two RN’s and one surgeon. This group had executive and editorial control over the project and had mandate to make final decisions in all stages of the process. Three former patients were part of the initial and continuous design as members of an *advisory group* together with two RN’s from the hospital were the PEM was to be tested. Additionally, a *scientific reference group* (n=8) contributed with their specific expertise later in the process, and a designer was involved in the production of layout and illustrations. Finally, a group of eight patients gave their opinion on the PEM before it was to be used in an intervention. The process of work is described in Figure 1 from Study III.



**Figure 1** Flowchart of workprocess.

*Constant comparative analysis.* The process for theory building has been given, according to Dick (69), surprisingly little attention in the AR-literature. He promotes using three pairs of analytic questions and to reach consensus on each before proceeding, using conflict resolution processes if necessary:

- 1a. What are the important features of the situation?
- 1b. Why do we think those are the important features?
  
- 2a. If we're right about the situation, what outcomes (that is consequences) are desirable and feasible?
- 2b. Why do we think those outcomes are desirable and feasible in that situation?
  
- 3a. What actions do we think will give those outcomes in that situation?
- 3b. Why do we think those actions will give those outcomes in that situation?

By answering the *a* questions, the situation, the consequence and the actions are provided, and the answers to the *b* questions surface assumptions and opens for dialogue and discussion. Together, these answers from the analytic questions will provide a basis for theory building, which is proceeded by performing a form of constant comparative analysis considered the “data engine” (69, 95). The process can be viewed as dialectic, using apparent disagreement to generate agreement at a deeper level. Throughout the process, the “data engine” was applied as an action research cycle. It was used on all sets of data to inductively find agreements and disagreements, which needed to be negotiated. Data (audio-recordings, transcriptions, field notes and e-mails) were compared with each other and added to the study documentation in the process.

- Overlaps between data were noted as agreements or disagreements. Disagreements also included when the same topic was mentioned but incompatibly.
- Where there was agreement, exceptions were explored and if found, treated like a disagreement.
- Where there was disagreement, explanations for these were explored and the disagreements were negotiated within the process groups.

Parallel to the co-design and development of the PEM in study III, a theoretical analysis was performed in study IV. In this analysis, the dimensions of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> person in Ricoeur's philosophy described as self (55) and in AR as voices (64) were theoretically compared for differences and similarities. When agreement was reached, new principles from the merged dimensions were described as principles on what to consider when developing new PEM.

## 8. Results

The results of the four included studies build upon each other, but can also be read and used separately.

### 8.1. Study I

In study I, 532 diary entries of the Daily Coping Assessment instrument from 105 patients were returned and analysed for situational coping. The frequencies of stressful events, mean levels of perceived distress, perceived control and perceived expectations are presented in table 6. The main finding was that even if many patients (n=180) reported that no stressful event had occurred during the day, almost half of the diaries report the experience of stressful events in the early postoperative recovery phase. The events were related to both illness and surgery and to life in general, and reported as highly bothersome with a total level of distress of almost five on a scale of 1-7 (not bothersome at all – extremely bothersome). The most stressful events were related to “Pain” followed by “Nausea and vomiting”. “Pain” was also reported as having the worst level of control and as being the least expected of the stressful events experienced. The areas causing most frequent stressful events were “Bowel related problems” and “Surgery and treatment related problems” together causing over 20% of the stressful events.

Most frequently used coping strategies were acceptance and direct action. The coping strategy that was considered most helpful on both a specific and a general level was religion, but it was used by very few. There was a wide range for perceived helpfulness of coping strategies related to specific areas of events, and coping strategies that seemed successful on a general level can not be generalised as useful or not.

**Table 6.** Frequency of stressful events, mean levels of perceived distress, perceived control and perceived expectations

Stressful event	Frequency (%)	Distress Mean (SD)*	Control Mean (SD)**	Expectation Mean (SD)***
No stressful event	180 (34.4)	-	-	-
Problems unrelated to cancer or treatment	54 (10.3)	4.7 (1.7)	2.6 (0.6)	2.4 (1.2)
Bowel related	53 (10.1)	4.7 (1.8)	2.5 (0.6)	2.6 (0.9)
Surgery or treatment related	52 (9.9)	5.1 (1.3)	2.4 (0.8)	2.7 (1.1)
Emotional function	49 (9.4)	4.9 (2.0)	2.3 (0.8)	2.5 (1.1)
Stoma related	40 (7.6)	5.3 (1.6)	2.3 (0.7)	2.4 (0.8)
Fatigue/sleep	36 (6.9)	4.2 (1.4)	2.2 (0.7)	2.6 (1.0)
Pain	27 (5.2)	6.0 (1.4)	2.4 (0.7)	2.3 (1.0)
Nausea/vomiting	13 (2.5)	5.5 (1.9)	2.6 (0.7)	2.2 (1.1)
Physical, role and social function	12 (2.3)	4.1(1.6)	1.9 (0.5)	2.8 (0.8)
Nutrition	7 (1.3)	4.6 (1.5)	2.1 (0.9)	2.6 (0.8)
Total (across all stressful events)	523 (100)	4.9 (1.7)	2.4 (0.7)	2.5 (1.0)

\* High Level corresponds to high distress (range 1-7)

\*\* High level corresponds to low control (range 1-3)

\*\*\* High levels correspond to high expectations (range 1-4)

## 8.2. Study II

In study II, 125 PEM from 27 Swedish hospitals were examined for readability, suitability and comprehensibility with a mixed methods design. Analysis by two raters with the validated instrument Suitability and comprehensibility assessment in materials (SAM + CAM) revealed that 13.6 % were not suitable, 76.8 % were adequate and 9.6 % were superior. Of the discharge brochures, 44 % were rated not suitable. In the adequate group there was a wide range and only PEM produced by stoma care companies were rated superior materials. Key variables

such as motivators to attend to text, inclusion, reader interaction and theoretical application were lacking even in PEM rated adequate. The automated language technology assessment was used to determine the readability level of the PEM and this analysis revealed that up to 29 % of the materials were considered difficult to comprehend from these measures. Additionally to the two quantitative methods, five focus groups with 15 former patients added important knowledge of patient perception and preference of PEM. Additional areas not covered by the two other methods were: general and personal care, personal implications, Internet, significant others, accessibility to health care, usability, trustworthiness and patient support groups.

### 8.3. Study III

Results of the one-year process revealed that predominant areas of tension focused on power (mandate to decide), organization (content, structure and scope of process, reader interaction), content (designing evocative illustration, types of knowledge, expression and form of language in text, the use of powerful patient quotes as inspiration) and application (usability in clinical work). It was hard for clinicians and researchers to find a different role as co-designers, and patterns of old behaviour kept reappearing during the process. Patients were considered as vulnerable and in some parts less knowledgeable, and it was hard to surrender the mandate to decide. Ethics was used as an excuse not to upset the patients by having too much involvement, both in the working process and in the end result, i.e. the PEM. Patients also found the role of co-designing challenging and the research group hierarchical.

### 8.4. Study IV

In study IV, the process from study III was analysed from a more theoretical perspective, where the dimensions of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> person described in action research as voices and in Ricouer's philosophy as self were combined into principles for the design of patient education materials. By comparing similarities and differences between the two perspectives a synthesis of the two emerged as: "Generic information" (3<sup>rd</sup> person) was concretized as generic information that all patients need and must entail to prepare for a specific medical procedure. This is hence on a group level, where valid research results are used to perform best evidence-practice. Knowledge is shared in society (voice) and in an institutional relation (self). "Arena of dialogue" (2<sup>nd</sup> person) was concretized as the

PEM enabling a face-to-face dialogue in a collaborative, democratic process (voice) and a dialogic relation (self). The person/patient should be encouraged by the text and the health care staff to share his or her narrative, in which both capacities and needs can be discovered and a partnership can be formed. Finally, in the principal of “Internal reflection” (1<sup>st</sup> person), the generic information which is processed in dialogue also inquires the persons own assumptions, needs, desires and behaviours (voice) in a relation to oneself (self) in order to relate and assimilate to the situation.

# 9. Discussion

## 9.1. General discussion

There is a call for improved information from persons undergoing surgery for CRC (22, 23). Apart from the need for improved oral information, patients ask for written materials as a complement (29), and evidence based guidelines highlights PEM as important for an enhanced recovery after CRC-surgery (13, 14). The policies related to this thesis request an orientation towards a more person-centred and patient- participatory health care, to which research must respond. Without it being explicit, the description of “My care-plan” can be seen to have a person-centred approach. Since it was also a practical thing supposed to be developed and implemented, but had very little evidence of both creating and usefulness, it was used as a practical framework for study III and IV of this thesis. Having a practical problem to solve, together with the stakeholders concerned, responded well to both the call for person-centred research as well as a pragmatic vision in an mixed-methods and action research framework. The idea of text as a mediator for assimilation was developed from the philosophical grounds of Ricoeur (55), but needed to be tested for workability (57) and hence generate knowledge and build theory. Also, even if text is produced from following guidelines of readability and comprehensibility, there needed to be another dimension to the text for it to become a tool for information and communication from the patients/persons point of view.

In order to suggest a change in the approach of PEM for patients undergoing surgery for CRC and hence enhance the persons preparedness and coping, there was a need to investigate what patients experienced as bothersome and how they described coping strategies as helpful or not (study I). It was also necessary to analyse and characterise the existing PEM within the context of CRC-surgery in Sweden, and learn from good and bad examples (study II).

### 9.1.1. Experiencing stressful events

The conclusion of study I was that patients experience a variety of stressful events in the early postoperative phase after CRC-surgery. Symptoms and perceived stressful events might affect coping ability and patients might benefit

from being better prepared for these symptoms and how to manage them with support from health care professionals.

Over 50 % of the diary entries reported of stressful events that had occurred during the day. Many of the events themselves are not particularly different from the earlier reports of symptoms in the recovery phase after CRC-surgery (12, 19-21), but the self-reported low level of control over the events was 2.4 of a scale of 1-3 where 3 is feeling no control. If also considering the relatively low level of expectation, 2.5 on a 1-4 scale where 1 is not expected and 4 is completely expected, it means that even if the symptoms and possible problems are known and informed about, the patients still experience them as very bothersome, unexpected and with low control. Patients in the focus groups of study II also shared these experiences, and talked about not feeling prepared for what could happen after leaving the surgical ward and returning home. One patient described it as: *“It would have been good if somebody had said, expect to feel crap but don’t panic about it, but if you start feeling like this or that you can pick up the phone and talk to somebody.”* He expressed in this sentence an understanding of a tough time recovering, but had wanted to be more prepared and reassured of his capability to know when to seek help. It also contains a desire to not be abandoned when this help was needed.

In previous studies (96-98), the reported bothersome events in the DCA were analysed using a descriptive inductive approach; content analysis. This might affect the possibility of comparing the results, since the different coding gave different categories that were not compatible to each other. Instructions to the DCA, however, do not give any guidance to how the analysis should be done (73). Using the EORTC QLQ-C30 categories to sort the reported stressful events was found both useful but also blunt. The fact that the participant had often filled in more than one, sometimes up to five events the same day was problematic. All the events described could be considered stressful, but the distinction of only using the first one mentioned was made to avoid interpretation from the researcher and instead rely upon the idea that the first event mentioned is most likely considered worst. The bluntness of the categories sometimes made it hard to distinguish between which categories to sort the event under, but the two researchers were in consensus of all the categorizations. Further, the need to merge categories due to statistical problems of having too few, suggests that a different method might have given a more diverse result.

The high drop-out rate in this study suggests the figures should be interpreted with caution, since the group of patients answering the DCA is smaller than the group of patients not included the study. It should nevertheless be noted that more patients partially filled in the DCA, but were excluded because they had not completed or filled it in correctly. Since the participants were in a recovery

phase and also involved in the larger study, filling in a questionnaire five days in a row might have been too demanding a task. Many participants did not complete the DCA even though they received reminders and were contacted via telephone with the research assistants. However, the 105 who participated did not differ from the non-participants (n=154) regarding gender ratio, diagnosis, presence of stoma and social status, but the **non participants** mean age was significantly higher than the study group's (68.4 vs. 66.4), the diagnosis of rectal cancer was lower (39.6 % vs. 47.6 %) and there was a higher percentage who had completed only primary school (30.5 % vs. 18.1 %) and also a lower percentage of employed participants (31.8 % vs. 44.8 %). What implications this has on the result is hard to pinpoint, but it is of great interest that a discrimination of care related to lower socioeconomic status has been shown in studies using the colorectal cancer register (99). If this discrimination can also be found in research participants it needs to be addressed.

### 9.1.2. Analysing existing patient education materials

The mixed methods design in study II made it possible to look at the same research question from three different views. What constitutes good written PEM was seen from a third person perspective, by using the validated instrument SAM + CAM (28), which responds well to the recommendations for designing effective written health education materials by Hoffman and Worrall (30). The collected PEM were given an objective quality control, where a rating system made it possible to compare them both between themselves and between others if the same instrument was used. Even if the PEM reached an adequate scoring, the areas that needed improvement could be easily identified. These areas were often the same areas as found by the developers of the SAM + CAM (28) i.e. they were weak in message design and communication techniques shown to be effective in promoting positive decision making and motivating change of behaviour. If using the SAM + CAM when developing PEM these areas can be highlighted and more materials can become superior. How these areas are best designed needs to be developed with the involved stakeholders, but already in the design phase to avoid major changes late in the process (35). To this day, only one study using the SAM + CAM has been found (28) reviewing cervical cancer prevention materials, but the results of that are similar to the ones of study II shown in table 4. In their study, 12 % were rated not suitable, 68 % adequate and 20 % superior. The difference between the adequate (76.8 %) and superior (9.6 %) in our results might recall the fact of only the PEM in our superior group were professionally produced, whereas the information materials in the

Helitzer et al (28) study contained newspaper articles, book chapters and web based health education materials, presumably produced by professional writers. One of the conclusions of study II was that only PEM produced by professionals were rated superior and this might be reflected in the two study results.

Also the atomized language technology (100) can be regarded a third person perspective on text, which also enables text to be compared from predefined standards. The knowledge gained from both these objective measures however need to be reflected upon from both a second and first person perspective. The raters using the SAM + CAM were both experienced in CRC-surgery. There is a risk of the preconceptions of wording and content made them grade the text as easier than perhaps a patient without this knowledge would have done. Taking the dynamic features of health literacy (52) into account, a text considered adequate by an objective, knowledgeable rater, might be experienced as completely incomprehensible by a person in shock after a cancer diagnosis. In language technology, short is considered better than long, both in words and in sentences (89). The Swedish language constitutes of many long words and sentences, which is also why some of the instruments for testing readability level may be unsuited since they were developed for the English language (101). Further, the atomized measures fall short on measuring complex dimensions, such as content, complexity, layout and familiarity. An example can be the word stoma, a short, but very rare word in the normal discourse between people and also not frequently used in third person information if not targeted towards a patient-group. Most people would probably use the word colostomy-bag, or not use it at all if you are not specifically exposed to a condition where a stoma is needed. Likewise the word die is very short, but is far too emotionally powerful to use in any PEM. It is however a very common word, both in every day life and in daily newspapers and other official means of information. This was also reflected in study III where the words dangerous and terror were discussed as being too powerful to use in the new PEM. Something considered as superior from a third person perspective, might thereby be considered as completely inadequate from a first person point of view.

The third method of study II was focus group discussions. How many participants that should be included in a focus group is something that literature is (90, 91) not in complete consensus of. All five focus groups had originally four participants, but due to different circumstances such as illness and other, it ended up with only three in each group. Having a smaller group can enhance the possibility for every voice to be heard and the person's contribution becomes more noticeable. The risk of only being three might be that one participant becomes a mediator between the other two to avoid tensions, or the opposite, to play one against the other. In all groups, the discussions were vivid and the group leader

did not have to intervene to get the participants talking. On the contrary, they opened up subjects and shared experiences of personal character that was not asked about, but still kept to the subject of discussion i.e. PEM. Significant for this was how one participant who, apart from being a previous patient, was also a colorectal surgeon. He shared how this new role made him need very simple information, when normally he would be the one giving the information to his own patients. This testimony was also an example of health literacy being something dynamic, affected in this case by an outside threat. The focus group discussions hence added a first person perspective on PEM, by the participants sharing their narratives on how they had perceived the written information during the CRC-process, but also a second person perspective through the discussions that derived within the groups where knowledge was shared and created in dialogue. Conclusion of study II was that even if most PEM were rated adequate for suitability and comprehensibility and medium for readability, there is room for improvement from the patients' perspective. Patients' knowledge should be integrated with manual and automated methods to further improve the development of PEM.

### 9.1.3. Using stakeholders' knowledge

Working as co-designers was, despite it being time-consuming, found productive and in line with person-centredness with focus on partnership and equality. Participatory design has been found time-consuming but productive (102) and an iterative negotiation of different opinions as something helpful and important (103, 104). Creating and safeguarding a partnership is nevertheless complicated, something that was also found in study III, with power structures remaining unchallenged if not made visible.

By using the SAM + CAM instrument in study II, it became visible that patient interaction and motivation to attend to text was not sufficient, even if the text itself was considered adequate. This is an important finding, but how these matters should be addressed needed the involvement and co-design with the stakeholders concerned. The results from study III reveal that patients have different preferences on these matters than both professionals and researchers, and only by using their experience and knowledge a true arena of dialogue can be developed from and in the PEM. The tensions that derived during the process were sometimes intense and probed for numerous negotiations. Particularly illustrations (used as motivators to read about emotions) turned out to be a hard subject to conclude consensus around. The opinions about the illustrations were completely diverse, some participants loved them and others found them de-

pressing. In the end, the patients voice about the matter was considered by the project management group as the one to give most consideration, and the fact that the eight new patients that were shown the last version all approved and liked them gave some validity to the use in the PEM. Since the PEM were also going to be used in the larger intervention study, more opinions on the matter would be available to enhance or weaken this validity. More subtle tensions, such as power structures, were more difficult to discover and address in the actual work process, and more found from reflection. The fact that professionals found it hard to see stakeholders (patients) as competent co-constructors of knowledge is in congruence with the findings of others (43, 44), probably due to the fact that healthcare staff are used to doing things for patients, but not seeing them as equal partners. More effort on using person-centredness as an approach is needed but there needs to be an understanding and a tolerance towards the fact that this shift might take time (105). It can be considered a paradox that AR is considered time-consuming, when it is actually addressing problem solving progressively during the data collection, and change can happen instantly instead of waiting for published results in studies.

#### 9.1.4. Combining person-centredness and action research

Study III and IV combined the philosophies behind action research and person-centred care in a practical setting and generated knowledge that can benefit both patients and other relevant stakeholders in the health care system when developing PEM. By combining the three principles of person it can be more evident in the development of new PEM how a partnership can be developed and safeguarded. Patient education materials can become a tool for shared communication instead of only information transformation in a static sender-receiver encounter. Since the theories and philosophies behind AR and PCC bare much resemblance, they were combined in an attempt to develop theory in both. Both strive to promote and encourage the knowledge and capacities in people in a constructivist paradigm, where knowledge-making between different stakeholders is a point of departure (4, 56). But where AR is more established as an umbrella of research practices (106) mainly aimed at problem solving and reflection on action together with the persons involved and in many different settings (56, 57), PCC is an approach to care actions grounded in philosophy and ethics (4). Ricoeur (55) speak of *homo capax* – the capable human - as someone who can be accredited to responsibility of his or her actions, both from others and oneself. By admitting to be capable, a person can be actionable from the reflected self-values and preferences made and reflect over the implications of her actions in a

relational evaluation with other capable persons. This “philosophy of action” however also includes the dialectic view of a person as being both capable and suffering, hence not promoting a naïve perspective of the subject as either having unlimited discretion nor inflationary responsibility. The combination of person-centredness and AR can be seen as fruitful, in that it added a defined theoretical analysis to the AR-cycle and made the PCC philosophy visible in a practical example. Action research has been criticised for not always being clear in what can be added as new theory and more focused on the problem solving of the inquiry (107, 108). Likewise, PCC struggle to find measurements to prove its efficiency, and by incorporating methodology from the AR paradigm, new approaches to valid research results can be encouraged.

#### 9.1.5. Enabling assimilation through text

There is a need to find different ways to enable patients to achieve knowledge to cope with stressful events and be prepared for surgery and recovery. Both study III and IV aim at finding new approaches, both in how to do it in a co-design, and also how it can be actionalized in text from 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> person perspective. To consider Fraser and Greenhalgh’s (109) take on competence (what individuals are able to do in terms of knowledge, skills, attitude) and capability (the extent to which individuals can adapt to change, generate new knowledge, and continue to improve their performance) might be a way to move forward. By changing the attitudes from a possibly one dimensional way of informing patients aiming at competence to a more process-oriented attitude where capability is enhanced can help overbridging the gap between information delivered and perceived provided. This might help patients to cope better with complex situations and also develop capacities to exert more control over their health (110). This might also indicate that traditional patient information, assuming linear communication, is not appropriate to support recovery from such a complex situation as being operated for a cancer tumour. Rather, patient information needs to be considered enabling the patient’s seeking for knowledge and understanding that enable their learning to take action (54, 111). This perspective responds well to the concept of assimilation of text by Ricoeur (55) where the self has to be expanded from reading the text, not purely understanding it. By bringing previous experiences, preconceptions, fears and needs to the text, the person can make it belong to his or her emerging new narrative. It can also relate to an AR-cycle, where previous knowledge is used to take new action and hence develop more knowledge on the matter (57).

Dixon-Woods (112) described how different orientation towards and conceptualisations of patients can be visible in the discourse of written information. A traditional biomedical discourse, where the patient is seen as incompetent and passive, has its origin in a reductionistic paradigm where biological explanations of disease are privileged over social, cultural and biographical explanations. The form of communication is based on “a stimulus-response sequence involving several elements, including a message, to be carried by a transmitter (the leaflet) to a receiver (the patient) in order to achieve some effect (cognitive, attitudinal or behavioural) in the receiver” (p. 1422). The job is to deliver a medical message as completely and efficiently as possible. As a contrast, Dixon-Woods described an emerging discourse aiming to empower patients through democratization. This discourse objects to the profession-driven agenda in PEM and promote the idea of patients being active partners in their care. Communication is seen as dialogue, where patients instead of just passively responding to a stimulus are actively constructing the meanings of text, something well in coherence with Ricoeur’s thoughts of assimilation (55).

The discourses of PEM described by Dixon-Woods (112) could be partly found in the PEM also analysed in study II, where Öresland et al (113) discovered a problematic mix of medical and a hospitality discourse. These results reveal a risk of still not seeing patients as competent partners and a use of power structures and traces of paternalism. Even if the hospitality discourse is meant to be welcoming, it may still exclude the patient’s from being partners and leaving them only as receivers of information. This adds yet another dimension to the development of PEM which adheres to a person-centred philosophy of including patients more in their own care. If considering the results from study IV, there is a lack of the 1<sup>st</sup> and 2<sup>nd</sup> person perspective, which could be enhanced in order to create a partnership where the PEM can be used as a tool for both the patient and the health care staff.

## 9.2. Methodological discussion

All methods used are believed to have a person-centred approach; i.e. they respond to the principles of person-centredness, where the person is prior to the patient without risking the quality of care. By also collecting and looping back the knowledge (56, 114), from previous studies, the development of the PEM becomes evidence based from a practice-based evidence point of view.

### 9.2.1. Pragmatic research approaches

The combination of studies in this thesis can be viewed as also having a pragmatic attempt to actually improve the PEM for patients undergoing CRC-surgery, and not just describe it. Mixed methods are used to answer research questions that have a complex dimension and need more than one method to hopefully reach the optimal answers (74). The sampling of a mixed methods study involves combining well-established qualitative and quantitative techniques in creative ways (115) something requested by McCormack and McCance (6) to develop and measure the outcomes of PCC. Johnson and Onwuegbuzie's description (116) of mixed methods being "the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study"(p.17) in fact makes this whole thesis rest on a mixed method design. Further, mixed methods is said to belong to a pragmatic paradigm of research (116) from which also AR has its roots. Considering AR as a pragmatic form of research, where all participants are change-agents that bring their own capacities and experience to the process, problems can be solved, reflected upon and knowledge can be added to theory. According to pragmatic philosophy diversity and conflict is seen as a democratic manner to use conflicting experiences, and scientific knowledge as a product of continuous cycles of action and reflection (57). This form of pragmatism with links and connections to knowledge, action, community and democracy remains, according to Greenwood and Lewin (57), important for AR. However, pragmatic research risk overlooking basic research in that it might appear to produce more immediate and practical results. Further, what is meant by usefulness and workability can be vague, unless the researcher is explicit enough in addressing this (116).

Having a more critical orientation to AR, as discussed by Huzzard and Johansson (59), might help the researcher to keep a possibly more professional distance from the stakeholders, but with the risk of not maintaining a close relationship believed necessary for building trust and relationships. The diversity of the group can be respected and used if a democratic arena for lively debate is created and made sustainable (107). This ethical conflict between AR being pragmatic or critical in its approach reveals itself from the focus of analysis and in how the research is presented; pragmatic approach being more focused on action and critical approach more on reflection on the process (117).

According to Johansson and Lindhult (117) these two orientations of action research influence power and reflection: the pragmatic being more suited to contexts dealing with immediate action where power to act is a desired outcome, and the critical focusing more on critical thinking and reflection, aiming at unveiling unequal and invisible power relations. These orientations can also be

seen as a north and south tradition, where north is more pragmatically problem-solving oriented, possibly due to often being performed in principally democratic contexts such as Scandinavia and North America. The south tradition orients from South America, with strong connections to Freire (61) and the emancipation of underprivileged groups (117). North (pragmatic) is thereby more focused on participation, exchange and collaboration, whereas south (critical) gives more room for dissension and reflection. This thesis can relate to both since it has a pragmatic purpose (developing a new material), but also a desire to promote a person-centred approach in the process, hence emancipating the patients' knowledge in a hierarchical structure such as health care.

### 9.2.2. Credibility and validity

Credibility and validity are presented as both theory providing generalizable results (study I and II) and as theory tested for workability in practice (study III and IV). Greenwood and Levin (57) describe a crux of the credibility-validity issue in AR vs. conventional research. In this thesis, both perspectives are used to enhance each other and were not seen as competitors but as complementary ways to gain knowledge. Internal credibility (57) was accomplished within the participants of study III and IV by being transparent about the process and its' agreements and disagreements and aiming at reaching a result that everybody could agree upon. This was of course not possible in study I and II, where the participants were not involved in the creation of the data in the same way. Here, the external credibility rests upon the third person presentation done by the authors of the manuscripts. By using validated instruments (the DCA and the SAM + CAM) and well-established methods such as language technology and focus groups, both validity and credibility was gained. Inter rater reliability controlled for the SAM + CAM by Krippendorff's alpha values was between 0.77 to 0.92 for the subscales and 0.99 for the total score. The magnitudes of the difference in total scores between two raters ranged from 0 to 2 points, with an overall standardized mean difference of 0.03. Standardized mean differences ranged from 0.01 to 0.29 for the subscales. None of the differences between the raters were statistically significant. The Krippendorff's alpha values were  $\geq 0.8$  for 10 of the items and between 0.67 and 0.80 for 5 of the items. The remaining 2 items were found to be less reliable, with values of 0.66 for *Subheading and advance organizers/C5-I3* and 0.47 for *Motivators to attend to text/C6-I1*. In all, the inter rater reliability was sufficient and added validity to the study results.

External credibility for study III and IV rests upon the competence of the researchers to convey the knowledge created by presenting the narrative of the process in a scientific third person manuscript.

*Validity in person-centred care.* Today, many PCC studies try hard to fulfil the validity demands established in the medical and nursing paradigm, and a lot of effort is put into how PCC can be measured to be proved an effective way of delivering care. Identifying outcome measures for these aspects are however described as a challenge, but as an essential aspect of testing the validity. Existing tools have been identified and also further developed to facilitate outcome measurements (118). There are other tools developed and tested to measure PCC (119-122) and PCC has also been measured in terms of length of for example length of hospital stay (8, 9, 119-127). McCormack and McCance (6,118) however request a development for creative strategies for evaluating PCC in practice.

There is however a problem in this attempt, where it may seem almost impossible to measure someone's attitudes and if care is delivered in a partnership. The effect of PCC has despite this been shown in even randomised controlled studies (128, 129), but needs further evidence from different study designs. This thesis tries to seek the similarities between, and thereby promote the idea that interventions with a PCC approach can benefit from using mixed-methods design, including action research. In study I, coping as a person's capacity to handle bothersome and stressful events in an early postoperative recovery phase can be seen to adhere to the PCC approach. By asking for the self reported bothersome events and allowing these to be illness related or not, the DCA instrument does not force any preconceptions on what should be bothersome, but instead allows the person to determine this by herself. The instrument can also be seen as having a person-centred approach in the way it asks for actions taken to feel better and hence consider the person capable to solve a demanding situation. This responds well to both the philosophy of Ricoeur (55) as to the GPCC approach (3) of seeing the patient as a competent person and a member of the care team, and means that even if the DCA is not explicitly said to measure effects of PCC, it relates well to the ontology and epistemology behind it. In study I, the DCA allows the person to make several decisions about the answers to the questionnaire. First, by deciding whether there was a bothersome event at all that day, and by determining what constitutes as bothersome for me, the person emanates from his or her experiences instead of predefined problems to respond to. Simultaneously, the bothersome events reported by patients in the early postoperative recovery phase were scrutinised and can be used in for example PEM to other patients in the same situation. A first person experience is then transformed into third person knowledge, but should be used in a second person encounter

where it can be discussed from the capacities and needs of that person stemming from listening to the narrative.

*Validity in action research.* Validity as seen from a positivistic point of view, is neither applicable nor desirable in AR (57). Instead of first learning something and then applying it, the learning process itself is the core of research (56, 107). Results from AR-studies must, according to Greenwood and Levin (57), be judged in terms of the workability of the solutions arrived at, meaning whether actions that arise from it actually solves problems or not. There are two parallel AR-cycles simultaneously, one about the actual problem-solving process, and one about the reflection on what is going on from a scientific point of view. Both are equally important, but have different objects and goals for the participants and the researcher (56). However, precisely not striving to reach positivistic outcome measurements has also been the criticism of AR created knowledge not being valid and generalizable. The suspiciousness for risk of the researcher not performing rigor research has also developed near related methods such as Interactive Research (IR) (107). There is also on-going discussion whether Action Research is in it self a contradiction in terms, where the focus on the inquiry is solving a problem and not on the research or development of theory (108). I here accept the idea of AR almost creating more valid and rigor knowledge and research, or robust knowledge used in practical situations, and that the researchers role is similar to how the approach of a nurse working with a person-centred approach must be to create partnership in care.

### 9.2.3 Ethics and power in co-design

In participatory design used in study III, as well as in other action research methods, ethics can be problematic and must be considered throughout the process (130). In particular, the risk of asymmetrical patterns of power must be documented and transparent in all stages of the iterative cycle. By doing this, protection and evaluation of the intended democratic knowledge sharing and generating can be facilitated. Eikeland (41) expresses this ethical question as a transformation from “How should we relate to them” to “How should we relate to each other?” and points out that action research is often torn between externally based academic research and the internal indigenous standards. Ethics need to be reflected upon, both before as in all research, but also iteratively during the process. If the suggested research is discussed in a democratic and participatory process, the stakeholders involved might consider possible risks worth taking. In this take on research ethics, focus is on the individuals and how they define a set

of values, which are then used as guidance for their behaviour (66). By considering the three views on power and knowledge in the reflection cycle and also promoting “conscientizacao”, tensions and negotiations will be regarded productive driving forces in action research. Both awareness of asymmetrical patterns of power and the possibility of all stakeholders’ knowledge need to be shared and enhanced in the project. Thus, action research (106) encompasses an endeavour to achieve reflexivity, described as “the extent to which the authors explicitly locate themselves as change agents”. This means that the researcher must have a plan, not only for action, but also reflection; i.e. be reflexive about the change process and the researchers’ impact on the intervention. Levin (131) describes it as action being followed by reflection, as reflection has to be accompanied by action and the rigor of action research depending on the capability to both solve problems but also scrutinize the experiences gained in order to communicate new knowledge. Scariot et al (43) however points out that crossing the boundaries between expert and participatory practice can be hard, particularly from being an expert and becoming a participant among others.

*First person reflection on power.* In study III and IV, it became evident that learning in a co-constructive environment was hard and took considerable effort and time. Most valid lesson learned was the sometimes obvious and sometimes subtle power structures. A powerful first person reflection was when the patient helping with the writing of the new PEM resigned, and described the research group as “very hierarchical with you at the bottom and the professor at the top”. This had not been evident to me as a researcher or a member of the project management group, and made me reflect considerably over the possible power structures within the group and how I contributed to them by subconsciously accepting a less democratic dialogue.



# 10. Implications

When a cancer diagnosis is set, a person also becomes a patient. Surgery of any kind implies a lot of preparation, both for the person and the temporary patient. Information passed between the health care providers and the person can be hard to assimilate and generate as knowledge in a threatening situation. Effort is made to enhance the person above the patient in Swedish health care, and policies demand a more person-centred approach. By seeing the patient as a competent person and a member of the care team, resources and needs can be discovered and given equal importance. This thesis brings more knowledge to the growing field of PCC-research.

Coping as a concept is generic, it's the context and situation that varies and with it the person experiencing stressful events. Situational coping occurs when recovering after surgery. If the person is helped to awareness of coping strategies, he or she might use them in a more conscious way. By being aware of what might happen and encouraged to find active strategies to cope with it, a person can be seen as competent instead of only vulnerable. Working in a person-centred way may enhance the possibility to enable such preparedness for the person and result in a less demanding postoperative recovery phase.

The thesis builds upon policies related to cancer care; the national cancer strategy and the Swedish patient law. Studies in this thesis can contribute with knowledge to enhance the evidence behind these policies. In particular, study II-IV can contribute with knowledge on how PEM can be improved developed in co-design and what theory can be adhered to during development. Written information is commonly used and asked for as a complement. Even if this is more and more transferred to IT-based e-solutions, there is still a need for the text to be of excellence in terms of readability, suitability and comprehensibility. Apart from following recommendations and guidelines on text production and design, the only ones with knowledge about what these words actually entail are the stakeholders, i.e. patients and professionals, and this knowledge must be acknowledged and used. Co-design is fruitful, but demanding, and the knowledge gained and theory developed can be applied to any context where patients and professionals collaborate in research, particularly in the design and development of written patient education materials.



# 11. Conclusion

Conclusions that may be drawn from these studies are:

- Patients need to be prepared for the early postoperative rehabilitation phase in order to cope with stressful events. These events might relate to the illness or surgery, but also to life in general. Pain and nausea after CRC-surgery are still experienced as stressful, unexpected and of low control. These symptoms might affect coping ability negatively.
- Coping strategies cannot be generalized as helpful or not, but depend on the person and his or her previous experiences and emotions connected to these experiences. Listening and responding to the narrative can help the person find coping strategies that may work in a specific situation.
- Patient education materials need improvement to become readable, suitable and comprehensible. Particular areas of improvement are related to patient interaction and motivation, which is highly relevant to enable an enhanced recovery after CRC-surgery, where patient participation is a key-component to success. Improvement of PEM needs to be approached from different angles and patients need to be involved as co-designers to ensure that all aspects are covered and addressed already in a design phase. Person-centredness as an approach works well in the design of PEM, both to co-design in partnership and to how the PEM is designed to enable partnership in care.
- Even if there is a desire to work in co-design with a person-centred approach, there are tendencies of old power structures remaining between patients and professionals. Having a transparent and structured reflection during the co-design process is crucial to notice and act upon such power structures.
- Person-centredness and action research are fruitful to combine and theory and knowledge can be developed in both fields by doing so. The dimensions of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> person works well as an approach and can simplify more complex theoretical and philosophical frame-works.



## 12. Future perspectives

Even if cancer treatment is progressing rapidly, surgery will remain a vital part of treatment. Healthcare is moving towards a more outpatient service, with fewer days in hospital and more responsibility for the person to handle the postoperative rehabilitation at home. For this to be sustainable, the team needs to involve the patient as a competent member with equally important knowledge, but from a different field; himself. Having such an approach must however not risk not seeing the person behind the patient as also sometimes vulnerable and someone with needs. Patients with cancer are often screened for distress (132), but rarely for coping strategies in an active process. Combining the two is of interest. If the concept of coping is used actively as a screening tool, and the person is made aware of his or her strategies, this might help preparing for stressful events. Simultaneously, distress and symptoms must be recognised and addressed. Interventions aiming for the use of the person's narrative in both adaptational and situational coping could give further knowledge to how a person can be helped in both short- and long-term recovery.

Further, testing of the principles for developing PEM is needed to investigate the workability in practice. The principles can be used and tested not only in printed PEM, but also in IT-based text aiming at assimilating knowledge for patients. The assimilation happens beyond the text and thereby the dialogue created between and within persons is what needs to be investigated further. If text can be produced to stimulate PCC, this needs to be established and further developed as tools.

Having person-centredness as a philosophical approach in research demands the interaction and use of patients as co-researchers to a greater extent than is found today. Creating partnership in all levels is needed for this approach to become sustainable, and there is a need to embrace methodologies that might not be coherent to traditional demands of validity. In a learning environment, such as cycles of action research, knowledge can flourish between participants, and true democracy occurs.



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# Appendix