

Person-centred e-support

*Foundations for the development of
nursing interventions in outpatient cancer care*

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“When you want something,
all the universe conspires in helping you to achieve it”
Paulo Coelho in *O Alquimista*

Abstract

This thesis explores the foundations of person-centred e-support for women undergoing treatment for early-stage breast cancer. It is designed to enhance the knowledge base on how nursing interventions, in the form of interactive health communication applications, might assist the provision of support tailored to the unique needs and preferences of the patient, in the shifting cancer care context from inpatient to outpatient settings.

In *Study I*, an integrative systematic review of literature was conducted on the design of e-supportive systems in cancer care. Analysis and synthesis of 28 studies revealed that e-supportive systems allowed meeting cancer patients' supportive needs. However, transferability across target populations was constrained by differences in features, theoretical structure and study designs. In *Study II*, a two-group ($n=226$), multi-centre, randomised, controlled trial was conducted to evaluate the impact of a computer-based educational programme on: health self-efficacy, healthcare participation, anxiety and depression of women undergoing treatment for early-stage breast cancer. Multi-level modelling revealed no statistically significant improvement in outcomes. Subsequent exploratory regression analysis revealed factors associated with use of the programme. *Study III* explored patients' efforts to satisfy their supportive needs throughout the treatment course. Guided by Interpretive Description, 19 women undergoing treatment for early-stage breast cancer participated in five focus groups. Through constant comparative analysis the results disclose women as self-driven resourceful agents as they seek knowledge and support from their network in a continuum of reaching-out behaviours. *Study IV* explored the early-stage development of a prototype of the *Care Expert*, a person-centred e-supportive system, and its usability for women undergoing chemotherapy for early-stage breast cancer. Subjective assessment and diagnostic evaluation of the prototype were conducted in four individual usability sessions. The prototype's supportive communication functions were perceived by women to support their self-driven and cooperative agencies.

Integration of the results suggests that interactive health communication applications have potential to complement care in meeting women's supportive needs. However, the exclusive provision of reliable and evidence-based information via a computer-based programme is not

enough. Integration of person-centred dimensions and user involvement early on in the development process may be the key to ensuring effectiveness of the application. Person-centred e-supportive systems may bridge the communication gap between the hospital setting and patients' homes by fostering a reciprocal partnership in care that acknowledges and reinforces patients' expertise and agency.

Keywords

eHealth, communication, intervention research, nursing, person-centred care, self-management

Sammanfattning på svenska

Denna avhandling undersöker grunder för personcentrerat e-hälsostöd, avsett för kvinnor som genomgår behandling för tidig bröstcancer. Den är designad för att bidra med kunskap till att skraddarsy stöd utifrån den enskilda patientens behov och preferenser, vilket vid cancerbehandling alltmer sker i öppna vårdformer i stället för slutenvård. Genom att öka tillgängligheten till vårdpersonal och möjliggöra individuellt anpassat stöd kan e-hälsostöd bli del av en lösning för att komplettera öppenvård i samband med cancer.

I Studie I genomfördes en integrativ systematisk litteraturstudie avseende design av e-hälsostöd inom cancervårdsområdet. Analys av 28 studier visade att e-hälsostöd kan möta behovet av stöd hos patienter med cancer. Överförbarhet och utvärdering av olika program begränsas emellertid av skillnader i programmens utformning, teoretiska utgångspunkter och studiedesign. I Studie II genomfördes en randomiserad kontrollerad studie med 226 kvinnor under behandling för tidig bröstcancer för att utvärdera ett datorbaserat stödprogram avseende tilltro till förmågan att hantera sin hälsa, delaktighet i vården, ångest och depression. Inga statistiskt signifikanta skillnader påvisades mellan interventions- och kontrollgrupp. Faktorer sammankopplade till att använda stödprogrammet påvisades genom regressionsanalys. Studie III undersökte patientens strategier och handlingar för att tillgodose sitt stödbehov under behandlingsförloppet vid tidig bröstcancer. Studien designades enligt tolkande beskrivning och data från fem fokusgrupper (19 kvinnor) analyserades med konstant komparativ metod. Kvinnorna beskrev sig som självständiga och resursstarka när de riktar sig utåt för att söka kunskap och har möjlighet att få stöd i sina nätverk, i vilka de inkluderar hälso- och sjukvård. Studie IV undersökte användbarheten i en prototyp av *Care Expert*, ett e-hälsostöd utvecklat med grund i personcentrerad vård avsett för kvinnor under behandling för tidig bröstcancer. Detta genomfördes i fyra sessioner med kvinnors subjektiva bedömning och utvärdering av prototypen. Deltagarna skattade användbarheten och de stödjande funktionerna högt och antog att *Care Expert* kan stödja deras förmåga att agera såväl självständigt som söka samarbete för att hantera sitt dagliga liv vid cancerbehandling.

Sammanfattningsvis föreslår avhandlingens resultat att interaktiva hälsokommunikativa e-applikationer har potential att möta patientens stödbehov på sätt som kompletterar personliga möten i vården. Att tillhandahålla datorförmedlad reliabel och evidensgrundad information om behandling och rehabilitering utgör emellertid inte ensamt tillräckligt stöd. Att i utvecklingsprocessen tidigt integrera patientmedverkan och personcentrerade dimensioner kan vara en nyckel för att säkerställa e-hälsostödets relevans. Personcentrerade e-hälsostöd kan fungera som brobyggare mellan sjukhusets vårdsammanhang och patienten i hemmet. Detta kan ske genom att möjliggöra ömsesidigt partnerskap mellan patient och vårdteam, vilket kontaktsjuksköterskor har en särskild roll för inom cancervården. E-hälsostöd kan bekräfta och stärka patientens kunskap och förmåga att hantera situationen till följd av cancer och cancerbehandling.

Nyckelord

Cancervård, e-hälsa, interventionsforskning, kommunikation, omvårdnad, personcentrerad vård, självhantering

List of papers

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

- I. Ventura F., Öhlén J., Koinberg I.
An integrative review of supportive e-health programs in cancer care

European Journal of Oncology Nursing 2013; 17: 499–507.
- II. Ventura F., Sawatzky R., Öhlén J., Karlsson P., Koinberg I.
Challenges of evaluating a computer-based educational program for women diagnosed with early-stage breast cancer: a randomised controlled trial

Submitted
- III. Ventura F., Koinberg I., Karlsson P., Sawatzky R., Öhlén J.
Purposeful agency in support seeking during cancer treatment from a person-centered perspective

Accepted for publication in Global Qualitative Nursing Research, 2015
- IV. Ventura F., Koinberg I., Sawatzky R., Karlsson P., Öhlén J.
Exploring the person-centeredness of an innovative e-supportive system aimed at person-centered care: prototype evaluation of Care Expert

Accepted for publication in Computers, Informatics, Nursing, 2015

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Abbreviations

CHESS	Comprehensive Health Enhancement Supportive System
ESBC	Early-stage Breast Cancer
FACT-B	Functional Assessment of Cancer Therapy – Breast
HADS	Hospital Anxiety and Depression Scale
HCT	Healthcare Team
ICT	Information and Communication Technology
IHCA	Interactive Health Communication Applications
PCC	Person-centred Care
PCI	Person-centred Intervention
PRO	Patient-reported outcome
RCT	Randomised Controlled Trial
SoC	Sense of Coherence

1. Introduction

Along with the enhanced awareness promoted by cancer screening programmes, breast cancer is increasingly being detected at an early-stage and its treatment is shifting from inpatient to outpatient settings. Consequently, women undergoing treatment for early-stage breast cancer (ESBC) spend most of the treatment course in their familiar environment in spite of the great psychosocial distress and strange bodily experiences that a cancer diagnosis and treatment entail. To cope with their unmet supportive needs, women turn to personal supportive resources, among which include those found on the Internet, to seek mainly knowledge and social support. In spite of the recognised value of this proactive behaviour in adjusting to cancer diagnosis, the results of that interaction are often overwhelming for women. Specifically, the information might be of doubtful quality and the support retrieved might not be tailored to their specific situation and needs.

From the care provider's perspective, supporting women beyond the hospital walls is a challenge concretely related to the inability to continuously monitor women's wellbeing, identify potential threats and harms and provide care advice at the needed time. The shifting of care from inpatient to outpatient settings then comes with the obligation to adjust healthcare systems towards the integration of strategies and solutions that enhance communication processes between care providers and patients. Among such strategies, interactive health communication applications (IHCA) are increasingly being developed and implemented as complementary solutions in cancer care with evidence of improving patient outcomes.

However, the complexity IHCA's challenges the success of their implementation. Such complexity is reflected in the heterogeneity of intervention models, where researchers apply multiple designs with varying theoretical foundations and outcomes. The available evidence advises caution in the interpretation of the effectiveness results and in the transferability of IHCA's across target populations. Furthermore, scholars urge the rigorous development of IHCA's that focus on the patient's unique preferences with the aim of accomplishing acceptable, feasible and successful methods of support. These have to necessarily acknowledge the person's values and priorities and must assist the care providers in meeting the unique person's supportive needs.

2. Background

In this chapter the peculiarities of women's supportive needs and their support-seeking behaviours throughout the course of treatment are uncovered. Furthermore, advances and challenges with regard to IHCA's are put forward as the background to person-centred e-supportive interventions.

2.1 Supportive needs of women undergoing treatment for ESBC

Being diagnosed with breast cancer and receiving cancer treatment has a great impact on women's lives. They go through a sudden transition from health to illness where their complex bodily experiences lead to uncertainty and psychosocial distress (Taha, Matheson, & Anisman, 2012; Tighe, Molassiotis, Morris, & Richardson, 2011). Furthermore, the nowadays-early detection of breast cancer and the advances in imaging and treatment, have allowed shifting the treatment course of early-stage breast cancer to outpatient settings (Kaufmann et al., 2013). Specifically related to the course of treatment, after breast surgery women are usually offered adjuvant therapies (chemotherapy, radiotherapy, targeted therapy and/or hormonal therapy), which might be combined in different way and might occur in variable order (Regional Cancer Centre, November 2014). While spending more time in a familiar environment is beneficial, women have to more actively engage in behaviours of adjusting to cancer and manage symptoms and treatment side effects themselves, similar to other individuals affected by long-term illness conditions (Paterson, 2001).

An extensive body of evidence-based knowledge has raised attention to the supportive needs of women throughout the course of their treatment for ESBC and their implication for women's quality of life and wellbeing (Härtl et al., 2010). Most of the research studies examining women's supportive needs focus on their informational needs commonly related to decision-making styles and self-management, general aspects of coping with breast cancer diagnosis and treatment, and psychological distress portrayed by anxiety and depression levels (Lim, Devi, & Ang, 2011; Malik & Kiran, 2013; Vogel, Bengel, & Helmes, 2008).

Although the studied needs vary significantly in relation to the course of treatment for ESBC (Hoskins et al., 1996; Sherman et al., 2012), both the

waiting phase, from diagnosis to the breast cancer surgery, and the chemotherapy phase appear to be particularly burdensome (Burton, Collins, Caldon, Wyld, & Reed, 2014; Rottmann, Helmes, & Vogel, 2010).

The period of time between diagnosis and the breast surgery is emotionally charged and might be the phase where coping styles, and thereby supportive needs, vary the most among women. Potentially as a result of such disparity, many of the interactions with the supportive network during this period are perceived to be unsupportive by women. In such a context, assessing women's perceptions of support and supportive relationships, while respecting their diverse informational needs, is of particular significance to the provision of person-relevant support (Dickerson, Alqaissi, Underhill, & Lally, 2011; Drageset, Lindstrom, & Underlid, 2010).

Evidence also shows that chemotherapy has the strongest effect on coping when compared to radiotherapy, stage of cancer and several other socio-demographic factors (Hervatin, Sperlich, Koch-Giesselmann, & Geyer, 2012). During chemotherapy treatment, cancer patients usually report cognitive dysfunction, functional impairment and fatigue (Edelstein & Bernstein, 2014) due to treatment side effects. In such a context, a variety of information methods might be required to meet the educational needs of patients affected by cancer during chemotherapy treatment in such a way that they influence the person's self-care abilities (Prouse, 2010). Particularly during this phase of treatment, evidence portrays the need to conduct routine symptom and coping assessments to promote the identification of the person's supportive care needs (Feyer, Kleeberg, Steingraber, Gunther, & Behrens, 2008). In addition to informational support, social support and strategies for patient enablement during the chemotherapy phase are of special significance for the coping process of women diagnosed with breast cancer (Hervatin et al., 2012).

More than just eliciting the specific supportive needs expressed by women, the evidence synthesized attempts to shed light onto the relationships between the manifested needs and their preceding factors, that is to say, antecedents of supportive needs. Departing from the manifestation of supportive needs as measured by patient-reported outcomes (PROs), the research endeavour attempts to predict the supportive care needs and the unmet supportive needs at a specific time point during the course of treatment or in relation to socio-demographic characteristics, coping styles or psychosocial variables, such as wellbeing, anxiety or depression (Ankem, 2006; Griesser et al., 2011; McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010). However, the same antecedents are rarely found across different cultures within the same target population. A particularly striking example is the informational needs across the illness and treatment continuum in relation to age. Where, in some cultures (e.g.

Japan), age is not relevant in predicting informational needs, in others (e.g. United States and Canada), higher informational needs become manifest in younger women (Ando et al., 2011; Fiszer, Dolbeault, Sultan, & Bredart, 2014; Molisani, Dumenci, & Matsuyama, 2014). On one hand, this body of evidence has recognised the value of raising the awareness of care providers to the existing supportive needs of women and informing clinical practice of the development of interventions targeting potential subgroups (Ankem, 2006; McDowell et al., 2010). On the other hand, the generalisability of the results has to be cautiously conducted. In the process of assisting the contextualisation of antecedents of supportive care needs, qualitative evidence on women's perceptions of support and supportive needs might be imperative to address the shifting person-relevant needs at the adequate time (Fiszer et al., 2014).

In spite of the available knowledge on the supportive care needs and their antecedents, the perceptions of supportive care and needs differ between care providers and women. Particularly considering informational support, varying perceptions have been found in relation to the importance of specific information topics for cancer patients and nurses during chemotherapy (Lei, Har, & Abdullah, 2011). In relation to general support, cancer patients have reported that the lack of referral to supportive services is potentially related to the fact that their supportive needs remained unperceived by their healthcare providers (Dilworth, Higgins, Parker, Kelly, & Turner, 2014).

To the discrepancy of perceptions between women and healthcare providers, the challenge of meeting women's needs at an adequate time point is considerably heightened in outpatient cancer care. Particularly with regard to the provision of support during short and sporadic face-to-face encounters, the research focusing on the process of meeting women's supportive needs has elicited that the provision of support at an undesired or irrelevant time point, from women's perspectives, might lead to increased distress (Case, Andrews, Johnson, & Allard, 2005 ; Lally, Hydeman, Schwert, & Edge, 2013).

Briefly, in a context where: a) the perceived needs continuously evolve, tightly following the adjustment process to cancer diagnosis and treatment; b) there is an absence of continuous contact with the healthcare providers; and c) during that contact in particular, the perceptions between women and healthcare providers might not be aligned, women's supportive needs often remain unmet.

The research work carried out to unravel these unmet needs brings forth several areas for improvement, among which the provision of information and support (e.g. emotional and psychosocial) are consistently mentioned (Smith, Hyde, & Stanford, 2015). With regards to the information needs, a desire for mostly informational support alongside the period of breast cancer treatment was identified (Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2013).

In the presence of these unmet supportive needs, women will engage proactively in knowledge and support seeking from their supportive network while at home between treatment sessions (Jones, Hadjistavropoulos, & Sherry, 2012). Beyond their loved ones and significant others, relevant supportive sources from women's perspectives are peer support groups, either face-to-face or online, and more generally, the Internet (Balka, Krueger, Holmes, & Stephen, 2010; Campbell, Phaneuf, & Deane, 2004; Carlsson, 2009; Manne, Siegel, Kashy, & Heckman, 2014).

Especially in relation to the Internet, women diagnosed with ESBC have been identified as being particularly active information-seekers (Nagler et al., 2010; Protiere, Mounjid, Bouhnik, Le Corroller Soriano, & Moatti, 2012). In such a context, the lack of tailored knowledge and support for the specific situation of individual women and the ambiguous quality of cancer websites is worrisome (Lawrentschuk et al., 2012). Women recognise these potential threats as they often experience difficulty in making sense of the standard of information displayed, and are exposed to emotionally-charged lived experiences from their peers. Accordingly, the results of the interaction with the Internet might diminish the benefits of the behavioural initiative of seeking knowledge and support in adjusting to cancer, due to increased distress and burden (Balka et al., 2010; Clayman, Boberg, & Makoul, 2008). In such a context, attending to the person's supportive resources outside the patient-clinician relationship is of special significance to the process of promoting an adequate adjustment to cancer and cancer treatment, both because patients need support in interpreting the acquired knowledge and because the care provider response ultimately influences patients' outcomes as it is perceived to be individual, reliable and trustworthy (Anker, Reinhart, & Feeley, 2011; Bylund, Gueguen, D'Agostino, Li, & Sonet, 2010; Carlsson, 2009).

Altogether, the evidence presented reinforces the necessary focus on the cancer patient's perceptions of their need for support, and the establishment of continuous monitoring and contact that allows real-time assessment of supportive needs and adequate provision of person-relevant support (Dilworth et al., 2014).

2.2 Person-centred e-supportive systems

To complement standard care in the provision of information and more general health services, healthcare professionals allied to health informatics have been developing IHCA (Eysenbach, 2001). These systems are mainly an answer to the demands of enhancing communication channels between healthcare providers

and patients, and providing accurate, person-relevant and customised support to the person (Kreps & Neuhauser, 2010).

As a single resource or a platform of multidimensional resources, the interventional goals of IHCAs vary widely in the literature, and might aim: to enhance decision-making, self-management or patient-clinician communication, or health promotion (Kreps & Neuhauser, 2010; McAlpine, Joubert, Martin-Sanchez, Merolli, & Drummond, 2015). Yet, what they all have in common is the Internet as a delivery means or intervention enhancement strategy (Eysenbach, 2001). Learning on the historical arising of the first IHCA able to improve person-relevant outcomes, that is, the Comprehensive Health Enhancement Supportive System (CHESS) (Gustafson et al., 2002), multidimensional IHCAs are usually designated by their developers as supportive systems, although a conceptualisation of support is not explicitly put forward. To this conceptual heterogeneity adds the variety of descriptors used to portray the embedding of the system in eHealth, e.g. online, web-based, computer-based, mobile ‘m’, electronic ‘e’ (Morrison, Yardley, Powell, & Michie, 2012).

Attempting to clarify the concept of eHealth, attention has been brought to the importance of seeing these resources beyond the mere technological sphere. More than just a technological development, eHealth is the characterisation of “a state-of-mind, a way of thinking, an attitude, and a commitment for networked global thinking, to improve health care” (Eysenbach, 2001). With this broad perspective of the eHealth concept, the author points out that the ‘e’ in eHealth should not stand for ‘electronic’ only; it should rather mirror: efficiency, enhancing quality of care, evidence-based, empowerment, education, encouragement, education, enabling, extending, ethics, and equity. The work carried out in this thesis endorses this broad perspective. Furthermore, consistent with the common trend in the scientific health literature and discourse in eHealth, the designation of e-supportive systems was adopted. When specifically referring to the explicit integration of person-centred dimensions within the IHCA, the designation of person-centred e-supportive systems will be used.

2.2.1. Brief historical perspective of IHCAs

The revolutionary growth of the Internet as a communication channel opened people’s horizons to a new world of information, particularly health information, and its nowadays-wide access enables improvements in health and healthcare (Ahern, 2007). The antecedents of eHealth may be traced back to the ‘80s, with a great amount of studies already published on behavioural informatics (slightly

over 1900 publications between 1980 and 1989). However, the precursors of the contemporary IHCA only emerged in the early '90s. The millennium represented indeed the beginning of a new era for information and communication technology (ICT), particularly eHealth and health communication, with almost the number of studies published doubling between 2000 and 2004, in comparison to its initial arising period (Ahern, 2007).

The development of CHESS started in the early '90s and its evaluation and implementation matched the exponential expansion in the eHealth field with the first effectiveness results being reported alongside the millennium shift (Gustafson et al., 2002; Gustafson et al., 1993). CHESS is the most extensively studied IHCA and is therefore the reference for what is feasible and effective within IHCA (Badr, Carmack, & Diefenbach, 2015). In its current format, CHESS is an Internet-based supportive system that has been comprehensively delivered to women diagnosed with breast cancer in the United States for over almost two decades now (Gustafson et al., 2002). The e-supportive system entails multidimensional services (e.g. asynchronous discussion groups and ask-an-expert boards) and assists patients with information, support and coaching to enhance both self-management and shared decision-making (DuBenske, Gustafson, Shaw, & Cleary, 2010).

CHESS is usually assessed on eight outcomes, among which are health self-efficacy and healthcare participation, with scales developed by the authors for the studies' purpose (Gustafson et al., 2005). Throughout the comprehensive evaluation of the programme in breast cancer populations, CHESS authors have carried out various scale modifications depending on the outcomes expected, either by changing the item pool or by excluding individual scales (Gustafson et al., 2001; Gustafson et al., 2005; Hawkins et al., 2010; Lu, Shaw, & Gustafson, 2011). Particularly in relation to the population of women diagnosed with breast cancer, CHESS has been helpful in improving: health literacy, health competence, healthcare participation, social support, and quality of life (DuBenske et al., 2010).

The eHealth research conducted in Europe is quickly closing in on the trend in the US (Kummervold et al., 2008) and one particular e-supportive system is following in CHESS's footsteps. WebChoice is another multidimensional IHCA and increasing evidence is revealing its potential to assist people diagnosed with cancer to manage their illness (Ruland et al., 2012; Ruland, White, Stevens, Fanciullo, & Khilani, 2003).

The state of the art on eHealth has come to the stage where conducting systematic reviews can ascertain the impact and cost-effectiveness of IHCA as health interventions (Ross, Stevenson, Lau, & Murray, 2015). Having passed the first wave of research focusing on the effectiveness of these e-supportive

systems, the second generation of research, still in its infancy, seeks to explore the person-centredness black box in relation to: a) the system components that allow reaching the outcomes; b) the mechanisms between the components through which they interacted to produce effective results; and c) for whom the e-supportive system actually works (e.g. Borosund, Cvancarova, Ekstedt, Moore, & Ruland, 2013; Högberg, 2015; Han et al., 2009; Resnicow et al., 2010; Ruland et al., 2013; Shaw et al., 2008; Shaw et al., 2006).

2.2.2. Purpose, theoretical structure and outcomes

Multi-dimensional IHCA's, particularly in cancer care, generally focus on enhancing patient-clinician communication, facilitate treatment decision-making, and promote lifestyle behaviour change. Overall, these programmes appear to enable the person by providing supportive services at the informational, educational, communication and coaching levels (Badr et al., 2015; Bouma et al., 2015; McAlpine et al., 2015). More concrete purposes than the ones mentioned above are also found with particular emphasis on enhancement of health literacy and self-management, for example, Darlow and Wen (2015); Jacobs, Lou, Ownby, and Caballero (2014). Although such supportive systems usually fall into the domains of education and information, they also entail communication services. Therefore, ascertaining which services are demanded by the IHCA's purpose and which are responsible for the IHCA's outcomes is a challenge (McAlpine et al., 2015).

Theoretical structures underpinning e-supportive systems are usually borrowed from the scientific fields of social and behavioural sciences, education and learning, and communication. The most commonly applied theories are: the self-regulation theory, self-determination theory, social-cognitive theory, and stress and coping theory. These theories seem to endorse the mechanisms of action of the e-supportive system as the studies most commonly describe them in relation to the improvement that the intervention is expected to generate, that is to say, the outcomes. However, their concrete link to the mechanisms of action, and influence on the development of the intervention components, are less understood (Badr et al., 2015).

This reality is expected to change along with the trend of the second generation of research of e-supportive systems, where the mechanisms of action are being explored *a posteriori* to elicit the IHCA theoretical structure from the antecedents leading to the interaction, to the mechanisms of action leading to the outcomes (Pingree et al., 2010).

The effectiveness of IHCA has probably been the most examined element during the first era of eHealth research (Agboola, Ju, Elfiky, Kvedar, & Jethwani, 2015; Bouma et al., 2015; Ryhänen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010). Particularly within cancer care, multi-dimensional e-supportive systems have been helpful in improving fatigue, social support and distress, regardless of the specific services provided (Bouma et al., 2015). Furthermore, impact has also been reported on behavioural and clinical outcomes, pain control, depression and anxiety levels, knowledge and health literacy, information and health competence, health self-efficacy, healthcare participation, issues pertaining to decision-making, wellbeing and quality of life (Agboola et al., 2015; Gustafson et al., 2002; Murray, Burns, See, Lai, & Nazareth, 2005; Ryhänen et al., 2010).

Although there is common agreement about the positive effectiveness of e-supportive systems (Bouma et al., 2015; Resnicow et al., 2010), the results from the second generation of research relating to the theoretical structure and person-centredness elements of e-supportive services, advise caution in the interpretation of the results (Badr et al., 2015; Black et al., 2011; McAlpine et al., 2015; Morrison et al., 2012). Specifically, the effectiveness of e-supportive systems outside their original development context varies depending on the intervention target, intervention components and the selected efficacy outcomes (Badr et al., 2015; Morrison et al., 2012). The issues contributing to these difficulties in the generalisability and transferability of e-supportive systems are manifold, but reflections commonly go back to the lack of effective development strategies (Black et al., 2011; McAlpine et al., 2015).

2.3 Bridging eHealth and person-centred nursing intervention research

The progress made within person-centred care (PCC) during the last decade have allowed for the clarification of concepts and the development of sound theoretical underpinnings of person-centred interventions (PCIs) (Coulter & Ellins, 2006; de Silva, 2014; Ekman et al., 2011; McCormack et al., 2015). Although many interventions have been tested, very few have shown empirical evidence of successfully improving person-relevant outcomes (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2013).

In the context of this thesis, an intervention is defined as an activity or action framed within the goals and values of nursing and undertaken by healthcare providers with the purpose of enhancing the wellbeing and quality of care of people with health-related needs. Such actions might even be undertaken by

patients themselves as in self-care activities (Naylor, 2003; Richards & Rahm Hallberg, 2015). Within the wider sphere of intervention research, the complexity of health interventions has gained special attention during recent years. Scholars argue that simplicity might be a chimera when interventions relate to the promotion, support or change of health behaviours (Richards & Rahm Hallberg, 2015). If defining ‘intervention’ is quite consensual and straightforward, identifying the complexity elements of an intervention is in itself a challenge.

Recent studies in intervention research have uncovered components of intervention complexity. Scholars have passed the initial analysis of behaviours, outcomes and intervention delivery (Medical Research Council, 2008) to include dimensions along the intervention lifecycle, that is, from early development to implementation. Within areas of complexity (e.g. intervention, design, evaluation, implementation, context, participant response), several sub-themes have been identified that correspond to the specific challenges (Anderson et al., 2013; Datta & Petticrew, 2013). The variability in potential complexity issues makes the process of defining ‘complex’ difficult and only reinforces the need to have a comprehensive methodological guidance from early development to long-term implementation. Such guidance is crucial to address key uncertainties, thereby ensuring that sufficient effort has been made to develop and pilot the intervention before departing to a full trial, and to ease the process of implementation into clinical daily practice (Richards & Rahm Hallberg, 2015).

The more an intervention is tailored to the specific situation of a person, the greater is its potential to actually assist in meeting the person’s unique needs (Lauver et al., 2002). Nursing interventions delivered at the care setting following a person-centred care philosophy, have this element naturally embedded (McCormack & McCance, 2006). Supportive interventions delivered through the Internet, however, are not congruent about the elements that allow an IHCA to be a person-centred e-supportive system.

Generally, person-centred interventions represent a movement from the one-size-fits-all view to having more respect for and integration of the person’s unique characteristics, values and preferences (Lauver et al., 2002). Authors have argued that, when developing person-centred interventions, it is important to reflect on: a) the dimensions of the intervention components that enhance person-centredness; b) the person-centred means of delivering it; and c) the actual relevancy of the improved outcomes to the person (Lauver et al., 2002).

When attending to the person-centred aspects of nursing interventions in particular, scholars elaborate on different dimensions (Aranda, 2008; Lauver et al., 2002; van Meijel, Gamel, van Swieten-Duijfjes, & Grypdonck, 2004). In spite of the variation, they all agree on the customisation dimension of the

intervention, which is commonly designated as the degree of person-centredness. Empirical evidence has highlighted that tailored health-related informational interventions were more effective when compared to standardised health-related informational interventions on health behaviours. Moreover, tailored messages are experienced as being more personal and better remembered when compared to general, standard information (Conn, Rantz, Wipke-Tevis, & Maas, 2001; Kreuter & Wray, 2003; Lauver et al., 2002; Morrison et al., 2012; Ryan & Lauver, 2002).

The degree of person-centredness of the intervention elements is best seen in a continuum of customisation from targeted, to tailored, to individualized (Aranda, 2008; Lauver et al., 2002). Targeted interventions are usually delivered at a group level, where people are brought together by socio-demographic characteristics or because they share a specific behaviour (Lauver, 2002). Such interventions might also involve baseline screening for a determined risk (Aranda, 2008). Tailored interventions are more customised than targeted, mainly because they move from the group to the individual level. Each person receives an intervention customised to her uniquely expressed characteristics after being assessed on attitudes, beliefs and other variables with a large number of possible values. The result will determine the content of the provided message (Lauver, 2002). The intervention remains structured because the messages are usually pre-determined according to a defined set of likely areas requiring individualisation (Aranda, 2008). At the maximal end of customisation are the individualised interventions. Such interventions are highly customised to the person's particular situation to the point where no two individuals might receive the same intervention. The intervention is therefore highly dependent on the interaction between the interventionist and the person, and is developed as the interaction occurs (Aranda, 2008; Lauver et al., 2002).

When discussing PCC in the eHealth realm, the topics emerging usually focus on the integration of IHCA in the care context with special considerations for the work flow or organisational structure of the care being provided (Atienza, Hesse, Gustafson, & Croyle, 2010). Another common topic is the integration of electronic health records and personal health records as a means of enabling a person's own decision-making and patient-clinician communication, thereby promoting a more person-centred care practice (Caligtan, Carroll, Hurley, Gersh-Zaremski, & Dykes, 2012; Caligtan & Dykes, 2011). Other scholars point out the importance of eliciting and integrating the person's perspective from the very beginning of intervention development (Berry, Blonquist, Patel, Halpenny, & McReynolds, 2015). In spite of a common focus on a holistic perspective of the person and the efforts to support the person involvement in their own care, the guidance of person-centred care philosophy is absent.

Looking at person-centredness within IHCA, many e-supportive systems have revealed positive and significant improvements in various person-relevant outcomes (Agboola et al., 2015; Badr et al., 2015; Bouma et al., 2015). Moreover, elements of person-centredness might be inferred from their general focus on the elements composing the broad perspective of eHealth, such as: enablement, through widening the access to the health-related knowledge and personal electronic records, thereby enabling evidence-based patient choice; and encouragement for making shared decisions between care providers and patient. The lack of explicit dimensions of person-centredness leads to difficulties in the interpretation of the potential success of those systems in mediating PCC. The embedding of principles from a person-centredness and PCC philosophy from the early development stage of e-supportive systems, aiming for mediation of PCC through the Internet, is an innovative step compared to the IHCA described in the previous sections.

3. Theoretical perspectives

This chapter introduces the person-centred care philosophy, theoretically structuring the work in this thesis and presenting its philosophical foundations in the concept of *person* and *person-centredness* dimensions. Specifically, in relation to person-centred care, the perspective adopted on the concept of support is explained.

3.1 Concepts of ‘person’ and person-centredness

The work in this thesis endorses the perspective that a *person* is someone with inherent capabilities and vulnerabilities, strengths and fragilities that emerge to more or less an extent along a continuum of wellbeing. This person is a resourceful agent, responsible for the actions they undertake, in spite of the potential weaknesses (Ricoeur, 1994). These weaknesses might eventually account for the *patient* in the person. However, that is only a portion of the person, and that still does not legitimize the objectification of the person that the term ‘patient’ entails.

Taking a stand from reductionist perspectives, the sum of any person should not be reduced a medical diagnosis and an illness. In spite of the illness, the capable being keeps their will and personal values embedded in a personal environmental and familiar context that altogether reinforce the person’s subjectivity beyond the object that is the illness. Furthermore, the environmental and familiar context portrays the element of reciprocity of being and becoming a person. The *person* is built and shaped in continuous relationship with others. Taking a stand from individualistic perspectives, a person should not be seen as an individual isolated from their surroundings, as their interdependence is also an inherent portion of the person as a whole (Eneau, 2008; Ricoeur, 1994). Both terms, ‘patient’ and ‘individual’, will certainly occur in this thesis, yet they should be considered in light of the conceptualisation of person here described.

Scholars have made efforts to elicit the person-centredness dimensions pertaining to structure processes and activities, and promote behaviours that are aligned and enhance the adopted person perspective (Coulter & Ellins, 2006; de Silva, 2014; Lauver et al., 2002; Leplege et al., 2007; Mead & Bower, 2000;

Zill, Scholl, Härter, & Dirmaier, 2015; Öhlén, 2015). Seeing beyond the themes into their descriptions, several common dimensions emerge across the empirical and theoretical literature reviewed. The most consensual is the recognition of the personhood, that is to say, a person's uniqueness characteristics embedded in the environmental and material world and the person's biography. Particularly related to this dimension is the respect for the person 'before' the patient, where the holistic perspective of the person highlights them as someone with strengths and weaknesses, both inherent to personhood. Departing from the ethical standards of dignity, privacy and autonomy, the person should be seen as an expert in the therapeutic alliance and enabled to make decisions about his/her health that reflect the person's needs, values, will and desires.

3.2 Person-centred care philosophy

PCC has gained particular attention as a result of the worldwide emergent policy of involving the person in their care, in the face of its great potential in accommodating illness management and enhancing the quality of healthcare to its highest level (de Silva, 2014). However, potentially as a consequence of the many cultural and scientific contexts wherein the philosophy is being explored and developed, a universally accepted definition of PCC is absent in the empirical literature. Researchers within their particular discipline or research area interchangeably use terms such as patient-centric or user-centred (technology development), client-centred or whole person care (social care and mental health), individualised or humanised (nursing), and patient-centred or personalised (de Silva, 2014). The duty of selection of one of these terms has to necessarily rest on the researchers' and care providers' perspective of person and person-centredness.

The work carried out in this thesis focused on *person-centred* care and its respective philosophical foundations on the concepts of person and person-centredness as described in the previous section of this chapter. Accordingly, it is the care provider's ethical obligation to allow the self-expression of the person, acknowledge the person's resources and fragilities and intervene in a collaborative manner, to promote the re-establishment of coherence in life and life plans that was threatened by the illness (Ricoeur, 1994).

From the care provider's perspective, PCC is highly valued and is a self-evident facet of clinical practice, yet empirical evidence has shown that it does not occur consistently and systematically (Ekman et al., 2011). Oftentimes the workflow tends to fall into routine and ritualistic activities that are necessarily focused on the disease or the illness rather than on the person affected by the

illness. The illness-centred routine, thereby, might lack space for self-expression of the person's needs, values and context, strengths and weaknesses, preferences and goals, and might not be aligned with prerequisites for PCC or person-centred processes of care provision (Ekman et al., 2011; McCormack, Karlsson, Dewing, & Lerdal, 2010; McCormack & McCance, 2006).

Two influencing perspectives in Europe have particularly explored the challenges in implementing PCC consistently and systematically in clinical daily practice (Ekman et al., 2011; McCormack & McCance, 2006). Within their respective perspectives, scholars elicit person-centred processes associated with care provision in order to initiate, integrate and safeguard PCC. In addition to the care setting's importance to the overall success of PCC's implementation, the perspectives have more or less explicit characteristics in common with the person's engagement in shared-decision making processes with respect for the person beliefs, values and goals (Ekman et al., 2011; McCormack et al., 2015; McCormack & McCance, 2006). Without neglecting the importance of embedding person-centred processes in a care environment that facilitates those processes, the research work carried out in this thesis particularly focuses on the partnership dimension of PCC.

Seeing the person with strengths and weaknesses, capabilities and vulnerabilities, also entails considering that the care provider is a resource, among many others, for the person, who is in continuous transformation with others. The extent to which the care provider is a resource should be collaboratively and in an equalitarian way shared and discussed between the person and the provider. The reciprocal partnership then comprises the care and treatment expert, that is to say, the provider, and the person expert, that is to say, the patient in the person (Ekman et al., 2011; Ricœur, 1994). Such a partnership encourages and enables the person's involvement in the establishment of a person-relevant care plan respectful of the person's values, preferences and goals (Ekman et al., 2011).

3.3 Person-centred support

The concept of support is widely used across research studies and is of great importance to clinical practice. Potentially as a consequence of the interdisciplinary interest on the concept, different perspectives and conceptualizations emerge with the definitions necessarily portraying the attributes of interest relevant to each discipline. Health care sciences, sociology and psychology are just a few of the scientific domains attending to the concept of support (Fingfeld-Connett, 2005; Langford, Bowsher, Maloney, & Lillis,

1997; Stoltz, Andersson, & Willman, 2007). On the face of the many potential conceptualisations, a clarification of the concept of support endorsing this thesis is demanded.

Scholars consider social support as “any process through which social relationships promote health and wellbeing”, write Cohen, Underwood, and Gottlieb (2000) in *Social support measurements and intervention: a guide for health and social scientists*, pp.19. In such a context, social support might be more accurately comprehended as a *meta-construct* comprised by many sub-constructs, reflecting the different processes through which social relationships influence the person’s disposition to health (Cohen et al., 2000). This particular conceptual shift from focusing on social support to focusing on the processes that allow social relationships to be perceived as supportive is of particular importance. Specifically, social support is not a guaranteed product of all social relationships and interactions. In other words, not all social processes lead to social support, with the perception of support being particularly influenced by the appropriateness of the match between the nature of the concern and the kind of support provided, the source of support, and the context of provision (Cohen et al., 2000; Nurullah, 2012).

Support is then a multi-dimensional concept entailing different supportive functions provided through social relationships, and might contribute to the adjustment of the person experiencing high levels of stress. Scholars have elicited five dimensions of support: emotional (provision of warmth and reassurance that the person is valuable and loved), instrumental (provision of practical assistance), informational (provision of advice, guidance and, generally, information that assists appraisal and problem-solving) and companionship support (availability of persons to participate in leisure, cultural or recreational activities), and feedback or validation (provision of information about the appropriateness or normativeness of a behaviour) (Cohen et al., 2000; Taylor, 2011). Adopting the lens of nursing and health care sciences, the specific functions of emotional, informational, instrumental and validation have been identified as attributes of the concept of support and are therefore considered useful within the discipline (Finfgeld-Connett, 2005; Langford et al., 1997).

Among the considered sub-constructs, perceived support and received support have gained special consideration in relation to their influence on wellbeing and health. Specifically, when experiencing a stressful event, such as illness, persons might perceive social resources to be available if needed (i.e. perceived support), or persons might report that the social resources were recently provided (i.e. received support). In particular, only perceived support has been consistently linked to improvements in the general health domain, particularly in recovering from life-threatening illness (Cohen et al., 2000;

Uchino, 2009). Attending to the specific supportive functions and experience of their perception by the person is essential to the adequate development of support-enhancing interventions and thereby health improvement (Cohen et al., 2000).

4. Thesis rationale and purpose

Women undergoing treatment for ESBC are increasingly receiving treatment at outpatient settings, which allows them to spend more time in a familiar environment and continue their daily activities. To satisfy their great need for knowledge to manage symptoms and side effects and support to cope with psychosocial distress, they turn to their supportive networks and, increasingly more commonly, to the Internet. The benefits of this behaviour in adjusting to cancer diagnosis might, however, be diminished when women are exposed to overwhelming information of uncertain quality that might not necessarily be specific to their situation.

From the perspective of the health care team (HCT), meeting women's unique needs during short face-to-face encounters at the clinic and attending to their emergent and inherently varying supportive needs while they are at home is challenging. Capitalising on the nowadays-wide access to the Internet, IHCA's have evolved considerably during the last decade to allow bridging of the communication gap between the hospital setting and patients' homes. In spite of the growing development and evaluation of these applications as interventions to improve health, their effect varies greatly depending on the target population and on the person-centred features of the intervention.

With research on intervention mechanisms of action still in its infancy, understanding the supportive needs, and the preferences and goals of patients when seeking support, is urgent in order to elicit the person-centredness elements from early intervention development stages. The research work in this thesis was therefore conducted with the aim of exploring the foundations of person-centred e-support for women receiving outpatient treatment for ESBC.

5. Methodology

This chapter introduces the Medical Research Council framework (MRC) for the development and evaluation of complex interventions in health. Furthermore, the research design of the individual studies is contextualised within the MRC framework activities anticipated for intervention development. Finally, the user-centred approach for the design of person-centred technologies is explained, as it endorsed studies III and IV.

5.1 The Medical Research Council framework

Methodologically, the research work is situated in the first phase of the MRC framework for development and evaluation of complex interventions to improve health. The overall goal in relation to the development stage is to construct a model of the intervention, that is to say, a scenario that puts together the intervention's active components and their content, explains the relationships among the components, and elucidates the intervention antecedents and outcomes. Such a model has its foundational roots in two major components: a) the evidence base on the intervention constituents, and b) the theory underlying the intervention's mechanisms. Having operationalised a preliminary intervention, with its inherent model theoretically explaining the intervention mechanisms, a third activity of modelling processes and outcomes is expected at this stage with the goal of enhancing the intervention's functioning and its optimisation and implementation. The described activity is referred to as intervention modelling (Richards & Rahm Hallberg, 2015).

The MRC framework anticipates four stages in intervention research: development, feasibility and piloting, evaluation and implementation. Each of these entails specific activities to be conducted and products to be achieved before moving on to other stages. As transversally advocated independently of the framework adopted for intervention research, the MRC stages do not purport to be linear steps. Rather, the framework is impregnated with feedback loops to both previous and subsequent activities within each stage and among different stages. In that sense, the research processes are reflexive and iterative, with each activity informing the continuously constructed intervention base.

Moreover, although methodological consensus is sometimes difficult to reach, intervention research is increasingly advancing methods to manage uncertainties throughout the different stages of development, feasibility, evaluation and implementation. The methodological heterogeneity demands even greater awareness in relation to the research problem, the context and the priorities and expectations of the persons involved in the intervention, that is to say, patients and healthcare providers.

5.1.1. Contextualisation of the individual studies

Towards the construction of the intervention’s theoretical model, following the MRC framework guidance, the results of the individual studies were synthesised according to the specific activities outlined in the MRC framework. Figure 1 depicts the contextualisation of the individual studies and their research design within the MRC framework and in its related activities during the development phase.

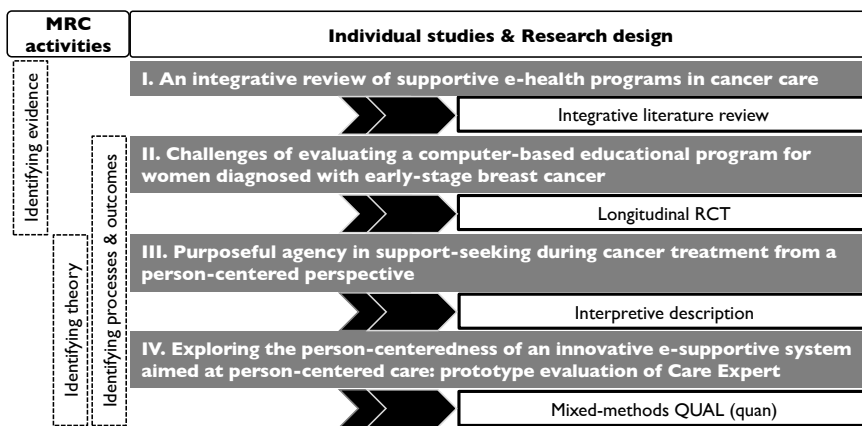


Figure 1 Activities in intervention development and study design of individual studies.

Attending to the methodological guidance provided by the MRC framework, the research work towards this thesis was initiated with a review of the existing evidence on e-supportive systems (Study I). This activity was conducted along with the already on-going randomised controlled trial (RCT) described in Study II, for which the data collection process began in 2007 and was nearly at its end. During the time elapsed since the development of the computer-based

educational programme and the design of the evaluation study, and the end of data collection (from early 2006 until the end of 2010), both information and communication technologies and intervention research have evolved considerably. Prominent changes included the use of the Internet as a delivery medium of supportive interventions and exploration of foundational theories guiding the mechanisms of action of the intervention components towards the accomplishment of specific patient outcomes. Such context demanded a review of the evidence according to the anticipated iterative character of the research activities in intervention research.

Most of the evidence synthesised in the integrative review originated from studies exploring the CHES, which inspired the development of the computer-based educational programme being evaluated in the RCT. The vast amount of studies conducted on that supportive system, towards the construction of an intervention theory, brought a positive reinforcement *a posteriori* to the methodological step of reviewing the existing evidence. Moreover, the integrative review assisted the process of making sense of the absence of evidence pertaining to the impact of the computer-based educational programme in light of the progress made during the past decade. Together, Studies I and II constituted the departing evidence pointing towards the development of the e-supportive system, that is to say, *Care Expert*.

In light of the absence of any evidence of impact from the computer-based educational programme on the primary and secondary outcomes and the different patterns of usage of the programme, an enhanced understanding of the variability among participants was imperative. Along with the increasing body of evidence on patient and public involvement in healthcare, the feedback loop led the research work towards further exploration of: a) the research problem, with special interest in the use of the Internet as a supportive resource; and b) possible solutions based on the patients' perspectives. With the emergent results from Study III, particularly considering the needs and strategies used by patients to seek support, the research work from this point on was influenced by the iterative character of another specific framework conceived by Wolpin and Stewart (2011) to develop person-centred technology.

5.1.2. User-centred design

The methodological description underlying the MRC framework endorses the value of patient and public involvement throughout the different stages of intervention research. When patients become partners in the research processes,

their perspectives complement those of healthcare professionals, ensuring that the research and healthcare providers' priorities are aligned with patients' concerns and expectations. Beyond the moral obligation, involving patients in research has been speculated to increase patients' acceptability of and adherence to interventions (Richards & Rahm Hallberg, 2015).

However, specific guidance on the development of person-centred interventions, concretely in the realm of eHealth, is not explicitly made available by the framework. Moreover, in the context of the designing and delivery of person-centred e-interventions, issues have been raised as to the adequacy between the research work and its applicability to clinical practice (Gao & Yuan, 2011; Kreps & Neuhauser, 2010). The guidance of a framework underpinned on principles of user-centred design might assist in the process of identifying implementation issues early in the development stage and anticipating possible solutions. The methodological approach of Wolpin and Stewart (2011) for the development of person-centred technologies endorses such principles and thereby promotes a systematic and rigorous involvement from participants in the development of the e-supportive system explored in studies III and IV.

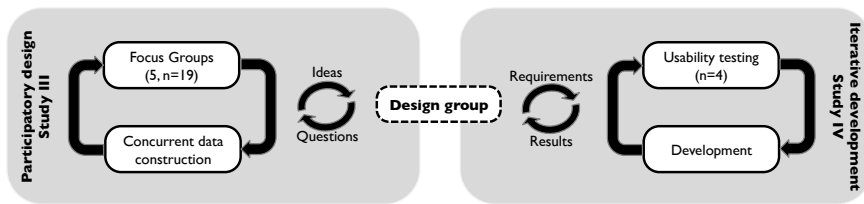


Figure 2 Development model of the first complete cycle of the e-supportive system
Adapted from Wolpin and Stewart (2011).

Figure 2 illustrates the development model adapted from Wolpin and Stewart (2011) for the purpose of guiding the research work carried out in Studies III and IV. Wolpin and Stewart (2011) suggest a systematic iterative development model comprised by two parallel cycles: a participatory design cycle and an iterative development cycle. The design group, who manage the findings from each iteration to be integrated into the next, bridge these two cycles.

6. Ethical considerations

The primary purpose of research within the field of medical and health care sciences is to generate new knowledge, yet such purpose should never outweigh the rights and interests of any person participating in the research studies (World Medical Association, 2013).

The Helsinki Declaration (World Medical Association, 2013) posits that ethical principles ought to guide research where human subjects are involved, in order to respect the unique person's rights to autonomy, privacy and confidentiality and protect her/him from harm.

The individual studies in this thesis were conducted following the ethical principles of the Helsinki Declaration and have received ethical approval by the Regional Ethics Board in Gothenburg, Sweden (diary numbers: 368-07 Study II, 882-12 Study III, T729-14 Study IV). Although Study I did not demand any ethical approval, its congruence with ethical principles was attained, as only studies that have been reviewed and approved by an ethical board in the respective countries were included in the final sample for review.

In relation to Studies II, III and IV, prospective participants were provided with verbal and written information on the respective study's rationale, aim and methods, and potential harms. Women were also informed that participation in the studies would not affect their care and that confidentiality would be ensured throughout the research process. Furthermore, in line with the need to maintain respect for the person's autonomy, participants were alerted to the possibility of leaving the interview or focus group session should that be their wish, without providing any further explanations. A written consent form was then obtained from the women who agreed to participate in the studies.

Particular consideration was made towards maintaining confidentiality throughout the research process of Study II; women's longitudinal self-reported assessments were kept on a secure web-based platform and could only be accessed and retrieved by the research team member responsible for the functioning of the program.

As with all studies in medical and health care sciences, Studies II to IV could involve certain burdens (World Medical Association, 2013). In particular, in Study II, women participating in the control group of the study would not have access to the educational programme, which could be perceived negatively. To minimize this potential harm, these women were offered enrolment in the

programme after completion of the 9-month period during its effectiveness evaluation. In relation to Studies III and IV, participating in group discussions or individual interviews might have led to the experiencing of negative emotions. This harm was addressed by offering participants counselling with an oncology nurse after the group meetings. Altogether, the knowledge generated from the individual studies was considered to improve the care of women undergoing treatment for ESBC, with particular potential for: greater acknowledgement and enhancement of women's autonomy within a context of shared responsibility that protects from harms; and more equal opportunities of access to supportive resources. Therefore, the benefits of participation outweighed the potential burden.

7. Summaries of individual studies

In this chapter, a summary of the individual Studies is presented. Specifically, for each Study, the aim, the research design, the procedures for data collection and analysis, and the main results are presented.

7.1 Study I

In relation to the MRC framework, Study I represents the major activity of critically synthesising the literature relating to existing e-supportive systems (Richards & Rahm Hallberg, 2015). More than following a strict framework that might lead to squeezing evidence on complex health interventions into a tight analytical structure (Richards & Rahm Hallberg, 2015), researchers reviewing the evidence on complex health interventions are advised to broaden their perspectives, as reflected in the Study's key research questions and searching strategies. Specifically, a detailed exploration of the available evidence should be conducted, bearing in mind potential heterogeneity issues (e.g. effectiveness study designs, target populations, design features, purpose of the interventions, and outcomes).

7.1.1. Aim and design

Aiming to analyse state-of-the-art design of e-supportive systems for patients diagnosed with cancer, Study I followed the methodological design of an integrative review (Whittemore & Knafl, 2005). Compared to other methodological strategies to synthesise and analyse evidence (e.g. meta-analysis or meta-synthesis), this approach was considered to be particularly appropriate for identifying the evidence base on e-supportive systems because it allowed the inclusion of studies with diverse methodologies. Specifically, non-experimental designs were just as important as experimental for enhancing the understanding of e-supportive systems, their features and outcomes (Richards & Rahm Hallberg, 2015; Whittemore & Knafl, 2005). The review posed the following queries:

- Who are the individuals using supportive e-health systems?

- Which features should the intervention incorporate in order to lead to satisfaction of supportive needs?
- What are the outcomes that truly measure the intervention's effectiveness? How should they be measured?
- Which individual- or system-related characteristics might mediate the outcomes?
- Is there a theoretical ground linking all these aspects? How are the various aspects related to each other?

7.1.2. Searching for and selecting the literature

PubMed, CINAHL and PsycINFO were searched for abstracts dating from 2000 through to June 2012. Eligible articles concerned education or support for adult cancer patients (over 18 years old), led by healthcare professionals and provided either on the Internet or using CD-ROM or DVD. Interventions aimed at the pre-diagnosis stage (e.g. enhancement of cancer screening awareness) were excluded. Studies were also excluded if they descriptively analysed health information websites, reported on the development (phase I) or exclusively on the usability, acceptability or feasibility (phase II) of interventions (Medical Research Council, 2008). These studies did not report on the specific intervention components (e.g. predictors of use, efficacy outcomes) needed for building the evidence base of e-supportive systems at the development stage. Given the broad definition of eHealth and the lack of consistency in terms when designating e-supportive systems, the search terms were: multimedia, Internet, web*, computer* or interact*, with the asterisk leading to retrieval of results with at least that part of the word and variations of it (e.g. computerised, computer-based). Moreover, interventions using videos, CDs or DVDs as a delivery medium were included. Such a methodological strategy has been undertaken by other researchers as these tools can constitute the precursor of interactive, computer-based interventions when access to computers/the Internet is not within reach (Ryhänen et al., 2010). Other articles reporting on the analysis and synthesis of evidence (e.g. meta-analyses and systematic reviews) retrieved from this search strategy were considered as secondary sources of evidence and were screened for eligible articles for the current review (Polit & Beck, 2012). Twenty-eight quantitative studies constituted the final sample, reporting on sixteen distinct interventions.

7.1.3. Analysis and synthesis of the literature

Data retrieved from each journal article were synthesised in two matrices, which facilitated the process of collecting systematic and structured data (Polit & Beck, 2012; Whitemore & Knafl, 2005). Specifically, one review matrix comprised description fields for each study and the other comprised intervention-related content concerning both design and evaluation aspects. Having accomplished data reduction and data display, the analysis process was initiated by examining and comparing the domains in each matrix in order to identify similarities and differences between the studies. Groups of data constituting patterns were brought together and further analysed to identify potential relationships (Cooper, 1998; Whitemore & Knafl, 2005). This process allowed the integration of the results in a potential explanatory model of the interventional mechanisms underlying e-supportive systems.

7.1.4. Results

Twenty-eight quantitative studies constituted the final sample, revealing that e-supportive programmes in the field of cancer were used by and helpful to individuals in spite of their age, gender, literacy level and disease-stage. The most commonly measured improved outcomes were: health literacy, decision-making, healthcare participation and quality of life. Each e-supportive programme usually constituted a single service with a variety of multimedia features, which lead to different designs yet have common outcomes. Some of these outcomes were theoretically explained, although a structure that linked all aspects of the intervention was rarely found. Moreover, a variety of research designs were adopted for testing the effectiveness of each intervention.

7.2 Study II

A randomised-controlled trial is a research design usually found in the evaluation phase of the MRC framework and not that commonly used at the intervention development stage. However, the results of the trial conducted in Study II presented relevancy beyond the mere evaluation of effectiveness. The common target population and similarities to the other studies in the development work related to specific intervention elements (e.g. intervention content, delivery medium), enabled the use of Study II to inform both the evidence base, relating to the research problem and effective/ineffective

solutions of the future intervention, and potential pitfalls in its evaluation and implementation.

7.2.1. Aim and design

The purpose of this experimental study was twofold. Study II was primarily conducted with the aim of evaluating the impact of a computer-based educational programme in comparison to standard care. Specifically, it was hypothesised that women who had access to the computer-based educational programme would report improvement in their primary outcomes, health self-efficacy (H1) and healthcare participation (H2), as well as improvement in their secondary outcomes, and decreased anxiety (H3) and depressive symptoms (H4). Secondly, the patterns of programme usage by the participants in the intervention group were explored to determine whether different patterns of programme usage could be explained by demographic, medical and psychosocial factors.

7.2.2. Sample and setting

Eligible participants were consecutively recruited at three independent medical centres according to the following criteria: a) diagnosis of breast cancer, stage I or II breast cancer; b) scheduled for breast surgery; c) ability to understand and provide written informed consent in Swedish; d) ability to use the computer-based educational programme; e) access to a computer with audio-playing software with at least Windows 98, Internet connection and an e-mail account; and f) absence of participation in other studies involving long-term follow-up with questionnaires. Study II included 226 Swedish-speaking participants.

7.2.3. Experimental design

The study involved a randomised controlled trial design. Research nurses at each medical centre carried out the enrolment of prospective participants in the study. All women agreeing to participate in the study provided their signed consent form and were assisted by the research nurse in accessing the programme's web-platform. Specifically, the participant created an account by registering their username, password and e-mail address. After completing the registration procedure, the computer automatically generated an identification number and

presented the participant with the baseline online questionnaire. Having answered the baseline measurement, participants were assigned to either the intervention or control group in accordance with a computer-generated list of random numbers, which allowed for group assignment concealment from the research nurse. Women randomised to the control group received standard care according to general current practice at each of the departments, which generally consisted of variable written patient education material provided during consultations with healthcare professionals throughout the course of treatment. The content of the written information material depended on the consultation time point in relation to the course of treatment and could include information on the disease, treatment, symptoms and side effects, and practical information. Women in the intervention group received a CD-ROM and a user manual with a programme demonstration. If they did not log into the programme for periods of longer than four weeks, reminders would be sent by e-mail and the research nurse would provide additional reminders by telephone.

The CD-ROM containing the software program connected with a secure web-based platform, where the self-reported data collection was automatically carried out at baseline, and 4 and 9 months after inclusion in the study. Moreover, the platform kept a register for each time a participant accessed the intervention with the goal of monitoring their exposure to the intervention. These log files contained the participants' username, date and time of login, and topics consulted. Only the research team member responsible for the functioning of the software program could access the data kept on the platform.

7.2.4. The computer-based educational programme

Within a socio-cultural perspective of knowledge and learning (Säljö, 2000), the Swedish Interactive Rehabilitation Information (SIRI) programme was developed to answer the supportive needs of Swedish-speaking women diagnosed with early-stage breast cancer. The programme's development was carried out by a multi-disciplinary team and followed a participatory design. Specifically, the topics included in the programme were generated through content analysis of data gathered from a focus group with six women after they had undergone surgery for breast cancer. Accordingly, the programme contained two modules: the first module addressed medical issues arising after breast surgery and treatment options; and the second module explored psychosocial aspects of illness and rehabilitation efforts. SIRI also included links to web pages with quality-assured information by the European Commission guidelines (2001), book recommendations and a glossary of common terminology that may

appear in publications on breast cancer. The programme was organised in a series of lectures led by experts in cancer care and a patient representative corresponding to a total of four hours of lecture time. The lectures were presented using the Microsoft PowerPoint software with audio commentary for each slide.

7.2.5. Measurement instruments

The instruments used to measure the primary and secondary outcomes, as well as the explanatory variables, are displayed in Table 1 with their respective values of internal consistency. Because SIRI was inspired by CHESS and a Swedish scale measuring the effects of such programmes was non-existent to our knowledge, two subscales of the CHESS measurement instrument were adopted: health self-efficacy, and participation in healthcare. The instrument was translated from the original English version to Swedish and was thereafter tested for construct and content validity, as well as reliability (validation procedures are described as supplementary material to Study II).

Additional explanatory variables to the Study's secondary aim were socio-demographic and medical variables. The socio-demographic variables included: civil status (living alone, separated, married and married with children), educational level (low, high), working situation (active, retired, other), economic situation (range 1-5), and contact with healthcare professionals, face-to-face and by phone (worked excellently, worked well, only worked, worked badly, not needed). The medical variables retrieved from patients' medical records were: type of breast surgery (mastectomy, partial mastectomy), type of axillary exploration (sentinel node, none), and complementary treatment (yes, no) in the form of radiotherapy (yes, no), chemotherapy (yes, no) and anti-hormonal treatment (yes, no).

Table 1. Measurement instruments and psychometric values in Study II.

Measurement purpose	Instrument	Sub-scale	Reliability ^a	
Primary outcomes	CHES	Health self-efficacy 3 items	0.81	
		Participation in healthcare 7 items	0.80	
Secondary outcomes	HADS, Zigmond and Snaith (1983)	Anxiety 7 items	0.85	
		Depression 7 items	0.86	
Explanatory variables	FACT-B, Brady et al. (1997)	Physical wellbeing 3 items	0.77	
		Functional wellbeing 6 items	0.80	
		Social wellbeing 7 items	0.66	
		Emotional wellbeing 5 items	0.84	
		Breast cancer specific concerns 8 items	0.35	
		SOC-13, Langius and Björvell (1996)	Meaningfulness 4 items	0.82
			Comprehensibility 5 items	
	Manageability 4 items			

^a Cronbach's alpha; ^b The measurement instrument is described in the supplementary material to Study II.

7.2.6. Data analysis

The distribution of the primary and secondary outcomes were primarily described by calculating mean values and standard deviations at baseline, 4 months (T1) and 9 months (T2), both in the intervention and standard care groups. Subsequently, multi-level modelling using restricted maximum likelihood (REML) was carried out to evaluate the impact of the programme on the primary and secondary outcomes (Heck & Thomas, 2009; Shin, 2009). Separate models were run for each outcome following an intention-to-treat approach and using the R (version 2) software.

To address the secondary aim, the participants' log registers were used to classify people into user and non-user groups. The sparsity of the data did not allow the classification of users into additional categories according to frequency and intensity of use. Women were considered users if they had accessed the programme at least once during the intervention period. The potential effectiveness of SIRI in relation to usage or non-usage of the programme was explored with the multi-level model. Here the intervention group was divided into users and non-users and compared to the control group on their primary and secondary outcomes. Thereafter, predictive logistic regression comparing only users to non-users was conducted following the guidelines suggested by Hosmer and Lemeshow (2013). The explanatory variables included in the final regression model were: birth year, type of axillary surgery (two categories), physical wellbeing (measured by FACT-B) and meaningfulness (measured by SOC-13). Interaction effects between each explanatory variable and the programme's usage were also explored according to the categories of users or non-users. The Box-Tidwell procedure was used to test the linearity between meaningfulness and physical wellbeing (continuous variables) and the logit of the programme's usage. Odds ratios of less than 1.00 were inverted for clarity of interpretation.

7.2.7. Results

Multi-level modeling revealed no statistically significant improvement in outcomes resulting from the computer-based educational programme, relative to standard care. The patients' health self-efficacy and healthcare participation improved in both groups over time. Subsequent exploratory regression analysis revealed that older women with axillary dissection and increased physical wellbeing were more likely to use the programme. Furthermore, receiving postoperative chemotherapy and increased meaningfulness decreased the likelihood of use.

7.3 Study III

Study III gave crucial contributions to the construction of the intervention theory, which was the second major activity during the development stage (Richards & Rahm Hallberg, 2015). Concretely, it allowed exploring the problem from women's perspectives and conceptualising solutions, strategies and outcomes inductively. This feedback loop into further exploration of the intervention theory was considered to be especially relevant given the inability to

identify statistically significant differences on primary and secondary outcomes between the intervention and control groups in Study II.

7.3.1. Aim and design

Aiming to explore the efforts of women diagnosed with early-stage breast cancer to satisfy their supportive needs throughout the treatment course, Study III was conducted following an interpretive description design (Thorne, 2008). Specifically, the inductive exploration of process of support seeking and support-seeking behaviours enquired:

- The time point in the course of treatment chosen to access the supportive resources;
- The process undertaken by women to meet their supportive needs;
- The supportive role of the Internet in relation to other supportive resources.

The research endeavour was framed *a priori* within the researchers' foreknowledge of the person seeking support (Ricœur, 1994; Taylor, 1985) derived from the epistemological roots in person-centred care (Ekman et al., 2011), and of the concept of support (Taylor, 2011; Uchino, 2006; Wills, 1991), both based on experiential and evidence-based knowledge (Hunt, 2009; Thorne, 2008).

7.3.2. Sample and setting

Women diagnosed with ESBC and undergoing adjuvant treatment were invited to discuss and reflect on their support needs and support-seeking behaviours at different stages in their course of treatment. Furthermore, women had to manifest interest in using the Internet for support seeking, and women of various ages and length of treatment were encouraged to participate in order to facilitate variation in the experiences of support needs and support seeking. Sampling procedures were initially purposive, resulting in the recruitment of participants from surgical, radiotherapy and chemotherapy departments at a university hospital from Western Sweden. Along with the progression of the concurrent data construction, participants' recruitment became theoretically grounded on an emergent pattern, leading to a focused exploration of the chemotherapy period. At each department, registered specialist nurses approached eligible participants,

presented the study and provided them with written information. Participants showing an immediate interest in participating provided their e-mail address and were subsequently invited to participate in focus group discussions. Participants showing an interest but who were unable to come to the meeting were invited to take part in individual interviews instead. Overall, a total of 19 women participated in five focus groups and one woman was interviewed individually.

7.3.3. Data construction

Following a concurrent data construction process (Thorne, 2008), interaction with participants occurred in two phases, with data being primarily collected through focus group discussions and new constructions reached through constant comparative analysis. During the first phase of data construction, two groups met twice at a four-week interval for focus group discussions. Women undergoing chemotherapy comprised one group and the other was composed of women undergoing radiotherapy. The second phase entailed three complementary focus groups that brought together a new group of recruited women undergoing chemotherapy, with a single meeting for each group. According to the specific aims for each of the interaction phases, the subject areas guiding the discussion sessions of the focus groups differed (Table 2).

Table 2. Data Construction in Study III: Phases of Interaction with Participants and Subject Areas.

Interactions	Groups	Sessions	Subject Areas
1 st phase	Groups A & B	A: 1 st meeting n=6	<ul style="list-style-type: none"> Existing supportive sources and resources, antecedents and consequences
		B: 1 st meeting: n=3 ^a	<ul style="list-style-type: none"> Internet as a supportive resource in relation to cancer and oncological treatment The ideal supportive resource
2 nd phase	Groups A & B	A: 2 nd meeting: n=5	<ul style="list-style-type: none"> Experience of web-support between meetings
		B: 2 nd meeting: n=3	<ul style="list-style-type: none"> Existing websites features
	Group C	Single meeting: n=2	<ul style="list-style-type: none"> Supportive resources and interdependence Process of engaging the supportive network
	Group D	Single meeting: n=3	
	Group E	Single meeting: n=4	

^a One woman unable to participate in the scheduled group meeting was interviewed individually.

All focus group discussions (lasting between 2 to 2.5 hours) and the individual interview (approximately 1.5 hour) were audio-recorded and transcribed verbatim. Constant comparative analysis adapted to interpretive description was applied (Hunt, 2009; Thorne, Kirkham, & O'Flynn-Magee, 2004). After intensive reading of the transcribed material to get a sense of the whole scope beyond the immediate impression of each discussion, the process of making sense of the data proceeded according to the following analytical goals:

- a) Identify data segments that answered the research questions, through an inductive open coding and broad-based questioning to allow structuring of the data (e.g. What are women talking about?)
- b) Question interrelation of relevant data segments to form patterns, by answering the questions: How are women talking about it? Is the discussion topic common to all women? Or is it an individual perspective? Is there a predominant point of view on the subject? Are women agreeing/disagreeing on the subject? Are there alternative approaches to the same subject?
- c) Identify interrelations among patterns to form relationships, by questioning: What are we learning about this pattern? Is it, and if so how, related to any of the other patterns?

Relationships between patterns were repeatedly discussed and probed at the research team meetings until clinically meaningful findings were constructed. Specifically in relation to the preliminary data generated from the first phase, the patterns that were constructed exposed a common behaviour of women actively engaging in support seeking at the start of the chemotherapy and intensification of support-seeking behaviours throughout the course of chemotherapy. These intermediate findings demanded further exploration in order to clarify the complexity associated with the variability of supportive resources they engaged with and their interdependence on the women's process of support seeking. Following the responsiveness of the concurrent process of data construction, the second phase of data construction was initiated. The empirical exploration from the second phase allowed the already identified and the new patterns and relationships to gain density. With the emergence of variation declining towards the fifth group discussion, no further exploration was considered to be needed.

7.3.4. Results

The results disclosed women as self-driven resourceful agents, a perspective underlying the process of reaching out along a continuum of intentionality as women appraised their need for support and engaged their supportive resources. Particularly in relation to the supportive role of the HCT, a mismatch between the support received from the HCT and the women's perceived need for support was identified. Specifically, women's receptivity to support routinely provided by the HCT did not always match their active support-seeking behaviours; and while active seekers, the women did not necessarily engage with the HCT, if at all, even though it was considered to be the most trustworthy source of health-related support. Only severe concerns demanded first-hand contact with the HCT.

7.4 Study IV

In Study IV, the evidence base resulting from the previous studies, in light of the principles of person-centred care and the concept of support endorsing this thesis, was preliminary operationalised in the first prototype of the e-supportive system, that is to say, the *Care Expert v1.0*.

The operationalization of the intervention was considered a necessary intermediate research step to intervention modelling. Specifically, by allowing women to interact with the prototype and inductively exploring their experiences along with the interaction, Study IV would inform the development of the theoretical model of the intervention, to be further modelled in a larger-scale test of feasibility (Richards & Rahm Hallberg, 2015). This Study was therefore expected to inform the intervention's theoretical model in relation to: a) the perceived supportive functions of the system and thereby its potential person-relevant outcomes; and b) the attributes of the intervention components leading to the perceived support, which should elicit the theoretical processes guiding the system's mechanisms of action.

7.4.1. Aim and design

Study IV aimed to explore the person-centredness of an e-supportive system prototype and its early-development stage usability. Specifically in the context of chemotherapy for early stage breast cancer, Study IV was design to answer the following enquiry:

- What is the perceived supportive potential of the *Care Expert* v1.0?
- What is the usability?

The Study followed a mixed-methods approach, QUAL (quan), with results integration at the interpretation stage, to conduct individual usability sessions entailing subjective assessment and diagnostic evaluation of the prototype.

7.4.2. *Care Expert*

The prototype was composed by three supportive components: *Symptom Expert*, *Report a Symptom* and *Calendar*. Specifically, *Symptom Expert* was designed to help women assess their concerns in relation to the oncological treatment. The program is an expert system designed to emulate the decision-making ability of an oncology nurse. *Report a Symptom* allowed women to express their unusual experiences in real time to an oncology nurse and receive personalized advice. *Calendar* allowed women to keep a real-time register of concerns and self-care actions, and automatically registered the results from the previous components.

7.4.3. Sample and setting

Eligible participants of the individual usability sessions should be women undergoing chemotherapy for early-stage breast cancer, at any stage of their treatment and with an interest in using the Internet for health-related knowledge and support seeking. At an outpatient department of a university hospital in Western Sweden, an oncology nurse working purposively approached eligible participants. Women showing an interest to participate in the study provided their e-mail address, which was forwarded to the researcher. Participants received an e-mail invitation to participate in the individual usability sessions, which lasted between 1.5 to 2 hours. Of the eight women invited, only six answered the invitation and two of the latter declined participation because of a reduction in their general wellbeing.

7.4.4. Data collection

The individual usability sessions followed the guidelines for user-centred design and entailed two methodological approaches: subjective assessment focusing on users' feelings and supportive experiences about the programme, and diagnostic

evaluation focusing on identifying usability problems (Bevan, 2006; Digital Communications Division, 2004; Wolpin & Stewart, 2011).

Three scenarios were developed, one for each supportive component. Before initiating their interaction with the *Care Expert*, women were asked about their expectations in relation to the programme. Based on their descriptions and reflections, the moderator chose between *Report a Symptom* or *Symptom Expert*, because the interaction with both supportive components was expected to be time-consuming and possibly too demanding for the participants. Therefore, each participant engaged with only one of these components and the *Calendar*. Table 3 depicts the specific data collection methods in relation to each of the methodological approaches and their purpose. The complete usability session was audio-recorded and, additionally, screen-recording software registered women's interaction with the programme.

7.4.5. Data analysis

The audio files were transcribed verbatim and were complemented with the screen-recorded information. All the material was analysed for potential supportive functions in the context of the subjective assessment and scanned for information on system performance and recommendations in the context of the diagnostic evaluation according to an inductive coding scheme. Further intensive reading of the transcribed sessions was conducted and a preliminary identification of words or sentences that caused an impression or that were specifically about usability was completed. The next analytical step entailed structuring the transcribed material related to each woman according to the supportive components tested and thereafter by content in relation to the aspects of subjective assessment and diagnostic evaluation. Further analysis was conducted for each of the methodological approaches according to specific data analysis methods, which are depicted in Table 3.

7.4.6. Results

The participants rated the system's usability highly. Their accounts allowed the identification of three supportive functions: continuous communication, reinforcement of self-driven agency and cooperative agency with a sense of being looked after.

Table 3. Data collection methods and purposes, and data analysis in relation to the subjective assessment and diagnostic evaluation in Study IV.

Methodological approaches	Data collection methods	Purpose	Data analysis methods
Subjective assessment	Component-related interview	At the end of each assignment: <ul style="list-style-type: none"> To gather an understanding of the component's supportive function To explore women's insights concerning recommendations for further development 	Constant comparative analysis as adapted to interpretive description (Thorne, 2008)
	Programme-related interview	At the end of each session to evaluate the prototype as a whole and explore: <ul style="list-style-type: none"> Met an unmet expectations Supportive function Advantages and disadvantages in relation to existing supportive resources and healthcare system 	
Diagnostic evaluation	Think-aloud	While interacting with the programme, women were asked to express their choices, impressions and experiences with the supportive component	Concurrent verbal reports were analysed for identification of: <ul style="list-style-type: none"> System performance information User expectations Suggestions for further development
	Concurrent probing	While women interacted with the programme and whenever a longer pause occurred: <ul style="list-style-type: none"> To elicit real-time feedback To understand women's approaches to problem-solving 	
	Usability survey	Evaluate usability (3 items) and usefulness (1 item)	Calculation of individual scores in Excel
	Satisfaction survey	Evaluate satisfaction with the programme as a whole (3 items)	

8. Integration and discussion of results

This chapter integrates the results from the individual studies according to the main research issues anticipated in the development phase of the MRC framework. Primarily, the participants' characteristics and their care context are presented to allow a contextualisation of support and support seeking in relation to the target population. Subsequently, the research problem and intervention goals are conceptualised and the operationalization of the intervention, that is to say, the *Care Expert*, is described in relation to its complexity components and person-centred dimensions, eliciting and discussing potential pitfalls where relevant. This last section of the chapter discusses the potential theoretical model of the intervention: from the components and respective mechanisms of action to the potential person-relevant outcomes that emerged from Study IV.

8.1 Participants' characteristics and care context

Although the women participating in each of the individual studies were enrolled following distinct sampling procedures, the eligibility criteria were rather common to all studies with particular emphasis on the diagnosis of ESBC and women's use or interest in using computers and the Internet for support seeking. Participants' characteristics are displayed in Table 4 for each individual study. For the purpose of characterising the studies' participants, it is important to stress that all participants had undergone breast surgery. However, the data on which kind of surgery that women had had on studies III and IV are absent. In addition, data relating to the course of treatment, information on targeted therapy and hormonal therapy were not systematically collected and are therefore not displayed as a characteristic of the sample, although it did comprise the course of treatment of several of the women. Overall, the samples were quite heterogeneous with the exception of the education level on Study IV, where all women had achieved a university degree.

Table 4. Participants' characteristics

Characteristics	Study II participants		Study III participants (n = 19)	Study IV participants (n = 4)
	IG ^b ^d (n = 105)	SCG ^c ^d (n = 121)		
Age	26–75	29–78	31–70	37–69
Civil status				
Living alone	30 (28.6)	30 (24.8)	1	2
Living alone w/children <18y old	5 (4.8)	3 (2.5)	1	0
Living together	53 (50.5)	55 (45.5)	9	2
Living together w/ children <18y old	17 (16.2)	33 (27.3)	8	2
Educational level				
Elementary school	11 (10.8)	23 (19)	1	0
Secondary school	32 (30.5)	27 (22.3)	8	0
University degree	57 (54.3)	65 (53.7)	10	4
Current occupation				
Employed	82 (78.1)	79 (65.3)	6	1
Sick leave	7 (6.7) ^e	8 (6.6) ^e	12	2
Retired	16 (15.2)	34 (28.1)	1	1

^a Data are frequencies (relative frequencies)

^b IG: Intervention group; ^c SCG: Standard Care Group

^d The education level included the alternative answer of 'other', which is not depicted in the table due to sparse cell counts – IG: 5(5.1); SCG: 6 (5.0).

^e Data include alternative answers of 'sick leave' and 'other' due to sparse cell counts.

Both study III and IV allowed for an enhanced understanding of the context of care and treatment in ESBC. Specifically, women's accounts across studies reflected the intermittent character of the healthcare partnership centred on regular face-to-face meetings for treatment or medical consultation. Figure 3 illustrates possible courses of treatment in ESBC, which might entail different therapies (eg. surgery, radiotherapy, chemotherapy, hormonal therapy and targeted therapy). Although the illustration depicts a linear course of treatment, the therapies are not necessarily combined in the same order as portrayed.

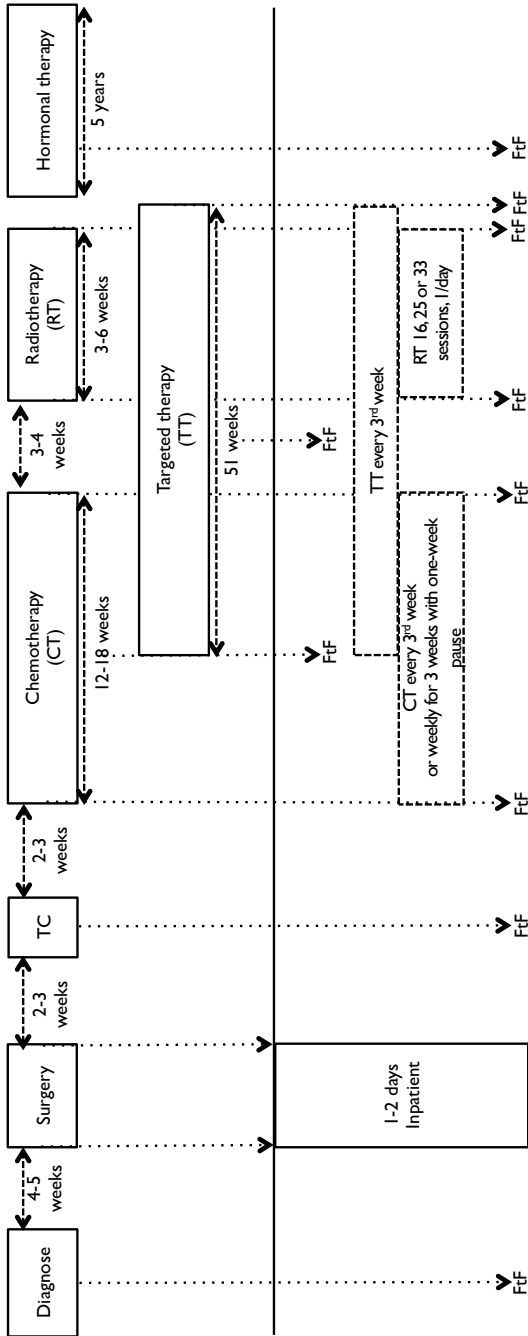


Figure 3 Care and treatment context in early stage breast cancer
 TC: Therapeutic conference; CT: chemotherapy; RT: Radiotherapy; TT: Targeted therapy; FtF: Face-to-face encounter.
 The central line in the figure separates two elements of the care and treatment context. Above the central line: the various treatment phases are depicted along with the time elapsed between them, and their duration, which is specified immediately below each treatment box (ex. chemotherapy might last between 12 to 18 weeks). Below the central line: the frequency and forms of contact with the healthcare team are depicted. The dashed boxes of CT, TT and RT representing intermittent contact, according to the treatment plan described in each box, in comparison to the continuous contact of being at an

8.2 Conceptualising the problem

The existing evidence at the debut of the research work underlined high levels of unmet supportive needs reported by women diagnosed with ESBC (McGarry, Ward, Garrod, & Marsden, 2013; Pauwels et al., 2013). Further, it advanced the possible reasons for that troubling condition occurring in women's daily lives. Specifically, women's perspectives of the perceived support diverged from healthcare professionals' perspectives on the provided support (Lei et al., 2011). The empirical evidence resulting from Studies III and IV strengthened that body of evidence. The evidence allowed for the identifying of the supportive needs that demand healthcare assistance in a context of proactive support-seeking behaviours and enhanced the understanding of the context leading to the divergent perspectives on perceived/received support throughout the course of treatment for ESBC.

The core of the research problem was considered to be the intermittent character of the healthcare partnership greatly underpinned by the face-to-face encounters for the provision of support. Throughout the course of treatment it also became clear that women actively seek support on a continuum of behavioural intentionality, that is to say, from observers to seekers. An immediate consequence of the variability in reaching out for support might therefore be that the maximal support-seeking behaviour did not occur at the moment of the face-to-face meeting with the healthcare providers. On the contrary, at these encounters women were more commonly positioned towards the observer's end of the continuum. As an observer, and in light of the concept of support as defined in the chosen theoretical background (Cohen et al., 2000; Taylor, 2011; Uchino, 2004), women would receive support but not necessarily perceive it, potentially leading to increased unmet supportive needs unrecognized by the healthcare providers, who had in fact provided the support and judged it to be relevant and adequate at that specific moment.

8.3 Conceptualising the intervention goals

Within intervention research, the experiential knowledge of patients in relation to the research phenomenon is usually unravelled as part of the problem's analysis (van Meijel et al., 2004). Indeed, understanding patients' perspectives and practices in relation to the research problem provides a significant contribution to the process of developing person-relevant interventions and promoting acceptability and adherence in the long run in intervention evaluation and implementation (Richards & Rahm Hallberg, 2015). In the context of this

thesis, women’s practices in the presence of a concern are instead part of the solution to the research problem.

8.3.1. From self-driven resourceful agency to a person-centred partnership in care

Women portrayed a general willingness to care for their health and wellbeing and be involved in their treatment. In light of the *Homo capax* perspective of personhood (Ricoeur, 2005; Uggla, 2011), women’s deliberate and determined behaviour of engaging with their supportive networks in the presence of a concern, managing their daily lives and seeking answers to their questions, are the person capacities that supplant the feelings of vulnerability associated with cancer diagnosis and treatment. If this perspective of personhood should inform the care partnership in ESBC, women’s agency has to be acknowledged and fostered. In a care process consistent with their priorities, expectations and goals, women’s capacities should be reinforced and their vulnerabilities restored (Ekman et al., 2011; McCormack & McCance, 2006).

8.3.2. A pathway of support seeking

The following model (Figure 4) represents an integrative perspective on the process of knowledge and support seeking in the self-driven resourceful agent.

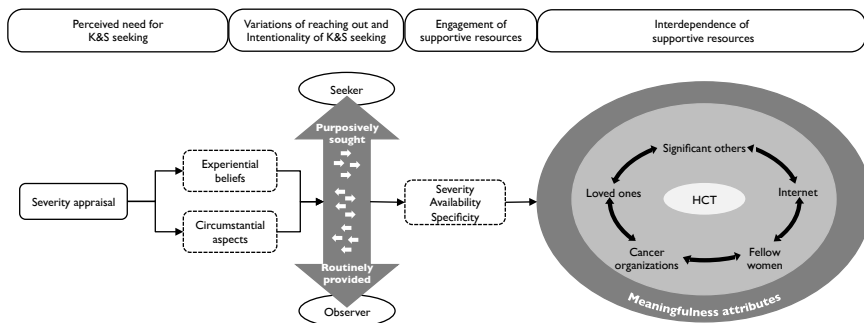


Figure 4 The self-driven resourceful agent’s pathway of support seeking
K&S: knowledge and support; HCT: Healthcare team
Significant others include individuals with both lived experience of breast cancer and/or healthcare expertise.

In summary, the model depicts the perceived need for knowledge and support seeking as a consequence of a severity appraisal, which interacts with experiential beliefs and circumstantial aspects to generate reaching-out behaviours along a continuum of intentionality. It further includes the process of engaging the supportive resources according to the perceived concern severity, perceived resource's availability and the perceived need for specificity. Each resource's meaningfulness attributes finally determine their first-hand engagement in a context of interdependency of interactions within the supportive network. The positioning of the HCT at the centre of the supportive network aims to portray its supportive relevancy from women's perspective rather than the frequency of contact or its perceived availability.

Women's reaching-out behaviours varied along a continuum of intentionality, that is to say, from observers to seekers. As observers, women were permeable to routinely provided support from the HCT and direct supportive actions coming from the nearest personal supportive assets. At the other end of the continuum, women purposively sought support and knowledge from the supportive network. Between both ends of the continuum, women expressed awareness of the eventual support made available, for instance, if it came from their personal supportive assets or if they were incidentally exposed to somewhat tailored support to their situation.

With regard to the supportive role of the HCT, the results from Study III portrayed a mismatch between received and perceived support, which might be understood in light of the concept of support endorsed in this thesis. Specifically, women's perceived wellbeing, the intentionality of the reaching-out behaviours, and their perception of support, in comparison to received support, appeared to go hand in hand with each other. Specifically, higher perceived wellbeing appeared to be one significant aspect associated with higher intentionality, which was intertwined with a greater perception of support. This pathway towards the perception of support along the wellbeing and intentionality continua might be substantiated on two dimensions of the meaning of social support. Concretely, Uchino (2004) points out that the perceived support is actually greater when a person experiences stressful events. Adding to this knowledge is that the provision of support at an inadequate time point, or the provision of support that does not adequately meet the stressor's character, might not be perceived as supportive behaviour (Taylor, 2011). On the basis of this rationale, women experienced a stressful event but lacked the energy and wellbeing to more purposefully seek support and, when they did, the support provided was not perceived as being supportive. Having recovered their wellbeing, women engaged at higher levels of intentionality in the process of seeking support and managing their daily lives, thereby having a greater perception of support.

8.3.3. Towards the restructuring of the accessibility between face-to-face encounters

From a person-centred care perspective, one could argue that there is a need to pay more attention to the women's agenda and elaborate a common person-centred care plan in which a woman's illness narrative is translated to supportive needs and her resources are strengthened to achieve person-relevant goals (McCormack & McCance, 2006). Without neglecting the value of such an approach to establish a reciprocal care partnership that meets the person's needs, respects her expectations and acknowledges and strengthens her resources, the challenge of following a naturally changing narrative of the illness experiences still remains. This aspect is particularly relevant in outpatient cancer care where women's wellbeing is considerably shattered as a consequence of the cancer treatment, that is to say, after the face-to-face medical encounter, and where having continuous space for expression is important.

Other authors have pointed out the importance of increased access to care and have acknowledged the importance of patient agency for the enhancement of patient health (Street, Makoul, Arora, & Epstein, 2009). From another perspective, the unexpected results from Study II also reinforce the need for types of interventions targeting on-going support throughout the course of treatment, particularly in light of the speculated natural state of low self-efficacy and healthcare participation registered longitudinally in both the intervention and control groups.

By applying knowledge and techniques from the domain of eHealth, e-supportive programmes might be an advantageous part of the solution to continuously assure the required space for expression that would bridge women and the healthcare team. Not only might these programmes increase the perceived availability of the health care system, but also, they might allow for an equitable provision of person-centred supportive resources (Jung, Ramanadhan, & Viswanath, 2013).

Departing from the pathway of support seeking underlying women's agency, and consistent with a person-centred care perspective, strengths in women's processes of support seeking were identified and areas requiring further assistance were pinpointed. Along with women's descriptions of reaching-out behaviours, both the strengths and strategies for the enhancement of their self-driven agency were transferred to the intervention design and together are considered to have the potential to restructure the accessibility between face-to-face encounters in ESBC.

Towards promoting a nudging from the HCT. The variability in the degree of intentionality of the reaching-out behaviours raises an issue of particular importance from the healthcare point of view: are women aware of potentially

harmful treatment-related events that may occur in the time between the face-to-face encounters? Empirical evidence has shown that having cancer and receiving cancer treatment demands a proactive behaviour in anticipating, reporting and managing symptoms and treatment side effects as has been seen in patients with chronic illness, for whom specific self-care actions have become naturally embedded in the daily life activities (Paterson, 2001). Without having assimilated the knowledge relating to such potential harmful events, women might be exposed to health risks that are preventable or that can be detected early with monitoring and awareness.

At the intermediate level of the behavioural continuum, nudging women to adopt preventive behaviours and enhancing their awareness of possibly harmful situations at the relevant time points might be accomplished through e-supportive programmes. Specifically, this intermediate level of engagement has similarities with the behaviour of scanning described by other authors in relation to the health-related information-seeking behaviours that women undertake. In such a context, a *scanning* behaviour entails information encountered in a purely incidental manner or mediated by interpersonal sources, that was meaningful enough to enable the construction of a memory trace that can be promptly retrieved later (Niederdeppe et al., 2007).

Attending to the interdependency of supportive interactions. Women's reaching-out behaviours were directed towards their supportive networks. In addition to the HCT, which was a common constituent of all supportive networks, women's personal supportive assets could also include: loved ones, significant others with lived experience of breast cancer or from a health care background, fellow women, cancer organisations and the Internet. Each supportive network could be composed of varying supportive assets but the existing ones were interdependently related to each other.

This aspect of interdependence of resources is of particular importance when attending to person-centredness, whether it is constructed at the care setting or mediated by an e-supportive programme (Ricoeur, 1994). Specifically, empirical evidence has highlighted that a single resource will hardly satisfy the supportive needs of the purposeful agent (Longo et al., 2009; Walsh et al., 2010). Following an inherent interdependent autonomy, these women will keep engaging their personal supportive assets to find comfort and reassurance, as their supportive surroundings are perceived as continuously available. Such personal supportive assets might raise more questions and vulnerabilities than actually enhance the perceived support (Uchino, 2004), but they are a natural component of the women's whole as a person (Eneau, 2008). Particularly for this reason, acknowledging the person's supportive resources outside the patient-clinician relationship is important (Anker et al., 2011).

Ultimately, a person is not a person without the other (Ricœur, 1994). The woman diagnosed with ESBC is a resourceful agent with each supportive asset being an inherent element of her being and necessarily influencing her behaviour. Accordingly, the establishment of a person-centred reciprocal partnership that persists between medical encounters may require awareness of the care provider to expand horizons beyond the person diagnosed with the cancer (Illingworth, Forbat, Hubbard, & Kearney, 2010). In that process, the person's interdependent autonomy has to be acknowledged as it fosters the balance in the wellbeing continuum (Ricœur, 1994).

Towards the enhancement of the perceived availability of the HCT. According to the women's current practices, establishing contact with the HCT was only considered adequate in the presence of a severe concern, that is to say, an experience of strangeness, something they had never experienced before and of which they could no longer make sense. Although the HCT was the considered to be the most reliable source of health-related knowledge and tailored support, minor concerns were unworthy of disturbing the medical services. Instead, women engaged with their own personal supportive assets because they were perceived as being continuously available. Translating the person-centred principles to the care partnership, the HCT should desirably be perceived as being continuously available in an environment of shared deliberations, decisions and responsibilities (Ekman et al., 2011; McCormack & McCance, 2006). In light of the importance of the perceived availability of resources to the process of successful illness management (Uchino, 2004), the perceived availability of the HCT as a supportive resource should then be enhanced to an equal level in relation to the remaining supportive resources in the network.

Towards assisting with the severity appraisal. The initial severity appraisal was the main process leading to the perceived need of support and the assessment's result, that is, from minor to severe, played a central role in determining the need to establish direct contact with the HCT. This process was conducted on the basis of women's insofar-constructed experiential knowledge about the illness, cancer treatment, symptoms and side effects. In the absence of immediately available knowledge tailored to their situations, women might ground such assessments on the lived experience of cancer of others, mediated through a significant other or the Internet. The first might be perceived as companionship support and validation, as it is the manifestation of a continuous presence and provides information consensus in relation to the prevalence of problems and the normativeness of women's experiences (Cohen et al., 2000; Uchino, 2004). The latter might facilitate access to a lived experience of cancer, when it is not available in the women's immediate surroundings, and to general

health-related knowledge. However, the perceived informational support needed to assist the appraisal of severity, and the further decision of establishing contact with the HCT, might still be lacking in both sources. The significant other might have perceived similar severities differently or in other circumstances; the Internet might portray emotionally charged stories, which further enhance distress, or overwhelming information, which further complicates the construction of knowledge. Ultimately, women might lack adequate foundations to the decision-making process and their subsequent problem solving actions.

In such a context, assisting women's severity appraisal is likely to bolster their capabilities by: a) facilitating their interpretation of their experiences; and b) assisting in the assessment of their need for further support. In the context of enabling patient knowledge-seeking and learning, this assistance might also help the women in building their health-related knowledge foundation, develop skills for self-care and raise confidence to manage their health (Friberg, Andersson, & Bengtsson, 2007; Jarvis, 2009).

Towards enhancing access to realistic lived experience. Among the supportive resources, significant reassurance was found from other women diagnosed with ESBC and undergoing treatment, that is to say, fellow women. The comprehension and empathy coming from similar quests in a shared care environment generated a group identity. Such supportive relationships were crucial to the women's process of making sense of their experience of cancer and cancer therapy.

In light of the support perspective framing the work carried out in this thesis, fellow women were not only a source of informational support and validation, but they were also instrumental and emotional (Cohen et al., 2000; Uchino, 2004), as they had an inherent lived experience of cancer and cancer therapy composed by both evidence-based and experiential knowledge. While constantly recognizing the specificity of each course of treatment, the women trusted each other's advice, particularly in regard to self-care tips. The supportive processes and outcomes resulting from the relationships with fellow women resemble the commonly designated peer support groups (Hoey, Ieropoli, White, & Jefford, 2008), which have empirically proven to be helpful care complements, even as an online intervention (Batenburg & Das, 2014). Integration of such a strategy in a supportive system should be attentive to the women's preferences concerning social processes and potential discomfort in interacting at a group level, and to the persisting risk of exposure to emotionally charged stories.

8.4 Operationalization of the intervention components

In the context of intervention research, the design of an acceptable intervention is not possible without a thorough understanding of the patients' perspectives on the research phenomenon (van Meijel et al., 2004). Going a step further, user-centred design principles state the importance of having patients' input throughout the cycle of software development (Wolpin & Stewart, 2011). Consistent with the latter, intervention goals previously identified were operationalised into intervention components (Table 5) and a prototype of the intervention was constructed to allow for patients' scrutiny.

Table 5. From the intervention goals to the supportive components

Intervention goals	Intervention components	Type of support	Supportive components
• Assisting the severity appraisal	Self-assessment	Informational	
• Automated nudging, through raising awareness	Concern-related evidence-based knowledge Tailored supportive messages Tailored self-management	Instrumental Validation	<i>Symptom Expert</i>
• Enhancement of the HCT perceived availability	Individualized supportive messages	Informational Emotional	
• Nudging from the HCT, through monitoring	Tailored messages Cooperative communication Concern's assessment		<i>Report a Symptom</i>
• Access to realistic lived experience	Lived experience Self-monitoring	Informational Instrumental	<i>Calendar</i>
• Nudging from the HCT	Cooperative communication	Validation	

The *Care Expert* entails three supportive components developed with the ultimate goal of mediating person-centred care in outpatient cancer settings (Study IV). The supportive system is strongly influenced by nursing values and principles in the way it is developed to assist the person to recognise and develop her own strengths and abilities, thereby enabling the achievement of person-relevant health-related goals in a reciprocal partnership in care (de Silva, 2014; Ekman et al., 2011; McCormack et al., 2015; McCormack & McCance, 2006).

At this initial stage of development, the supportive system allows for a dyadic relationship, in which the woman is at one end and the oncology nurse is at the other end of the communication process. This aspect characterises the system as an intervention at the individual level, rather than at the group level

(Conn et al., 2001). Along with the development progression to systematically involve all intervention actors, more complex relationships are expected to emerge to include the healthcare team and fellow women.

8.4.1 Complexity dimensions

At a glance, the *Care Expert* encompasses several aspects that allow its qualification as a complex intervention. Adopting Aranda (2008) elements of complexity, the *Care Expert* is a bundled intervention comprising three components (Conn et al., 2001) and apparently targeting more than one patient-relevant outcomes. The main reason for these elements of complexity is the process of development undertaken, which is so closely informed by patients' perspectives and therefore closely portrays their needs and the care reality as naturally and inherently complex. If the inclusion of patients' perspectives is in itself a strength, it is also a challenge, because it adds difficulty to the process of determining which individual component contributes to each outcome (Aranda, 2008; Conn et al., 2001).

Establishing a meaningful communication channel that provides space for the expression of the person's illness experiences and allows for the provision of adequate and person-specific advice in real time is complex. The delivery medium is one of the elements that should be considered when reflecting upon complexity. In the particular case of the *Care Expert*, the Internet was considered to be the most straightforward medium to allow for the meeting of women's reaching-out behaviours beyond the hospital walls. This methodological choice followed the trends in PCIs (Coulter & Ellins, 2006; Lauver et al., 2002) and empirical results from other research studies on eHealth, where web-based supportive programmes have been successful in reaching positive patient-related outcomes (Gustafson et al., 2002; Ruland et al., 2012; Ryhänen et al., 2010). Although the specific intervention outcomes were rather uncertain at the initial stage of development, the Internet was considered to be the best solution to enhance accessibility between face-to-face encounters. In Sweden, Internet access reaches 98% of the population (Findahl, 2014) with the target population being particularly interested in using it to seek health-related knowledge and support (Kowalski, Kahana, Kuhr, Ansmann, & Pfaff, 2014).

In spite of the stated advantages, the Internet might add disturbance to the intervention delivery per protocol due to the great variability of access settings and the exposure to other sources of knowledge and support while interacting with the intervention online. At this level, the complexity brought by the delivery medium and the complexity brought by the context of delivery become

blurred (Anderson et al., 2013; Datta & Petticrew, 2013). These issues were especially discussed in Study II and both dimensions continue to present a potential pitfall in the evaluation and implementation of the intervention. Specifically, while accessing the programme, participants are able to interact with other Internet resources and unintended contents, which are not active components of the intervention (Eaton et al., 2011, Bosak et al., 2012).

To elicit engagement with the intervention and, in particular, allow understanding of the outcomes as a result of that engagement, other authors have described the advantage of e-supportive systems compared to non-electronic interventions for the collection of *paradata*, that is to say, measurements regarding how a participant interacted with the intervention (Resnicow et al., 2010). To the log-data collected in Study II, which elicits process measurements in relation to the intervention dose and exposure (number of log-ins, which pages are viewed and for how long), authors add process measurements in relation to technical specifications (e.g. browser type, connection speed, and available plug-ins), which might elicit usability and feasibility issues, and data on message processing collected through tracking eye movements to objectively measure in real time how the intervention content is processed (Resnicow et al., 2010). In relation to eHealth trials, analysing and discussing usage metrics and determinants of attrition, as well as reporting for which sub-population the intervention eventually works, is as important as reporting efficacy measures (Eysenbach, 2005). This is of particular significance considering the substantial proportion of participants that stop using the e-intervention or drop-out before the evaluation is completed, which seems to be a typical feature of eHealth trials when compared to more traditional RCT (Eysenbach, 2005).

The particular tailoring process of the *Expert Symptom* entailing longitudinal assessments, with feedback loops between assessments, transpires a differing number and strength of doses of supportive content between individuals interacting with the programme. The tailoring per se is already an element of complexity (Medical Research Council, 2008); the process by which it occurs adds further challenges to determining the adequate intervention dose, that is to say, its amount, frequency and duration (Aranda, 2008).

The continuous communication channel that the *Care Expert* attempts to create is maintained by both automated mechanisms and the latent presence of a healthcare provider. The latter demands an intermittent engagement of the healthcare provider, who is in fact the interventionist. The characteristics of this involvement are also a source of complexity (Datta & Petticrew, 2013) and should already be addressed at the design stage of the intervention, but should continue throughout, particularly during the feasibility phase. Specifically in relation to the *Care Expert*, a colour scheme was embedded in the submitted

reports of the *Report a Symptom* to allow the healthcare provider to directly identify the perceived urgency from the women's perspective. The systematic involvement of healthcare providers in the form of an expert panel in the planned further development of the e-supportive programme is expected to additionally advance strategies that ease the engagement process of the healthcare provider with the programme and future evaluation in a person-centred care setting.

8.4.2 Integration of design features

In light of the continuously evolving context of ICT, which was a striking challenge in relation to Study II, a discussion was undertaken with IT experts in order to prepare a prototype that could be accessed from personal computers, laptops, tablets and mobile phones without losing usability. Accordingly, the intervention was constructed within responsive web-design principles.

Moreover, considering the initial guidance on the features and formats, the e-supportive system should support a two-way communication process, which was consistent with results from Study I and Study II. In particular, the less interactive features and one-way communication solutions were less attractive with the potential to lead to a lack of relevancy and non-usage for the duration of the evaluation and implementation stages of the intervention.

Other authors have stated that e-supportive systems and Internet-based support require a more pro-active behaviour from the patients in terms of knowledge and support seeking (Muusses *et al.*, 2012). In this context, the integrated results from Studies II and III reinforced the importance of following a simple design such that the usability of the e-supportive system would be highly rated even at lower states on the wellbeing continuum. Specifically, Study II revealed that women undergoing chemotherapy were less likely to access the computer-based educational programme, which was speculated to be related to a lack of energy due to cancer treatment. On the contrary, women in Study III would commonly engage in more active knowledge and support seeking during the chemotherapy phase. However, assuming the women experienced a shattered wellbeing directly after the treatment session, their desire for reaching out could be hindered by the access or interaction features of the e-supportive system.

Furthermore, in line with user-centred design, women's priorities and expectations in relation to support seeking synthesised from Study III provided a set of requirements for the format and features of the intervention. Accordingly, it was important to have a variety of multimedia features, as reflected by the results of Study I, yet women had to be able to select the extent of exposure to

specific images, videos or text. A final overall requirement was the need to provide tailored knowledge and support in both an automated and human way.

Establishing a line of reflection with the overall results from Study I, the design element of IHCA appears to be the research component that has evolved most towards consensus in comparison with the methodological aspects of evaluation and implementation. An example of the advances towards congruency of design features made in the field is the behavioural intervention technology model (Mohr, Schueller, Montague, Burns, & Rashidi, 2014). The model conceptually defines behavioural information technology, from the clinical goal to the technological framework for delivering the intervention. The technological framework allows the integration of the components and implementation of the workflow for delivering the entire intervention over time.

8.5 Exploring the person-centred dimensions in the *Care Expert*

Although there is common agreement about the positive effectiveness of e-supportive systems (Bouma et al., 2015; Resnicow et al., 2010), many literature reviews advise caution in the interpretation of the results (Badr et al., 2015; McAlpine et al., 2015; Morrison et al., 2012). Specifically, variation in the impact of these interventions may occur depending on the intervention target, intervention components and the selected efficacy outcomes (Badr et al., 2015; Morrison et al., 2012). Study II is consistent with the discrepancy in the effectiveness results reported in these recent literature reviews. Reinforcing the lack of effectiveness in the selected outcomes in Study II, these reviews alert to the many factors that may account for the success of a complex intervention and call for rigorous evaluation methods. Additionally, the need to systematically elicit and incorporate the users' perspectives from development to implementation, that is to say, the intervention's person-centredness, is once more highlighted.

Studies alluding to person-centredness in relation to e-supportive systems interventions most commonly refer to the process of eliciting and incorporating the person's requirements through the development and feasibility phases, for example, Berry et al. (2015), or to the intervention's degree of customization to the person's characteristics, for example, Darlow and Wen (2015). In relation to the *Care Expert*, the selection of a user-centred design was a deliberate methodological strategy to ensure continuous integration of participants' perspectives. Such a strategy was considered mandatory in light of

the results of Study II. Specifically, the incorporation of the participants' perspectives was expected to foster the development of an intervention that was patient-relevant, feasible and with an acceptable study design for evaluation. In so being, such a strategy and its consequent implications would ultimately allow overcoming one of the major pitfalls identified in Study II and overall in eHealth research, that is, non-usage and lack of adherence throughout the evaluation and implementation stages of the intervention (Eysenbach, 2005).

In line with the second trend of eHealth research of exploring the person-centredness black box, and guided by the principles of person-centred care (Ekman et al., 2011; McCormack et al., 2015; McCormack & McCance, 2006), the development of the *Care Expert* was driven by three main queries:

- Are the intervention components relevant for the person and for the person's particular situation?
- Is the interaction with the intervention perceived to be relevant and occurring in a relevant way?
- What is the relevancy of the interaction results for the person?

The continuous reflection on these queries allowed addressing the person-centred dimensions of the e-supportive system (Lauver et al., 2002), towards promoting the development of an actual person-centred intervention with the potential to be effective and successfully implemented (Lauver et al., 2002; Richards & Rahm Hallberg, 2015; Wolpin & Stewart, 2011).

Attempting to elicit the person-centred dimensions explored in this thesis, from the initial severity appraisal that leads participants to seek for knowledge and support, throughout the interaction with the e-supportive system, to the resultant outcomes, the explanatory model from Study I was restructured to address the integrated aspects that will be further discussed in this section (Figure 5).

Briefly, as portrayed by the integrated results from Studies III and IV, women initiate their interaction with the e-supportive system upon an overall need of reassurance, that is to say, a need of having their concerns acknowledged, and receive advice to minimize, overcome and prevent the concern in the further course of treatment. Usage predictors influence their use of specific intervention components. These entail: the positioning in the continuum of reaching-out behaviours, the experiential beliefs and circumstantial aspects, the supportive network, and the severity and specificity of the concern.

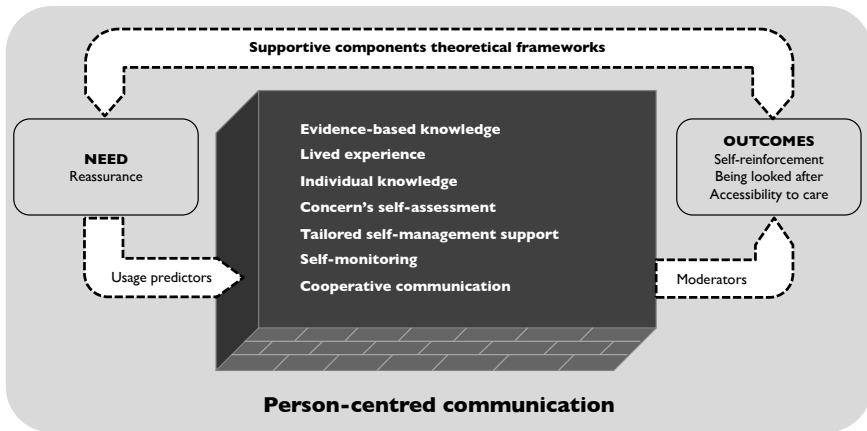


Figure 5 Integrated framework for the person-centred e-supportive system.

Each of the supportive components in the intervention is endorsed by their specific theoretical framework, which explains the component mechanisms of action. The theoretical structures of the components should be congruent with person-centred communication, the overarching perceived supportive function in relation to the *Care Expert* that might be suitable to endorse the theory-driven platform of supportive resources. Similar to the explanatory model from Study I, a set of factors designated as moderators will condition the outcomes. The moderators serve to elicit the variation occurring in women’s knowledge and support-seeking behaviours that are related naturally to, for example, personality and motivational characteristics, in addition to the selective exposure to the multi-dimensional intervention components. The consequent intervention products might reflect both person-relevant and process outcomes.

8.5.1. Customization degree

A commonly discussed dimension of PCI is its degree of person-centredness (Aranda, 2008; Lauver et al., 2002; van Meijel et al., 2004), which is usually related to the customisation level of the supportive messages to individual aspects, such as: theoretical constructs, and behavioural or demographic characteristics (Morrison et al., 2012). Women’s perspectives emerging across the group discussions in Study III, portrayed on one hand, the need of having access to evidence-based knowledge and support related to cancer and cancer

therapy, and on the other hand, the relevancy of having access to knowledge and advice specific to their situation. The latter was in fact the least available form of support, only found to be provided by the HCT.

Based on women's perspectives and needs, the prototype of e-supportive programme encompasses several levels of degree in the continuum of person-centredness. At the least customised end, women might have access to targeted evidence-based knowledge in relation to a specific concern that led them to the *Symptom Expert*. Specifically, after completing the process of concern diagnosis, women are offered further reading of quality-secured web pages recommended by the HCT.

Moving further along the customisation continuum, tailored messages are provided both by the *Report a Symptom* and the *Symptom Expert*. Considering the *Report a Symptom*, the system allows the nurse to provide a standardised message to the report submitted by the woman, but it also allows the provision of an individualised supportive text message.

At its current development stage, the messages from the *Symptom Expert* are tailored to the concern and women's answers associated to concern-specific questions. A further development will lead to the embedment of a database with women's personal records (e.g. socio-demographic and medical characteristics and women's health-related goals). Such a database is expected to inform the diagnosis process thereby enhancing the tailoring of questions that are posed and the messages that are provided after completion. In so doing, the described tailoring process involves multiple assessments over time and multiple corresponding messages delivered accordingly, with each tailoring process having a feedback loop to the previous one (Lauver et al., 2002).

8.5.2. Usage predictors and effect moderators

Following the trend of the research endeavours on person-centredness dimensions, the analysis of the patterns of programme usage in Study II were considered important to add empirical evidence on specific characteristics of users, that is to say, a person perceiving the interaction with the programme to be relevant and/or occurring in a relevant way such that he/she actually accesses it at least once. Summarily, the exploratory analyses revealed that, in addition to the physical wellbeing and receiving postoperative chemotherapy discussed above, the woman's age, type of axillary surgery and meaningfulness also influenced the use of the programme.

Interpreting the results in light of the state-of-the-art and the information and communication structure of the Swedish population, highlighted two main

discussion points. On one hand, general wellbeing, availability and wide Internet access should be further explored as predictors of usage influencing the perceived relevancy of these kind of programmes. Such discussion suggested a more complex predictive model connecting both societal and socio-demographic characteristics to the actual usage of the programme. On the other hand, the need to understand the supportive role of the Internet in the broader context of the individual supportive network emerged. Accordingly, only women indicating a preference for the Internet instead of face-to-face or telephone-mediated support should be enrolled in effectiveness studies of e-supportive interventions (Leykin et al., 2012).

Study III allowed qualitative exploration of the discussion points elicited in Study II, especially relating to the role of the Internet as a supportive resource. The preference for a medium to establish a supportive contact varied in relation to several aspects (i.e. severity, specificity, availability and meaningfulness attributes) rather than being a static predefined characteristic. Accordingly, the only potential requisite to consider for baseline screening would be whether the Internet is an inherent component of the supportive network.

Other authors have discussed individual responses to e-supportive interventions on the basis of those initial characteristics and designated them as moderators of the effect of the intervention (Resnicow et al., 2010). Indeed, consistent with the continuum of reaching-out behaviours and in light of the continuously tailoring processes, the interaction with the e-supportive system will naturally vary from person to person upon individual characteristics, which might lead to large differences in intervention response. Resnicow et al. (2010) highlight that these moderators might extend beyond socio-demographic variables to include both personality and motivational factors. Generally, the thorough collection and analysis of the above mentioned paradata (Resnicow et al., 2010), complemented with the inductive exploration of the person's supportive seeking processes (van Meijel et al., 2004), will elicit such person-centred variation, assist in the refinement of intervention components and inform the dose-response processes (Lauver et al., 2002). In the context of exploring the person-centred dimensions of e-supportive systems, the moderators' analyses will enhance the understanding of not only the intervention's relevancy for the person, but also the variation in the effects related to person-specific characteristics, that is to say, for whom did the intervention work..

8.5.3. Perceived support functions and person-centred care

Another aspect commonly discussed in relation to the person-centredness of PCIs is the relevancy of the improved outcomes to the person participating in the intervention (Aranda, 2008; Lauver et al., 2002). Study IV was central to exploring whether the reflection queries were actually driving the system's development towards meeting the person-centred dimensions. While exploring the prototype, women's reflections on its supportive functions were expected to contribute to the development of the intervention theory by informing potential person-relevant outcomes. The *Care Expert* allowed for a continuous communication established upon a perceived cooperative agency and a reinforcement of women's self-driven agency (Table 6).

Table 6. Perceived support function in relation to each supportive component

Perceived supportive function	Supportive mechanisms	Supportive components
Self-driven agency: self-reinforcement	Register to remember	<i>Report a Symptom</i>
	Ventilating concerns	
	Coping with strangeness	<i>Symptom Expert</i>
	Enhancing self-management	
	Learning with symptom's pattern	<i>Calendar</i>
Cooperative agency: being looked after	Community of experiences	
	Keeping the caregiver informed	<i>Report a Symptom</i>
	Fostering care efficiency	
	Legitimacy to establish contact	<i>Symptom Expert</i>

The results from Study IV show qualitative evidence of the reinforcement of women's self-driven agency portrayed in Study III by the specific mechanisms of each of the supportive components. Furthermore, the cooperative agency emerging as a perceived supportive function portrays women's willingness to be in a reciprocal care partnership. This established relationship between the HCT and the woman takes a stand from paternalistic models of patient-healthcare provider relationships (Longtin et al., 2010). The partnership emerging is the reflection of a collaborative and equalitarian relationship between two experts, i.e. the care and treatment expert and the person expert, where the person involvement in care is acknowledge, fostered and enabled with respect for the person's values preferences and goals (Ekman et al., 2011; Ricœur, 1994).

Altogether, these results strengthen what was posited earlier in this section in relation to women being part of the solution to the identified research problem. Concretely, the requirements for development and implementation of person-

centred care, that is to say, person involvement and establishment of a partnership, already existed as reflected in women's self-driven agency portrayed by Study III. The results from Study IV strengthen the potential of the *Care Expert* to mediate person-centred care as reflected in the reinforcement of women's self-driven agency and cooperative agency.

Study IV also allowed further understanding of women's communication needs, particularly considering the need for feedback. Revisiting the results of Study II, a two-way communication channel was discussed to be an important element to enhance the intervention's relevancy from the women's standpoint. Particularly considering the interdependence of resources portrayed by the results of Study III, to provide space for discussion of the knowledge acquired from other sources reinforced the need to allow for continuous communication. The results from Study IV add further detail to the specific communication needs of the self-driven agents. Specifically, not all the concerns demanded an immediate contact, and in the need of contact, not all queries demanded an immediate answer or an answer at all. Sometimes the single act of acknowledging the reception of the concern's description was enough; women trusted that if needed, the HCT would return the contact for further assistance. In such a context, women felt that they were continuously being looked after, even if they no longer were in the hospital setting.

Consistent with the results of Study IV, elements related to each of the perceived supportive functions might be related to person-centred care principles: women's involvement in care is acknowledged and reinforced in an environment of shared responsibility and deliberation (Ekman et al., 2011; McCormack & McCance, 2006). This is also in line with the common definition behind the holist concept of person-centred care emerging from the evidence that highlights the aim to acknowledge the person as an equal partner in their healthcare (de Silva, 2014). Furthermore, in the last decade, discussion on the different aspects that facilitate person-centred care have brought clarity in relation to the relationships between person-centred processes and person-relevant outcomes (de Silva, 2014; McCormack et al., 2015). Moreover, in light of a recent review of the evidence about approaches and tools used to measure person-centred care, the perceived supportive functions in relation to the *Care Expert* are consistent with activities from the HCT considered to support person-centred care, that is to say, person-centred processes. The person-centred processes that might be inferred from the perceived supportive functions of the *Care Expert* are: person-centred communication; engagement, support and information provision; self-management support; and shared decision-making (de Silva, 2014). Altogether, the empirical evidence synthesised from Study IV on the prototype for perceived supportive functions so far, in light of the

available evidence, appears to point towards the accomplishment of the programme's intent of mediating person-centred care.

8.5.4. Person-centred outcomes

The discussion remaining is, whether these perceived supportive functions are person-relevant outcomes and by which means should they be measured. The review of the evidence elicits intangible subcomponents of the holistic concept of person-centred care that have been commonly measured across studies. In the context of the *Care Expert*, continuity, empathy, enablement, health literacy, individuality, partnership and involvement might be inferred as being relevant and in line with perceived supportive functions (de Silva, 2014).

Quantitative and qualitative methods are both needed to enable a comprehensive and person-relevant measurement of person-centred processes and outcomes (van Meijel et al., 2004). With regard to quantitative tools, more than one instrument might be required to allow measurement of relevant patient-reported outcomes (PROs). In such a context, the careful triangulation of measurements is advised (de Silva, 2014). Moreover, and particularly considering the applicability of the empirical evidence on PROs to cancer care, a recent systematic review of the literature raised attention to the lack of patient-reported outcome measures with acceptable psychometric properties and developed with cancer patients that allow capturing all dimensions of person-centred care in cancer care (Tzelepis et al., 2014).

Without neglecting the importance of the recent evidence to inform the development and evaluation of person-centred e-supportive interventions, cautious has to be taken when considering the generalizability and transferability of results to electronic interventions from institutional interventions, which are the only type represented in these major reviews of the evidence (de Silva, 2014; Tzelepis et al., 2014).

Evidence synthesised in another comprehensive review of studies involving person-centred interventions, found that specific strategies towards improving self-care are consistent with the supportive mechanisms incorporated in the *Care Expert* components. The authors present evidence on self-management education, self-monitoring, peer support, facilitating patient access to personal medical information through what they designate as patient-centred telecare (Coulter & Ellins, 2006). With special caution in the interpretation of these findings, as there have been considerable advances in IHCA research during the last decade, this evidence might allow the informing of the theoretical structure, concretely the mechanisms of action, of the *Care Expert*. These authors group

the effectiveness outcomes according to: a) person's knowledge and information recall; b) a person's experience, including communication and psychological outcomes; c) health behaviour and health status; and d) utilisation and cost of health services. These outcome areas are consistent with the trend in more recent studies, where person-centred interventions focus on experiences, that is to say, examination of the extent to which care feels person-centred, and outcomes, that is to say, examination of what happens as a result of person-centred care (de Silva, 2014).

Beyond the person-centred outcomes that might be inferred from the perceived supportive functions of the *Care Expert*, others are worth considering, given their weight in reflecting a person-centred practice. Specifically, across the literature, satisfaction with care, involvement in care, wellbeing or quality of life are all considered to be outcomes of person-centred care with varying efficacy results (de Silva, 2014; McCormack et al., 2015; McCormack & McCance, 2006; Olsson et al., 2013).

The selection of intervention-sensitive and person-relevant outcomes is generally considered to be a challenging process. This was a discussion topic arising in Study II, particularly considering the materialisation of those outcomes by measurement instruments that do not necessarily cover the entire aspects relevant to a study sample or are too multi-dimensional to be sensitive to the intervention components (McCambridge et al., 2011). In the specific context of the population in this thesis, the continuously changing supportive needs and the corresponding perception of support along the continuum of reaching-out behaviours should be taken into consideration in the outcome selection process. In light of the personhood perspective put forward here, the person has capabilities and vulnerabilities along a continuum of wellbeing (Ricoeur, 1994). The general corollary of such a perspective might be that specific constructs inherently vary along that continuum.

The importance of this general consideration might be better elucidated with an example of a potential common outcome of person-centred care. Analysing the case of person involvement in care, the results from Study III particularly emphasise that although women portray a general willingness to be involved in their care, the actual involvement occurs at varying time-points along the course of treatment and entails different forms for different women. In such a context, a single measurement of person involvement as an efficacy outcome could be misleading. Similarly, evaluating health competence at a time point when the wellbeing is more shattered might lead to incongruent results relating to the efficacy of the intervention.

8.5.5. Theories underlying the mechanisms of action

If the components and outcomes vary widely with regards to e-supportive interventions, their theoretical underpinnings are even more scattered. As highlighted in Study I, not all studies reported the use of a theoretical framework structuring the intervention, and if in existence, the theory did not necessarily facilitate the entire process of engaging with the supportive components to reach the outcomes, that is to say, the intervention mechanisms.

A common trend along with the second generation of research into e-supportive systems is the exploration of its mechanisms of action to elicit these theoretical structures (Pingree et al., 2010). Potentially related to the early steps being taken in this research issue, theoretical information endorsing the mechanisms of action continues to be rarely found across reports from systematic reviews of the literature on e-supportive interventions. Concretely, among five recent reviews on the kind of e-supportive interventions and their effects specifically within cancer care, only one reported this information (Agboola et al., 2015; Badr et al., 2015; Bouma et al., 2015; Darlow & Wen, 2015; McAlpine et al., 2015).

Consistent with the results from Study I, the elicited theories have been brought from various fields (social sciences and behavioural sciences, education and learning, and communication) to endorse the mechanisms of action depending on the supportive aim of the IHCA. Across studies of e-supportive systems, the most frequently applied theories are the self-regulation theory, self-determination theory, social-cognitive theory and stress and coping theory. These are usually addressed in relation to what authors designate as psychosocial interventions and commonly target social support and communication as intervention components. Although they endorse the rationale for the intervention, their influence on the development of the intervention components and mechanisms is not clearly described (Badr et al., 2015). Overall, these reflections are consistent with those of Study I with regard to the theoretical underpinnings of e-supportive interventions and might therefore be indicative of the slow rate of evolution in the field, in spite of the many new IHCAs that have emerged since Study I was conducted (Badr et al., 2015; McAlpine et al., 2015).

Bridging the evidence on e-supportive interventions that to some extent attends to the principles of person-centred care, to theories commonly used to structure person-centred nursing interventions, two theories have been found (Lauer et al., 2002). The theory of representational interventions (Donovan & Ward, 2001; Donovan et al., 2007) and the transtheoretical model and stages of change (Prochaska, Redding, & Evers, 2008) have been particularly useful in tailoring behavioural and educational interventions to the individual level.

The continuous communication process, emerging as the overarching supportive function of the *Care Expert*, might be indicative of the adequacy of theories from the field of communication to enhance the development of the system as a whole towards a platform of integrated supportive components. However, they might not be enough to structure the supportive function of each of the components.

If attending to the potential overarching person-centred goal of assisting self-management, several fields should be integrated to particularly address each of the person-centred components of self-management support, that is to say, self-management education and learning, self-monitoring, peer support and clinician-person communication (Coulter & Ellins, 2006). Scholars have indeed raised attention to the multi-dimensionality of specific concepts across different knowledge fields.

The dominance of a single theory or conceptual framework in research and practice regarding health behaviours is unrealistic in the face of the constructs of complexity (Glanz, Rimer, & Viswanath, 2008). In such a context, theories are constantly brought from outside the nursing theoretical sphere to elucidate concepts of interest in nursing science and practice. This is especially prominent in the development of nursing interventions to promote health-enhancing behaviours (Polit & Beck, 2012). A theoretical model that elicits the perspectives on the concepts from the standpoints of various fields of science is no single-researcher endeavour. Rather, it demands the involvement of a multi-disciplinary team including patients and care providers that fosters discussions towards the enhancement of the construct validity of the intervention.

8.5.6. The next research chapter in the *Care Expert*

Along with the construction of a theoretical model for the intervention, most of the research steps to be undertaken for further development of the *Care Expert* are related to processes and outcome modelling. Although this activity is part of the development phase of the MRC framework, the suggested methodological guidance includes intervention optimisation activities ending with evaluation endeavours. In so doing, the first, second and third phases of the framework slightly overlap, which reinforces the reflexive and iterative processes in intervention research (Richards & Rahm Hallberg, 2015). In that context, the main activities to be undertaken concern:

- Modelling of the multiple active components: How are the supportive components interrelated?

- Optimising the intervention: Which components contribute most to the effectiveness? What is the optimal intervention dose?
- Embedding implementation strategies: What are the perspectives of care providers on the intervention and on the intervention evaluation and implementation?

This research chapter began with a small workshop with oncology nurses to present the *Care Expert* and briefly explore their acceptance and willingness to integrate this e-supportive system in their daily clinical practice. In the sphere of intervention research, scholars usually evoke Maier's Law, which posits that the effectiveness of the intervention is the result of its quality multiplied by its level of acceptance (Richards & Rahm Hallberg, 2015). In so doing, a large-scale qualitative assessment with both care providers and women is required to validate this intervention, yet the acceptability expressed so far is promising.

Finally, the spread of and easy access to information and communication technology, has the great advantage of allowing the rapid dissemination of the evidence resulting from research endeavours, both in intervention research and in supportive care. Indeed, developing complex interventions is time-consuming and new evidence reaches the final implementation stage before the intervention's theoretical model is constructed. In line with this greater access to information comes the challenge of keeping the intervention foundations up-to-date in terms of design and content. In such a constantly evolving context, systematically synthesising the evidence on e-supportive interventions needs to be more than just the first step. Specifically, it should be considered an on-going research activity throughout the development and evaluation stages (Medical Research Council, 2008). Therefore, upon the new theoretical understanding endorsing the intervention a new review of the evidence should be conducted. The scope of the review should entail the exploration of the person-centred elements and mechanisms underlying the conceptual framework and their potential effectiveness, as well as the perspectives of patients and care providers.

9. Methodological considerations

Intervention researchers agree that intervention development and evaluation demands a multi-method strategy to uncover the realm of a person's needs, expectations and priorities underlying the effectiveness of the intervention itself (Medical Research Council, 2008; Richards & Rahm Hallberg, 2015). In light of these demands, the research work has to necessarily entail both inductive and deductive reasoning (Collins & O'Cathain, 2009; Johnson & Onwuegbuzie 2004; Onwuegbuzie & Leech, 2005). In line with the overall aim of this thesis, to explore the foundations of person-centred e-support for women receiving outpatient treatment for ESBC, the research work conducted here focused on both explanatory and exploratory approaches with the ultimate goal of theory generation rather than theory validation. In the overall context of this thesis, the mixed-methods approach emerges in relation to the integrated interpretation and discussion of results, which were generated through both qualitative and quantitative methods (Tashakkori & Teddlie, 2010). In particular, the integrated interpretation and discussion of the results is made upon the four individual studies, with Study I being an integrative systematic review of empirical studies, Study II following a randomised-controlled trial design (deductive reasoning and exploratory approaches), Study III being guided by Interpretive Description (inductive reasoning and interpretation and explanatory approaches) and Study IV being guided by user-centred mixed-methods design (dominant inductive reasoning and descriptive, interpretive explanatory and exploratory strategies). To the ultimate goal of inferring the transferability and generalisability of the results and conclusions of this thesis, potential limitations should be highlighted in relation to the design of each individual study.

The research design of the studies composing the final sample of the integrative review in Study I should be addressed as a potential limitation. Along with uncovering the design of e-supportive systems and their potential effectiveness while providing supportive care, a review of the literature should systematically synthesize evidence on the intervention mechanisms of action, and thereby bring forth the conceptual framework that interconnects the person's needs, the intervention design and its content, and the person-relevant outcomes (Richards & Rahm Hallberg, 2015). Several scholars have raised attention to the challenges in this research activity, specifically in relation to the need to: a)

combine research with various study designs; and b) answer such a wide scope of intervention queries.

Towards assisting the activity of combining various study designs, methodological approaches to systematically revise and synthesise the literature have been put forward (Richards & Rahm Hallberg, 2015). Among these formats of systematic reviews, integrative reviews are considered to be appropriate for synthesising and combining evidence on complex interventions (Richards & Rahm Hallberg, 2015).

In spite of the congruent study design, the final sample of studies included only deductive study designs. *A posteriori*, one specific exclusion criterion might have had a particular influence on the resulting sample, that is, the exclusion of studies reporting results on phase I and II of intervention development. The work conducted so far towards the development of the person-centred supportive system in this thesis has raised attention to the importance of attending to the description of other researchers' development work and the early feasibility evaluation. These reports should be especially elucidative of the design features, intervention components and outcomes in relation to the expected mechanism of action. Accordingly, they are of considerable relevance to other researchers conducting development research as they have great potential to inform the interventions' theoretical foundation. In spite of this potential limitation, the final sample of studies allowed the synthesis of knowledge on design features, intervention components, outcomes and theoretical structures, which is replicated to some extent in more recent systematic reviews (Badr et al., 2015).

The research design of Study II might be uncommon in the development stage of interventions. However, the need to conduct primary research to enhance the evidence base of the intervention is recognised by various researchers and anticipated as an adequate methodological step within the MRC framework (Conn et al., 2001; Richards & Rahm Hallberg, 2015). Specifically, exploring the potential reasons for the absence of impact of the computer-based educational programme on the primary and secondary outcomes in comparison to standard care, allowed reflection on potential pitfalls, along with the evaluation and implementation of the intervention. Interventionists agree that such considerations are important during the development stage in order to integrate evidence-based strategies into the intervention design that will prevent and help to overcome identified obstacles during the evaluation and implementation phases (Richards & Rahm Hallberg, 2015). Moreover, the explanatory analysis conducted to determine whether different patterns of usage could be explained by demographic, medical and psychosocial factors, brought additional evidence on the antecedents of the usage of computer-based educational programmes that were critically integrated into the evidence base of

the person-centred e-supportive system. Finally, in relation to Study II, one particular limitation should be considered in the interpretation of the overall conclusions in this thesis. Specifically, many women in the intervention group did not use the computer-based educational programme at all. Although the intention-to-treat is the recommended approach, these women were retained in the analysis without having actually used the intervention, which may have reduced the sensitivity to detect an effect.

Particularly in relation to the qualitative string of this thesis (Study III and, dominantly, Study IV), the research endeavours within intervention research should go beyond description to explanation and interpretation (van Meijel et al., 2004). In relation to the work carried out in this thesis, this was considerably important in order to not only uncover the person's supportive needs but also their context and the processes embedded in the person's support-seeking behaviours. Intervention researchers posit that the more closely an intervention matches the manner in which the problem is experienced, the greater is its effectiveness potential (van Meijel et al., 2004). Furthermore, both face-to-face interviews and focus group discussions are valued methods for involving patients in intervention development, a method of participation that has been increasingly endorsed (Richards & Rahm Hallberg, 2015).

Particularly in relation to Study III, the inclusion criteria might be considered to limit the study's theoretical generalisability. Specifically, in relation to the second phase of data collection, the participation of women after completion of chemotherapy could have elicited point of views not yet relevant for women undergoing chemotherapy, as they could retrospectively account for their experiences during that course of treatment. However, the women participating in the second phase of data collection had a varied number of chemotherapy sessions completed, which was expected to allow for variability in the experiences of support seeking during that phase of the course of treatment. Moreover, given the smaller group sizes, we had the opportunity to explore the experiences in depth (Krueger & Casey, 2009; Morgan, 1997). Such in-depth inquiry was considered to produce rich descriptions of the studied phenomenon that enabled the fostering of insights into the clinical context which is the ultimate endeavour within interpretive description (Thorne, 2008), and is argued to be an important goal when discussing external validity issues in qualitative research (Groleau, Zelkowitz, & Cabral, 2009).

For the purpose of continuously assuring the processes of eliciting and integrating the perspective of the person, and thereby their needs and preferences, in the development of the person-centred e-supportive system a framework of user-centred design was adopted, intertwining Studies III and IV (Wolpin et al., 2015). This aspect of the conjugation of these studies is

considered to be a strength that should be discussed in light of potential sample limitations of Studies III and IV.

The sample size in Study IV might be considered an issue affecting credibility. Although most of the usability problems of an application can be found by including only 3-5 participants (Nielsen, 2000), the inclusion of additional women could have been beneficial, especially because women participating in the study were rather well educated and proficient in terms of their computer and Internet skills. However, going back to the conjugation of Studies III and IV, this exploratory step needs to be seen in relation to the participatory cycle in which nineteen women participated in focus group discussions. Specific design features and system requirements elicited along the latter interaction with participants have not been reported, but were integrated in the prototype of the *Care Expert*. Furthermore, the identified and inferred features and system requirements constituted the foundations upon which the subjective assessment and diagnostic evaluation of Study IV were conducted. Altogether, all four participants endorsed the perceived supportive functions of each component. Additionally, the recurrence of patterns throughout the constant comparative analysis (Thorne, 2008) and the matching between the research team's thoughts for further development and the women's recommendations, revealed that the functioning processes of the *Care Expert* were understood.

At this early development stage the major activities entail exploratory and descriptive research with the goal of inductively uncovering the concepts and theories underlying the e-supportive system as an intervention. In the context of exploring the concept of person-centredness underlying the foundational structure of the *Care Expert*, the sample size of Study IV was therefore considered to be adequate and in line with the international literature for this initial evaluation of the prototype (Polit & Beck, 2012; Richards & Rahm Hallberg, 2015; van Meijel et al., 2004).

10. Conclusions

The research studies allowed for an in-depth understanding of women's communication and supportive needs throughout the course of treatment for early-stage breast cancer. Core concepts and features of the provision of person-centred e-support were identified and their articulation was discussed to enhance the possible processes underlying support seeking and the outcomes resulting from those behaviours. The research work conducted in this thesis suggests that:

- The person receiving outpatient cancer care is a resourceful agent in spite of her illness and potentially shattered wellbeing due to treatment. Her expertise and agency should be acknowledged and fostered in an inherently shifting continuum of capabilities and vulnerabilities.
- The healthcare team represents a particular important supportive resource, as it is the single asset that customises the provision of standard supportive measures for each patient's individual situation.
- The single provision of reliable and evidence-based medical and rehabilitation information via a computer-based programme might not be enough to influence multi-dimensional outcomes in women.
- Interactive health communication applications have shown potential to complement care in the process of satisfying women's supportive needs. However, the methodological variety relating to evaluation and implementation disturbs the process of applying interventions across target populations.
- Focusing on person-centred dimensions from the early development stage might be of considerable significance to increase the interventions' effectiveness.
- Person-centred e-supportive systems may bridge the communication gap between the hospital setting and patients' homes by fostering a reciprocal partnership in care that acknowledges and reinforces patient's expertise and agency.

11. Future perspectives

The involvement of the general public in care, and particularly of the person undergoing cancer treatment, is a reality, to which ICT has contributed considerably by allowing for wide access to health-related knowledge and social networking. Emancipatory models of care provision are moving from the traditional authoritative institutional relationships to those advocating shared expertise through the establishment of reciprocal partnerships in care. Here, the recent advancements in the fields of electronic and personal health records are just one of the many examples portraying not only the acknowledgement, but also the enhancement, of the person's expertise and agency.

Person-centred e-supportive systems might successfully complement the care partnership within the new healthcare paradigm, particularly for the person exposed to long-term illness conditions that demand self-management activities, compared to those in acute situations. Yet the scope of challenges associated with these innovative tools is still very comprehensive, and tackling them is no one researcher's endeavour. To the constantly evolving eHealth field and the increasingly available empirical and theoretical knowledge, is added the methodological diversity in conducting feasibility, evaluation and implementation work. The work has to necessarily be trans-disciplinary, including clinicians and researchers from numerous scientific fields, such as communication, social psychologists, linguistics, health informatics, statistics and health economics, in addition to the naturally present health care sciences. And yet the product of this interaction might be in vain if it does not attend to the person-centred dimensions of such tools.

Person-centred dimensions vary widely and although some consensual elements can be elicited from both the empirical and theoretical literature, their operationalization is still in its infancy. To uncover the material person-centredness elements of e-supportive systems, the perspectives of all users, that is to say, clinicians and patients, must be elicited and integrated throughout the system's lifecycle, from the early steps of needs assessments to long-term evaluation.

Altogether, person-centred care is more than a gold standard within this new paradigm of healthcare provision; it might be the only possible care philosophy, if the care providers and healthcare institutions are to meet their equal partner in care, that is, the person before the patient.

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