

TIINA YLI-UOTILA

Adult Cancer Patients' Perceptions of Electronic Social Support

The background of the lower half of the cover is white, featuring a decorative arrangement of numerous blue spheres of varying sizes. These spheres have a glossy, semi-transparent appearance with darker blue spots and gradients, giving them a three-dimensional, molecular or cellular look. They are scattered across the page, with some appearing in the foreground and others receding into the background.



TIINA YLI-UOTILA

Adult Cancer Patients'
Perceptions of
Electronic Social Support



ACADEMIC DISSERTATION

To be presented, with the permission of
the Faculty council of the Faculty of Social Sciences
of the University of Tampere,
for public discussion in the auditorium F115 of the Arvo building,
Lääkärintie 1, Tampere,
on 24 February 2017, at 12 o'clock.

UNIVERSITY OF TAMPERE

TIINA YLI-UOTILA

Adult Cancer Patients'
Perceptions of
Electronic Social Support

Acta Universitatis Tamperensis 2257
Tampere University Press
Tampere 2017



UNIVERSITY
OF TAMPERE

ACADEMIC DISSERTATION

University of Tampere, Faculty of Social Sciences

Supervised by

Professor Tarja Suominen

University of Tampere

Finland

Professor Marja Kaunonen

University of Tampere

Finland

Reviewed by

Professor Marit Graue

University of Bergen

Norway

Professor Elina Haavisto

University of Turku

Finland

The originality of this thesis has been checked using the Turnitin OriginalityCheck service in accordance with the quality management system of the University of Tampere.

Copyright ©2017 Tampere University Press and the author

Cover design by

Mikko Reinikka

Acta Universitatis Tamperensis 2257

ISBN 978-952-03-0363-1 (print)

ISSN-L 1455-1616

ISSN 1455-1616

Acta Electronica Universitatis Tamperensis 1758

ISBN 978-952-03-0364-8 (pdf)

ISSN 1456-954X

<http://tampub.uta.fi>

Suomen Yliopistopaino Oy – Juvenes Print
Tampere 2017



This dissertation is dedicated to those adult cancer patients and counselling nurses in the ECS who volunteered to participate in my study and share their valuable perceptions.

Acknowledgements

This dissertation would have never been possible without the support of a large number of people. First, I express my deepest gratitude to Professor Tarja Suominen. She supervised and guided me in my studies with inspiration and determination and provided many types of support throughout all the developmental phases of this dissertation. My other supervisor, Professor Marja Kaunonen, deserves my sincerest appreciation for sharing professional, innovative comments and suggestions throughout the research process. I also wish to thank the members of my dissertation committee, particularly Dr Anja Rantanen for giving constructive comments regarding the social support phenomena and co-writing two articles. Furthermore, I extend my gratitude to Dr Harri Vertio, MD, who provided insights into the psychosocial aspects of cancer patients and helped me build networks. Thank you for your commitments to this project! I would also like to thank Adjunct Professor and Chief Medical Officer Liisa Pylkkänen, MD, for her contributions as a co-author of three articles. I'm very grateful for biostatistician Anna-Maija Koivisto's guidance in statistical analysis techniques and the Tampere University Library's help throughout these years.

To Professors Elina Haavisto with the University of Turku and to Professor Marit Graue with the University of Bergen, Norway, I express my sincerest appreciation for their constructive criticism, suggestions for improvements and dedication as pre-examiners of this dissertation. To Professor Anna-Maija Pietilä with the University of Eastern Finland, I give thanks for serving as the official opponent of my dissertation.

My deepest gratitude goes to all the study participants - cancer patients and counselling nurses - and participating sites - cancer societies and cancer patient associations across the country. I am very grateful for their positive attitudes and genuine interest in this study. They were the leading inspiration for this research.

No research is possible without funding. Therefore, I am very grateful to the parties who financially supported my research and conference participations: the Finnish Cancer Foundation, Finnish Nurses Education Foundation, School of Health Sciences at the University of Tampere, Finnish Association of Nursing

Research, Finnish Nurses Association and Finnish Oncology Nursing Society. I also thank the City of Tampere for the publication grant for this dissertation.

I thank my fellow doctoral students for their support and encouragement. I have enjoyed sharing our experiences in monthly seminars. I especially want to thank Dr Birgitta Lehto for empowering discussions and support over these years. I also fondly recall my times with my fellow EANS students at summer school the past three years. Furthermore, my gratitude goes to my immediate superiors for their understanding and the leaves of absence to complete my research. I thank my work colleagues who showed genuine interest in my research and took the time to listen to my problems.

Although research is sometimes lonely, one does not live alone. I express my sincerest thanks to my long-time friend Marja with whom I have shared many memorable, invigorating moments over nearly forty years. My deepest and warmest thanks go to my dearest treasures Emmi, Santtu and Olli. They are the light of my life and have ensured that my feet have remained firmly on the ground. I express my deep gratitude to my husband Harry for his support and patience over these years. I appreciate that he has taken primary responsibility for the domestic work, especially cooking. It has been the best form of emotional and tangible support for me!

Akaa 15.1.2017

Tiina Yli-Uotila

Abstract

The purpose of the study was to explore adult cancer patients' perceptions of electronic social support. Furthermore, this study looked to measure the needed and received electronic social support in the electronic counselling services (ECS) of non-profit cancer societies with an instrument developed for the study. Electronic social support is defined as consisting of the cognitive, perceptual and transactional processes of initiating, participating in and developing electronic interactions to seek beneficial outcomes, which may include improvements in patient's healthcare condition, self-perceived health or psychosocial processing ability. ECS of cancer societies included of phone, email and online chat counselling.

The study was conducted in three phases. In phase I, the purpose was to describe the current state of online social support for adult patients with cancer. Data were collected using an online survey with open-ended questions and analysed with inductive content analysis. Altogether 74 adult cancer patients participated in the study. The purpose of phase II, was to describe cancer patients' perceptions of electronic social support in ECS, the phases in the cancer trajectory when electronic social support was needed and the integration of the received electronic social support into their cancer care in public healthcare. Furthermore, the purpose was to describe facilitators and barriers for electronic social support as perceived by CNs. Twelve adult cancer patients were interviewed face-to-face or by phone and ten CNs were interviewed in three groups. In phase II, data were analysed using inductive content analysis. In phase III, the purpose was to develop and pre-test an instrument to measure the needed and received types of electronic social support from the ECS of the non-profit cancer societies. Accordingly, the instrument was based on the previous phases of the study. Furthermore, the purpose was to measure whether the received electronic social support matched the patients' needs. The NRESS instrument consisted of 38 items to be answered using a 5-point Likert scale. Within each item, the needed and received electronic social support was queried. Data from 28 eligible adult cancer patients in phase III were analysed using nonparametric statistical analysis techniques.

In phase I, the results revealed motives related to informational and emotional needs as well as to familiarity with use of information and communication

technology that drove cancer patients to use the Internet to seek social support. In addition, cancer patients perceived that online support made their life easier and empowered them, although the support received could be negative in nature as well. In phase II, the cancer patients perceived that ECS can ensure a personalised matching type of support to enhance their ability to cope with cancer but limited ECS resources may prevent this. The phases in which support from ECS was needed differed from the traditional biomedical phases of cancer care. Furthermore, ECS support compensated for the deficiencies of public cancer care under certain circumstances. The results also revealed some organisational, individual and counselling processes in ECS that either facilitated or prevented electronic social support for cancer patients. In phase III, the NRESS instrument employed consisted of four support areas, namely Network support, Informational support, Promotion of well-being and Customer service support. The content validation and internal consistency measures employed herein can be considered acceptable but the instrument needs further testing. The analysis revealed that the needed electronic social support was correlated significantly to the received electronic social support only for network support. The most needed electronic support was informational. The least needed and received electronic social support was related to the promotion of well-being. Email was the most used form of counselling, and none of the participants had used online chat counselling.

This study contributes towards enhancing understanding and awareness of the needed and received electronic social support for adult cancer patients in different phases of their cancer trajectory. The results can be used for educational purposes, to improve patient education, as well as to assist nurses in understanding the types of social support needs of cancer patients and act in accordance with them. These procedures have the potential to improve patients' well-being and, therefore, to reduce regional health inequalities.

Key words: electronic social support, adult cancer patients, electronic counselling services, counselling nurses, non-profit cancer societies.

Tiivistelmä

Tutkimuksen tarkoituksena oli tutkia aikuisten syöpään sairastuneiden käsityksiä sähköisestä sosiaalisesta tuesta. Lisäksi tutkimuksen tarkoituksena oli mitata tarvittua ja saatua sähköistä sosiaalista tukea syöpäyhdistysten sähköisistä neuvontapalveluista käyttäen tutkimusta varten kehitettyä kyselylomaketta. Sähköinen sosiaalinen tuki voidaan määritellä kognitiivisen, kokemuksellisen ja vuorovaikutuksellisen prosessin käynnistymiseksi, siihen osallistumiseksi ja sähköisten vuorovaikutusten muodostamiseksi tarkoituksena saavuttaa myönteisiä muutoksia terveydentilassa, koetussa terveydessä tai psykososiaalisessa prosessointikyvyssä. Yleisen Internetin lisäksi sähköiset neuvontapalvelut käsittivät kolmannen sektorin syöpäyhdistysten puhelin-, sähköposti- ja chat-neuvonnan.

Tutkimus koostui kolmesta vaiheesta. Tutkimuksen ensimmäisen vaiheen tarkoituksena oli kuvata aikuisten syöpään sairastuneiden sähköisen sosiaalisen tuen nykytilannetta yleisessä Internetissä. Aineisto kerättiin avoimia kysymyksiä sisältävällä verkkokyselylomakkeella. Yhteensä 74 aikuista syöpään sairastunutta osallistui tutkimukseen. Aineisto analysoitiin induktiivisella sisällön analyysillä. Tutkimuksen toisessa vaiheessa tarkoituksena oli kuvata aikuisten syöpään sairastuneiden käsityksiä sosiaalisesta tuesta sähköisissä neuvontapalveluissa, vaiheet, jolloin sähköistä sosiaalista tukea tarvittiin sekä saadun sähköisen sosiaalisen tuen integroituminen syövän hoitoon julkisessa terveydenhuollossa. Lisäksi tarkoituksena oli kuvata sähköistä sosiaalista tukea edistäviä ja ehkäiseviä tekijöitä neuvontahoitajien näkökulmasta. Kaksitoista aikuista syöpään sairastunutta haastateltiin kasvokkain tai puhelimitse ja kymmenen neuvontahoitajaa haastateltiin kolmessa eri ryhmässä. Aineistot analysoitiin sisällön analyysillä induktiivisesti. Tutkimuksen kolmannessa vaiheessa tarkoituksena oli kehittää ja esitellä mittari mittaamaan tarvittua ja saatua sähköistä sosiaalista tukea syöpäyhdistysten sähköisistä neuvontapalveluista. Mittari pohjautui tutkimuksen aikaisempiin vaiheisiin. Mittarilla tutkittiin vastaako saatu sähköinen sosiaalinen tuki sairastuneiden tarvittua tukea. Lomake sisälsi 38 väittämää, joihin vastattiin viisi-portaisella Likert-asteikolla. Jokaisen kysymyksen kohdalla kysyttiin sekä tarvittua että saatua sähköistä sosiaalista tukea. Aineisto koostui 28 tutkimuksen kriteerit täyttävästä aikuisesta syöpään sairastuneesta ja aineisto analysoitiin parametrittomilla tilastollisilla menetelmillä.

Vaiheen I tulosten mukaan tiedolliset ja emotionaaliset tuen tarpeet sekä kommunikaatio- ja informaatioteknologian tuttuus olivat tekijöitä, jotka motivoivat aikuisia syöpään sairastuneita käyttämään Internetiä sosiaalisen tuen lähteenä. Lisäksi sairastuneet kokivat, että sähköinen sosiaalinen tuki helpotti heidän elämäänsä ja voimaannutti heitä vaikka sähköinen tuki voi myös olla negatiivista. Tutkimuksen toisessa vaiheessa aikuisten syöpään sairastuneiden käsitysten mukaan sähköiset neuvontapalvelut varmistivat yksilöllisen, tarpeita vastaavan tuen saannin, joka vahvisti heidän selviytymistä syövän kanssa mutta sähköisten neuvontapalveluiden rajoittuneet resurssit saattoivat ehkäistä tätä. Vaiheet, jolloin aikuiset syöpään sairastuneet tarvitsivat tukea sähköisistä neuvontapalveluista, poikkesivat periteisestä lääketieteellisistä syövän hoidon vaiheista. Sähköisistä neuvontapalveluista saatu tuki täydensi syövän hoitoa julkisella sektorilla tietyn edellytyksin. Tulosten mukaan organisatoriset, yksilölliset ja neuvontaprosessiin liittyvät tekijät sähköisissä neuvontapalveluissa voivat joko edistää tai ehkäistä syöpään sairastuneiden sähköistä sosiaalista tukea. Tutkimuksen kolmannessa vaiheessa kehitetty strukturoitu verkkokyselylomake koostui neljästä osa-alueesta: verkostotuesta, tiedollisesta tuesta, hyvinvoinnin edistämisestä sekä asiakaspalvelun kaltaisesta tuesta. Tutkimuksen perusteella mittarin sisällön validointia ja sisäistä johdonmukaisuutta voidaan pitää hyväksyttävänä mutta mittari tarvitsee jatkokehittelyä. Tulosten perusteella tarvittu sähköinen sosiaalinen tuki oli merkitsevästi yhteydessä saatuun sähköiseen sosiaaliseen tukeen ainoastaan verkostotuen osa-alueella. Aikuiset syöpään sairastuneet tarvitsivat eniten tiedollista tukea. Eniten sähköistä sosiaalista tukea aikuiset syöpään sairastuneet saivat verkostotuen osa-alueella. Vähiten tarvittu ja saatu sähköinen sosiaalinen tuki liittyi hyvinvoinnin edistämiseen. Aikuiset syöpään sairastuneet käyttivät eniten sähköpostineuvontaa eikä kukaan ollut käyttänyt chat-neuvontaa.

Tutkimus tuottaa uutta tietoa aikuisten syöpään sairastuneiden tarvitusta ja saadusta sähköisestä sosiaalisesta tuesta syövän jatkumon eri vaiheissa. Tuloksia voidaan hyödyntää opetustarkoituksissa parantamaan potilasohjausta ja auttamaan hoitajia ymmärtämään syöpään sairastuneiden erilaisia sosiaalisen tuen tarpeita. Näiden toimien avulla voidaan parantaa potilaiden hyvinvointia ja siten vähentää alueellisia terveyseroja.

Avainsanat: sähköinen sosiaalinen tuki, aikuinen syöpään sairastunut, sähköiset neuvontapalvelut, neuvontahoitaja, kolmannen sektorin syöpäyhdistykset.

Tables in text

Table 1.	Categories of social support and examples of their definitions
Table 2.	Instruments developed to measure cancer patients' electronic social support
Table 3.	Participants' use of ECS in phase III
Table 4.	Cronbach's alpha coefficients (α) and 95% confidence intervals of alpha reliabilities
Table 5.	Items with corrected item-total correlations (ρ_{gxc}) $< .30$ in the needed and received support subscales and Cronbach's α if item deleted
Table 6.	Items in the needed support subscales that correlated better to other needed support subscales than their own
Table 7.	Items in the received support subscales that correlated better to other received support subscales than their own
Table 8.	Correlations between needed and received electronic social support
Table 9.	Description of and differences between needed and received electronic social support at item level
Table 10.	Statistically significant relationships between summated scales of NRESS and background variables

Figures in text

- Figure 1. Theory of online social support (LaCoursiere, 2001, p. 63). The figure has been reprinted with the permission of the respective copyright holder.
- Figure 2. Starting points of the study
- Figure 3. Study process
- Figure 4. Summary of main results

List of appendices

- Appendix 1. Studies measuring adult cancer patients' electronic social support
- Appendix 2. Data collection sites in phase III
- Appendix 3. NRESS instrument and background variables
- Appendix 4. Content validity indices
- Appendix 5. Participants in phase III

List of abbreviations

ECS	Electronic counselling services
CN(s)	Counselling nurse(s)
CSF	Cancer Society of Finland
HINTS	Health Information National Trends Survey
QOUCSG	Questions on the Use of Internet Cancer Support Groups
MOS-SSS	Medical Outcomes Study Social Support Survey
IPRI	Interpersonal Relationship Inventory
ISEL	Interpersonal Support Evaluation List
MMR	Mixed methods research
NRESS	Needed and Received Electronic Social Support
OSS	Online social support
S-CVI/Ave	Scale level content validity index using averaging calculation method
I-CVI	Item level content validity index
SD	Standard deviation
Md	Median
Q ₁	Lower quartile
Q ₃	Upper quartile
r	Pearson's product-moment correlation coefficient
r _s	Spearman rank order correlation coefficient
α	Cronbach's alpha coefficient
Sig.	Significance
ρ_{gxc}	Corrected item-total correlation
NS	Network support
IS	Informational support
PW	Promotion of well-being
CS	Customer service support
ICT	Information and communication technology

List of original publications

This thesis is based on the following original articles, which are referred to in the text by their Roman numerals, I-V.

- I Yli-Uotila T, Rantanen A & Suominen T. 2013. Motives of cancer patients for using the Internet to seek social support. *European Journal of Cancer Care* 22(2), 261–271. Doi: 10.1111/ecc. 12025.
- II Yli-Uotila T, Rantanen A & Suominen T. 2014. Online social support received by patients with cancer. *CIN: Computers, Informatics, Nursing* 32(3), 118–126. Doi: 10.1097/CIN.0000000000000028.
- III Yli-Uotila T, Kaunonen M, Pylkkänen L & Suominen T. Cancer patients' perception of social support in electronic counselling services. *Submitted*.
- IV Yli-Uotila T, Kaunonen M, Pylkkänen L & Suominen T. 2016. The need for social support provided by the non-profit cancer societies throughout different phases in the cancer trajectory and its integration into public healthcare. *European Journal of Oncology Nursing* 21, 97–104. Doi: 10.1016/j.ejon.2016.02.004
- V Yli-Uotila T, Kaunonen M, Pylkkänen L & Suominen T. 2015. Facilitators and barriers for electronic social support. *Scandinavian Journal of Caring Sciences* 30(3), 547–556. Doi: 0.1111/scs.12277.

The articles have been reprinted with the permissions of the respective copyright holders. Article III is not included in the dissertation because it has not been accepted for publication yet. In addition, some unpublished data are presented.

Contents

Acknowledgements

Tables in text

Figures in text

List of appendices

List of abbreviations

List of original publications

1	Introduction	21
2	Starting points of study	24
2.1	Patients’ perceptions of cancer and its treatments	24
2.2	Electronic social support for adult cancer patients	27
2.2.1	Defining social support	27
2.2.2	Electronic social support.....	31
2.2.3	Electronic social support mediums	36
2.2.4	Needed and received electronic social support	39
2.2.5	Measurement of electronic social support.....	41
2.3	Summary of the starting points.....	45

3	Purpose and aims of study.....	47
4	Empirical implementation of study.....	48
4.1	Methodological basis	48
4.2	Development of NRESS instrument.....	49
4.3	Samples and data collection.....	51
4.3.1	Online survey with open-ended questions (phase I)	51
4.3.2	Individual and group interviews (phase II)	52
4.3.3	Structured online survey (phase III)	53
4.4	Data analysis	53
4.4.1	Inductive content analysis (phases I and II).....	54
4.4.2	Statistical analysis (phase III).....	54
5	Results.....	57
5.1	Participants.....	57
5.2	Current state of online social support for patients with cancer (phase I).....	59
5.3	Adult cancer patients' and CNs' perceptions of electronic social support (phase II)	60
5.4	Pre-test of NRESS instrument (phase III).....	63
5.4.1	Instrument validity	63
5.4.2	Instrument reliability.....	63

5.5	Needed and received electronic social support for adult cancer patients (phase III).....	67
5.6	Summary of main results	77
6	Discussion	80
6.1	Ethical considerations	80
6.2	Inference quality and inference transferability	81
6.2.1	Inference quality	81
6.2.2	Inference transferability.....	85
6.3	Discussion of results.....	86
6.4	Importance of the study.....	91
6.5	Conclusions.....	92
6.6	Implications for further research.....	93
7	References	95
Appendices		
Original publications		

1 Introduction

Every third person is affected with or will be affected by cancer at some point in their lifetime (Finnish Cancer Registry, 2013). In Finland, a total of 32 311 new cancers were diagnosed in 2014, and the proportion of diagnosed men was slightly higher than that of diagnosed women. Prostate cancer and breast cancer were the most common cancers among men and women, respectively (Finnish Cancer Registry, 2016). There is no precise definition of neoplastic diseases, but as a rule of thumb, a tumour refers to abnormal growth of a tissue. The growth of malignant tumours is faster than that of benign tumours, and they can also spread to the other parts of the body, often resulting in the death of the patient. (Isola & Kallioniemi, 2013) To date, there are national Current Care Guidelines for five cancers. These guidelines are independent, evidence-based clinical practice guidelines for medical treatment of cancers. However, thus far, the psychosocial aspects of cancer care have not been included in the guidelines. (Current Care Guidelines, 2014)

Cancer patients may need support in addition to that from family and healthcare professionals. The demand for support as a natural part of cancer care is justified (Loscalzo et al., 2013; National Institution for Health and Welfare, 2014) because social support has been found to be beneficial for cancer patients' health and well-being (Heinze et al., 2015; Hughes et al., 2014; Leino, 2011; Mattila, 2011; Salonen, 2011; Thoits, 2011; Uchino, 2006). Although a multifaceted concept, social support simply refers to positive interaction or helpful behaviour provided to persons who need support (Hupcey, 1998). Disenchantment with healthcare relationships (e.g. King et al., 2015) may drive cancer patients to seek additional social support from electronic sources (Andersen & Ruland, 2009; Dickerson et al., 2011). Furthermore, shorter follow-up times in cancer care and the aim to transfer patients to the outpatient clinics at an earlier stage may result in patients turning to cancer societies (Mäklin & Rissanen, 2006). Most often social support is offered by significant others to whom the person is emotionally tied or by secondary groups, which tend to be larger, and offer more formal interaction, where the persons offering and receiving support have less personal knowledge about each other. Non-profit organisations can be considered to belong to the secondary group. (Thoits, 2011) Although cancer patients value peer support (Farrelly et al., 2015; Power & Hegarty, 2010; Stickel et

al., 2015; Wong et al., 2014), they especially prefer informational support from healthcare professionals (Devitt et al., 2010; Holt et al., 2014; Koutsopoulou et al., 2010; Li et al., 2011; Pedersen et al., 2013) as well as emotional and tangible support (Hill, 2015; Merluzzi et al., 2015).

Cancer patients can turn to the non-profit Cancer Society of Finland (CSF) when need. CSF, which consists of 12 regional cancer societies and six national patient organisations, is one of the largest patient and public health organisations nationally and aims to ensure a high quality of life for people in Finland, both with and without cancer. In cancer societies, health care professionals (e.g. CNs) with specialised knowledge of cancer provide support and information on health promotion and cancer prevention, early detection, symptoms and identification, treatment, recovery and rehabilitation. In addition to personal meetings, support is delivered through electronic counselling services, including phone calls, email and online chat forums. (Cancer Society of Finland, 2016)

Face-to-face communication is a salient source of social support, but it may neglect the fact that social support can be offered through a variety of communication modalities, and electronic social support may even be preferred under some circumstances (Wright et al., 2011), for example, when dealing with taboo topics, such as dying and death (Taubert et al., 2014). Electronic communication enables cancer patients and healthcare professionals to communicate in a novel way and, preferably, at the right time with the right support (Kreps & Neuhauser, 2010; Wright et al., 2011). However, it is noteworthy that, despite the need for support, the mere provision of support does not predict positive outcomes in all cases. Under this mismatched condition, that is, the received support does not meet the needs of the recipient, there may be processes that are not optimal for a cancer patient to benefit from the support provided (Merluzzi et al., 2015).

Along with the increasing number of cancer survivors (Finnish Cancer Registry, 2016; Popat et al., 2013), the costs of cancer care are high (estimated to be 1.5 billion euros by 2020 in Finland) (National Institution for Health and Welfare, 2014). In addition to the healthcare costs (Han et al., 2015; National Institution for Health and Welfare, 2014; Skolarus et al., 2012; Tipsmark et al., 2015), productivity costs (Hanly et al., 2015a; Hanly et al., 2015b; National Institution for Health and Welfare, 2014) and out-of-pocket costs (Azzani et al., 2015; Isshiki, 2014), there are psychosocial costs, which are difficult to transfer into monetary terms, such as decreased quality of life and its consequences (Callahan & Brintzenhofesoc, 2015; Mäklin & Rissanen, 2006). However, psychosocial interventions for cancer patients have been proved to be less expensive than ‘standard care’ (Arving et al., 2014; Gordon et al., 2011;

Mewes et al., 2015), especially if delivered using electronic devices (Belkora et al., 2012; Gordon et al., 2015; Harrison et al., 2014).

To date, hardly any studies have addressed both the needed and received social support when using electronic mediums with healthcare professionals. Often, studies address cancer patients' or survivors' certain unmet needs or needs or how these needs are met (e.g. Geller et al., 2014; Maguire et al., 2015; Majumder et al., 2014; Paterson et al., 2015; Valero-Aguilera et al., 2014) but attempts to address these matters together in one study are rare. These studies implicitly include different types of social support (e.g. emotional support) but they are not expressed explicitly as social support needs. In addition, studies regarding different types of social support, such as, information and satisfaction with the received information most often result in unclear results, depending on where, when and what type of information is desired (e.g. Bergenmar et al., 2014; Braybrooke et al., 2015; Kullberg et al., 2015), which does not serve the needs of those treating and caring for cancer patients. Furthermore, the instruments developed to measure electronic social support rarely focus on the types of social support. Therefore, the purpose of the present study was to explore adult cancer patients' perception of electronic social support. Furthermore, the purpose was to develop and pre-test an instrument to measure the needed and received electronic social support from the ECS of non-profit cancer societies.

2 Starting points of study

The starting points of the present study (excluding chapter 2.2.4) were based on the results of annual literature searches between 2010 and 2016. Medline (Ovid), Pubmed, CINAHL, PsycINFO, Communication & Mass Media Complete and Medic databases were searched. The searches criteria were articles in the English or Finnish (Medic) language, abstract and full text accessibility and between the years 2010 and 2016. Older research literature was included in some cases. Additionally, manual search was performed. The following search terms were used, both individually and in various combinations (also in Finnish in the Medic database): cancer, cancer patient, neoplasms, cancer care, cancer treatment, cancer trajectory, cancer continuum, perception, social support, support, help, supportive services, informational support, emotional support, tangible or material or instrumental support, spiritual support, needs, unmet needs, formal support, informal support, Internet, www, World Wide Web, online, electronic, phone, telephone, mobile, cell phone, helplines, email, electronic mail, chat, synchronous, real-time, non-profit, organisation, cancer associations, patient advocacy, cancer advocacy, counselling, counselling nurse, counselling services, communication, interaction.

Based on the search results, the titles of articles were reviewed first to identify relevant sources. Next, the abstracts of the selected articles were assessed and finally, articles were selected based on their full-text relevancy. (Burns & Grove, 2005)

2.1 Patients' perceptions of cancer and its treatments

Cancer patients face many physical and psychological consequences due to their cancer and its treatment. Physical symptoms are frequently related to pain and fatigue but other physical symptoms exist depending on the cancer type and treatment. Cancer and cancer treatment also have impacts on patients' psychological well-being, including distress, depression, decreased quality of life and fear of the recurrence of cancer. Cancer and cancer treatment are family affairs, affecting not only patients but also their families. As well, sociodemographic factors influence how cancer

patients perceive their symptoms. These perceptions are discussed in the following paragraphs.

Different types of cancers and their treatments may cause pain (Brant et al., 2011; Genc & Tan, 2011; Hall et al., 2014; Matthews et al., 2012; 2014; Reichardt et al., 2012; Soltow et al., 2010; Sun et al., 2012; Trudel-Fitzgerald et al., 2013; Wu et al., 2013; Zucca et al., 2012). Pain has been associated significantly with the age of a cancer patient. Younger cancer patients experience pain more strongly than do older patients (Moye et al., 2014; Soltow et al., 2010), whose experience of the severity of pain varies (Soltow et al., 2010). Moreover, comorbidities impact the pain experienced by increasing its severity (Soltow et al., 2010; Walling et al., 2015). Pain relief in cancer care can be unmitigated, and inadequate analgesia may impact patients' daily living and functioning (Moye et al., 2014; Wu et al., 2013).

In addition to pain, cancer patients may suffer from fatigue (Brant et al., 2011; Genc & Tan, 2011; Hall et al., 2014; Matthews et al., 2012; Sun et al., 2012; Trudel-Fitzgerald et al., 2013; Yanez et al., 2013; Zucca et al., 2012), which is a common symptom and they may be clustered together (Matthews et al., 2012; Zucca et al., 2012). Studies have showed that fatigue is prevalent throughout the cancer trajectory (Peters et al., 2014; Sun et al., 2012). The failure to treat pain and fatigue is not always a result of lacking medical treatment. Instead, patient-related barriers, such as fear of addiction, tolerance to opioids or knowledge deficits on these issues may be at play. Moreover, the belief that fatigue is an inevitable part of cancer and its treatment may be a barrier to providing optimal symptom relief. (Sun et al., 2012) One barrier to treat these symptoms is that patients may not report their altered health issues to healthcare professionals or may do so in a limited manner (Cooney et al., 2015).

Other physical symptoms related to cancers include digestive tract symptoms (Lehto et al., 2013; Matthews et al., 2012) such as nausea (Yanez et al., 2013; Zucca et al., 2012), constipation, diarrhoea and vomiting (Zucca et al., 2012), dysphagia (Rogus-Pulia et al., 2014); menopausal symptoms such as dryness and hot flashes (Waldrop et al., 2011); symptoms related to the bladder (Lehto et al., 2013) such as urinary tract infections and urine incontinence (Drageset et al., 2014; Pieterse et al., 2013); symptoms related to sexual function (Lehto et al., 2013) such as narrow/short vagina (Pieterse et al., 2013); neurological symptoms such as numbness (Waldrop et al., 2011); respiratory symptoms such as dyspnoea/shortness of breath (Reichardt et al., 2012; Walling et al., 2015; Zucca et al., 2012) and cough (Reichardt et al., 2012; Walling et al., 2015) and sleep disturbances (Brant et al., 2011) such as changes in sleep duration (Alfano et al., 2011) and insomnia (Hall et al., 2014; Trudel-Fitzgerald et al., 2013; Zucca et al., 2012) .

Patients with cancer may also suffer from psychological symptoms such as distress and depression. Distress is common amongst cancer patients, but it is often heterogeneous. Dunn and colleagues (2013) found four distinct distress continua in the cancer trajectory of colon cancer patients. Distress either stayed low during the entire continuum, decreased from the baseline but increased later, increased steadily from the baseline or decreased gradually from the high baseline during the continuum (Dunn et al., 2013). Others have also reported such heterogeneity of distress: during treatment, approximately every third breast cancer patient was distressed, but only a minority of patients became or remained distressed after the end of treatment (Henselmans et al., 2010). The extent of distress is related to the type of cancer and its treatments (Trudel-Fitzgerald et al., 2013), as well as to physical complaints and personal factors such as lack of optimism (Henselmans et al., 2010; Zhang et al., 2015), lower sense of mastery and neuroticism (Henselmans et al., 2010).

Depression is associated with cancer and its treatments, especially if patients suffer from pain as well. Clustered together, depression and pain may lead to disability, unemployment, poorer quality of life as well as to increased and untargeted use of health care services (Kroenke et al., 2010). The trajectory of depression differs between men and women: men's trajectory is convex, whereas women's trajectory is concave (Brant et al., 2011). In addition to gender, age impacts the prevalence of depression among cancer patients. Younger cancer patients tend to be more depressed than older patients. Moreover, depressed patients have greater number of physical and psychological symptoms (Mystakidou et al., 2013)

Cancer and its treatments decrease patients' quality of life (Huang et al., 2013; Kroenke et al., 2010; Lowery et al., 2014; Simard et al., 2013; So et al., 2013). Especially, health-related quality of life decreases when symptom burden increases (Lowery et al., 2014). The level of quality of life has been shown to vary during the cancer trajectory. Understandably, patients with metastatic cancers and patients in palliative cancer care have poorer quality of life than patients with localised cancers (Reichardt et al., 2012; Torvinen et al., 2013). In addition to the symptom burden and the phase of disease, pain and depression, especially if clustered, decrease quality of life (Kroenke et al., 2010). Furthermore, financial difficulties have found to be related to poorer health-related quality of life (Torvinen et al., 2013). Financial burden as a result of cancer has been identified as one of the most prevalent unmet need (Hall et al., 2015).

Cancer patients often worry about the impacts of cancer on their families (Ezer et al., 2012; Waldrop et al., 2011). The evidence shows that only few family members

are at risk for psychological morbidity (the loss of a child is an exception) but women are at risk of experiencing distress (Hagedoorn et al., 2011). Cancer patients fear the recurrence of cancer (Kanatas et al., 2015; Simard et al., 2013; Waldrop et al., 2011). Although, the fear of recurrence stays rather stable in the survivorship phase, younger age, the presence and severity of physical symptoms, psychological distress and poorer quality of life increase the fear of cancer recurrence (Simard et al., 2013).

Sociodemographic factors impact the manner in which cancer patients perceive their symptoms. For instance, greater income, higher education and religiosity increase positive emotions (Hall et al., 2014) and decrease insomnia (Brant et al., 2011; Hall et al., 2014). Furthermore, women, younger patients, unmarried patients, less educated patients and patients with lower incomes report greater symptom prevalence (Walling et al., 2015).

Cancer patients may not always perceive serious adverse effects, and cancer and its intrusiveness in everyday life may remain fairly stable regardless of how much the disease interferes with everyday life (Henselmans et al., 2010; Sohl et al., 2014). In addition, researchers have obtained positive results in patients' physical recovery over the long term (e.g. Zucca et al., 2012).

2.2 Electronic social support for adult cancer patients

2.2.1 Defining social support

Social support has been defined in many ways. The majority of the definitions are from the 1970s and 1980s. Before the mid-1970s, social support was used in a concrete sense to describe a person, relationship or transaction. After that period of time, it transformed from a concrete term to an abstract construct referring to a construed characteristic or function of social relationships or transactions, as opposed to observable relationships or transactions themselves. (Veiel & Baumann, 1992) The term social support is used in a broad sense, referring to mechanisms through which social relationships promote health and well-being or protect people from the damaging effects of stress (Andrews et al., 1978; Cohen et al., 2000; Cohen & Wills, 1985). In most cases, social support is defined as the resources provided by other people. Resources refer to potentially useful information or things, which may impact health or well-being positively or negatively. (Cohen & Syme, 1985) It has been stated that social support acts only as a resistance factor, which means that

support reduces or buffers the adverse impacts of exposure to negative life events but support has no direct effects on psychological symptoms when stressful circumstances are absent (i.e. buffering-only view of social support) (Cohen & Syme, 1985; Goldsmith, 2004; Thoits, 1985). By contrast, the lack of social support and changes in it over time are stressors in themselves and, as such, ought to have direct effects on psychological symptomatology, regardless of the occurrence/presence of stressful circumstances (i.e. main/direct-effect view of social support) (Cohen & Syme, 1985; Thoits, 1985).

The theoretical definitions of social support can be placed into five categories (Hupcey, 1998): the type of social support provided (Antonucci & Jackson, 1990; Cobb, 1976; Cohen et al., 1985; Jacobson, 1986), which is the focus of the present study and is described in detail in the next paragraph; recipients' perception of support (Heller et al., 1986; Procidano & Heller, 1983); intentions or behaviours of providers (Shumaker & Brownell, 1984; Thoits, 1985); reciprocal support (Antonucci, 1985; Shumaker & Brownell, 1984; Vaux, 1992) and social networks (Lin et al., 1979; Thoits, 1992) (Table 1). Four other categories are briefly described after the types of support.

Types of support are associated with theories of stress, according to which stress can be defined in terms of unmet needs or the absence of social relationships through which support may be provided. Therefore, social support is defined in terms of "resources that meet the needs, social relationships through which an individual's needs are met, or both". (Jacobson, 1986, p. 252)

The type of support is important for understanding the buffering effect of social support. The buffering effect of social support occurs when the type of support matches the needs corresponding to the stress a person is experiencing (Cohen & McKay, 1984; Wilcox & Vernberg, 1985). The types of support may be seen as a functional aspect of social relationships (House & Kahn, 1985). There are several distinct types of support, and commonly recognised types include emotional support (e.g. expressions of caring, empathy, reassurance of worth), informational or cognitive support (e.g. information, advice, new perspectives on a problem) and tangible/material/instrumental support (e.g. financial support, offers of goods and services) (Cobb, 1979; Cohen & Syme, 1985; Goldsmith, 2004; Jacobson, 1986; Wilcox & Vernberg, 1985). Furthermore, individuals' religious beliefs (e.g. reading the Bible and praying) have been found to influence the need for spiritual social support (Wesselmann et al., 2015). Appraisal support (providing new perspectives on a problem), in some schemes, may be differentiated from other kinds of informational support, and esteem support (giving reassurance of worth) may be

separated from emotional support. In some taxonomies, opportunities for socialising or belonging to a group can be seen as network support. (Goldsmith, 2004) Additionally, opportunities to provide nurturance (individuals' need to feel needed by others) (Robinson & Tian, 2009; Weiss, 1974) and active support (the receipt of care by target persons) (Cobb, 1979) have been described as types of social support. It should be noted that these types of support may overlap considerably and that no taxonomy includes all of the above types (Cutrona & Russell, 1990; Wortman, 1984). Only when relationships provide appropriate forms of support, will they reduce distress and influence health outcomes (Wortman, 1984).

Cancer patients need informational support on issues such as information concerning cancer and its treatments (Holt et al., 2014; Li et al., 2011; Morrison et al., 2012; So et al., 2013). Emotional support is needed, for example, to cope with the emotional distress caused by the disease (Patterson et al., 2012; Preyde et al., 2010). As a common type of support, tangible support such as support for activities in daily living (Griesser et al., 2011; Wong et al., 2014), and financial support (Wong et al., 2014), as well as support for role functioning (Ernst et al., 2013; Hirschman & Bourjolly, 2005), have been reported. In addition to the type of support, it is necessary to consider the temporal dimensions of support because support unfolds over time (Jacobson, 1986; Tilden, 1986). It has also been shown that variation in the amount and type of support required is age-related (Vivar & McQueen, 2005).

Family and friends (informal support) are often identified as sources of social support called the recipient's natural network. Some scholars argue that the recipient's natural network is a unique aspect of social support and that the support provided by professionals (formal support) does not constitute social support. (Hupcey & Morse, 1997) However, others define social support more broadly and either include professionals and the community as sources of social support or do not specify the relationship between the provider and recipient (Dunkel-Schetter & Skokan, 1990; Norbeck, 1988). Studies that report on the recipient's support outcomes favour informal support (Guidry et al., 1997; Shiba et al., 2016). In the present study, the characteristics of the support provided by non-profit ECS (e.g. types of services provided and duration of the relationship) lie somewhere between informal social support and formal professional support and so are considered to be sources of social support. Furthermore, the theory of online social support (described in detail later) does not preclude interactions with healthcare providers (LaCoursiere, 2001).

Table 1. Categories of social support and examples of their definitions

Category of social support (Hupcey, 1998)	Examples of theoretical definitions of social support
Types of support provided	<p><i>"Social support may be defined in terms of resources that meet the needs, social relationships through which an individual's needs are met, or both"</i> (Jacobson, 1986, p. 252).</p> <p><i>"The resources that are provided by other persons"</i> (Cohen et al., 1985, p. 75).</p> <p><i>"Social support is information leading a person to believe that (s)he is cared for and loved, esteemed and valued, and/or that (s)he belongs to a network of communication and mutual obligation"</i> (Cobb, 1976, p. 300).</p> <p><i>"Social support is defined as interpersonal transactions that include one or more of the following: affect, affirmation, and aid"</i> (Antonucci & Jackson, 1990, p. 175).</p>
Recipients' perception of support	<p><i>"Social support is defined as the extent to which an individual believes that her/his needs for support are fulfilled"</i> (Procidano & Heller, 1983, p. 2).</p> <p><i>"A social activity involves social support if it is perceived by the recipient of that activity as esteem enhancing or if it involves the provision of stress-related interpersonal aid"</i> (Heller et al., 1986, p. 467).</p>
Intentions or behaviours of the provider	<p><i>"Social support is an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient"</i> (Shumaker & Brownell, 1984, p. 13).</p> <p><i>"Social support most commonly refers to helpful functions performed for an individual by significant others such as family members, friends, co-workers, relatives and neighbours"</i> (Thoits 1985, p. 53).</p>
Reciprocal support	<p><i>"The actual giving, receiving and exchange of support is commonly referred to as the function of social support"</i> (Antonucci, 1985, p. 25).</p> <p><i>"Social support refers to a complex and dynamic process involving transactions between individuals and their social networks within a social ecology"</i> (Vaux, 1992, p.194).</p> <p><i>"Social support is an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient"</i> (Shumaker & Brownell, 1984, p. 13).</p>
Social networks	<p><i>"Social support may be defined as support accessible to an individual through social ties to other individuals, groups, and the larger community"</i> (Lin et al., 1979, p. 109).</p> <p><i>"Social network generally refer to people's ties to one another, in particular to the structure of those ties"</i> (Thoits, 1992, p. 57).</p>

The second category of theoretical definitions of social support presented by Hupcey (1989) consists of the recipients' perceptions of support, which refers to the impacts that networks have on individuals. When networks provide support, perceived social support is defined as the extent to which individuals believe that the support fulfils

their needs (Procidano & Heller, 1983). Social support encompasses objective and subjective elements, and both must be addressed to gain a complete understanding of social support (Vaux, 1988).

The third category is the intentions or behaviours of the provider (Hupcey, 1998). Shumaker and Brownell (1984, p. 13) define social support as ‘an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient’. However, the provider’s intentions or behaviours might not always produce positive results. For example, problem-avoiding support from significant others can undermine psychological adjustment to cancer (Shiozaki et al., 2011).

The fourth category is related to reciprocity, or the exchange of resources between the recipient and the provider (Hupcey, 1998). This giving, receiving and exchanging of support is considered to a function of social support (Antonucci, 1985). Equal exchange or reciprocity is optimal (Antonucci & Jackson, 1990). Asymmetrical exchanges between the provider and the recipient, regardless of the direction of the asymmetry, lead to negative outcomes (Rook, 1987) and can cause stress and feelings of inadequacy in the recipient (Hupcey, 1998).

The final category consists of social networks (Hupcey, 1998), defined as the support available to individuals through social ties to others (Lin et al., 1979). Social networks can be measured through structures, such as size, density, reciprocity, durability, intensity, frequency and homogeneity (Berkman et al., 2000; House & Kahn, 1985). Structural measures are considered to indicate the objective characteristics of social networks and provide information about the properties of networks (Cohen & Syme, 1985).

2.2.2 Electronic social support

Electronic social support is defined according to the theory of online social support and therefore, it is defined as the cognitive, perceptual and transactional processes of initiating, participating in and developing electronic interactions to seek beneficial outcomes, which may include improvements in patients’ healthcare conditions, self-perceived health and psychosocial processing ability. According to the theory, electronic social support is a dynamic process that incorporates all components of traditional social support in a virtual setting. (LaCoursiere, 2001) In this study, the virtual setting is called online setting and it included the general Internet, email and online chat counselling through which social support is mediated. Phone counselling

is considered a part of online social support and, therefore, the term ‘electronic social support’ is used to refer online social support, including phone counselling. Phone counselling is included because older cancer patients (>65 years) display increased reluctance to use the Internet and electronic devices in order to exchange health-related information (Saied et al., 2014).

Online social support theory was chosen as a framework for the study because it presents a holistic conceptualisation of electronic social support, in which the process of support is described by interpersonal relationships with persons who are unknown and unseen to each other (LaCoursiere, 2001). This study adopts the same aspects of the nursing metaparadigm as does the online social support theory (LaCoursiere, 2001). Therefore, *health* can be considered a dynamic process that fluctuates over time, including both acute and chronic aspects and alterations in health status and perceived health. The *person* is an individual seeking electronic social support and engaging in health-seeking behaviour. *Nursing* includes thoughts and behaviours of the counselling nurse (CN) engaged in electronic social support activities and mediating social support through electronic communication devices (phone and computer). The *environment* is electronic, and it includes the general Internet, phone, email and online chat counselling by non-profit cancer societies. The main characteristic of the electronic environment is the lack of face-to-face contact. (LaCoursiere, 2001)

Parts of online social support theory (Figure 1, oval black circles) are used as a framework in the present study. The theory encompasses two focal concepts, namely, online social support and linking, and it is divided into four sections, namely, initiating events, mediating factors, online social support and outcomes (LaCoursiere, 2001). In this study, the sections initiating events, mediating factors and qualitative outcomes through evaluative functions in transactional filter in the process of online social support were used to guide the research.

Online social support, as defined above, can be depicted as a trajectory, including the positive feedback phenomenon. This means that positive supportive experiences increase positive outcomes and provide impetus to seek support when there are alterations in health status. Online social support occurs through three filters: perceptual filter (the feeling or emotional state of the individual seeking support online), cognitive filter (intellectual processing of information) and transactional filter, through which all information received from electronic support interchanges are evaluated and processed for personal relevance. The second focal concept **linking** is defined as the conscious and/or unconscious process of relating and weaving emerging awareness to previously learned thoughts or information, it is

the final outcome of online social support and it cannot be measured directly. (LaCoursiere, 2001)

The four sections of the online social support theory begin with **I) the initiating events**. These events, typically, alterations in health status or in perceived health, may occur on an acute or a chronic basis. Initiating events are influenced by **II) mediating factors**, which include the following: (1) health factors, (2) demographic factors, (3) perceived individual factors and (4) Internet use factors (and the use of ECS in the present study). Initiating events and mediating factors cause the individual to seek electronic social support. Another section of the theory is **III) online social support**, as defined above. The last section of the theory comprises **IV) outcomes**, both quantitative and qualitative. (LaCoursiere, 2001)

Quantitative outcomes occur at the perceptual level (as a result of support mediation) and at the cognitive level (as a result of information processing). These are testable measures and they may be related to health status (e.g. functional status and quality of life), perceived health (e.g. valuing of support, hope and empowerment) and psychosocial processing ability (e.g. decreased stress, depression, anxiety and increased coping). Quantitative outcomes may be either positive or negative, and they create changes in behaviours, thoughts, feelings and actions and cause the individual to engage in linking behaviour. (LaCoursiere, 2001)

Qualitative outcomes occur as a result of the evaluative function of electronic social support, and they occur in cyberspace (in ECS in the present study) or as a result of transactions in cyberspace. The term 'cyberspace' is used in the theory instead of 'online' to differentiate the primarily qualitative aspect of online encounters and to describe the electronic environment. Qualitative outcomes are influenced by quantitative, phenomenological and ethnographic mediating factors, which influence how individuals perceive interactions in cyberspace (e.g. number and type of conversational interchanges and their content; explicit and implicit meanings of messages and information relevance). Using, for example, content analysis to analyse electronic transactions, not only the outcomes of support but also the findings related to the process involved can be provided. In cyberspace and electronic environments, the conversational exchanges follow a continuum starting with awareness of the interaction. Awareness, which refers to what is known to the self and others, can be open, closed, hidden or blind. Awareness of the interaction (the psychological perspective) mediates the participants' ability to engage in effective interactions, which, in turn, influences the multiple transactions level (the sociological/communication perspective). At the multiple transactions level, many simultaneous interchanges can occur, for example between nurses and patients,

giving rise to relevancy development and need differentiation. In relevancy development, the individual decides, which transactions have personal meanings. New meanings can be found, or meanings once considered to be important might no longer be perceived as relevant. In need differentiation, basic and secondary needs are refined as a result of relevancy development. Based on these processes, the individual engages in further cognitive, perceptual and transactional filtering shifting to the network (Web) formation/expert development level (the anthropological perspective). At this level, further need differentiation occurs, and networks and networks of networks are developed. (LaCoursiere, 2001)

Network (Web) formation/expert development leads to embeddedness, which is characterised by the process of engagement (new users continue to return, for example, to ECS), adoption (after repeated interactions, a belief in the power of electronic social support is developed) and diffusion (the individual transmits the belief in the power of electronic social support to others). These qualitative and quantitative outcomes produce the final outcome of the electronic social support, **linking**, which is the synthesis of an individual's experiences. If the case of inconsistency between quantitative and qualitative outcomes, linking is not supported, and impetus to further seek electronic social support might be absent. (LaCoursiere, 2001)

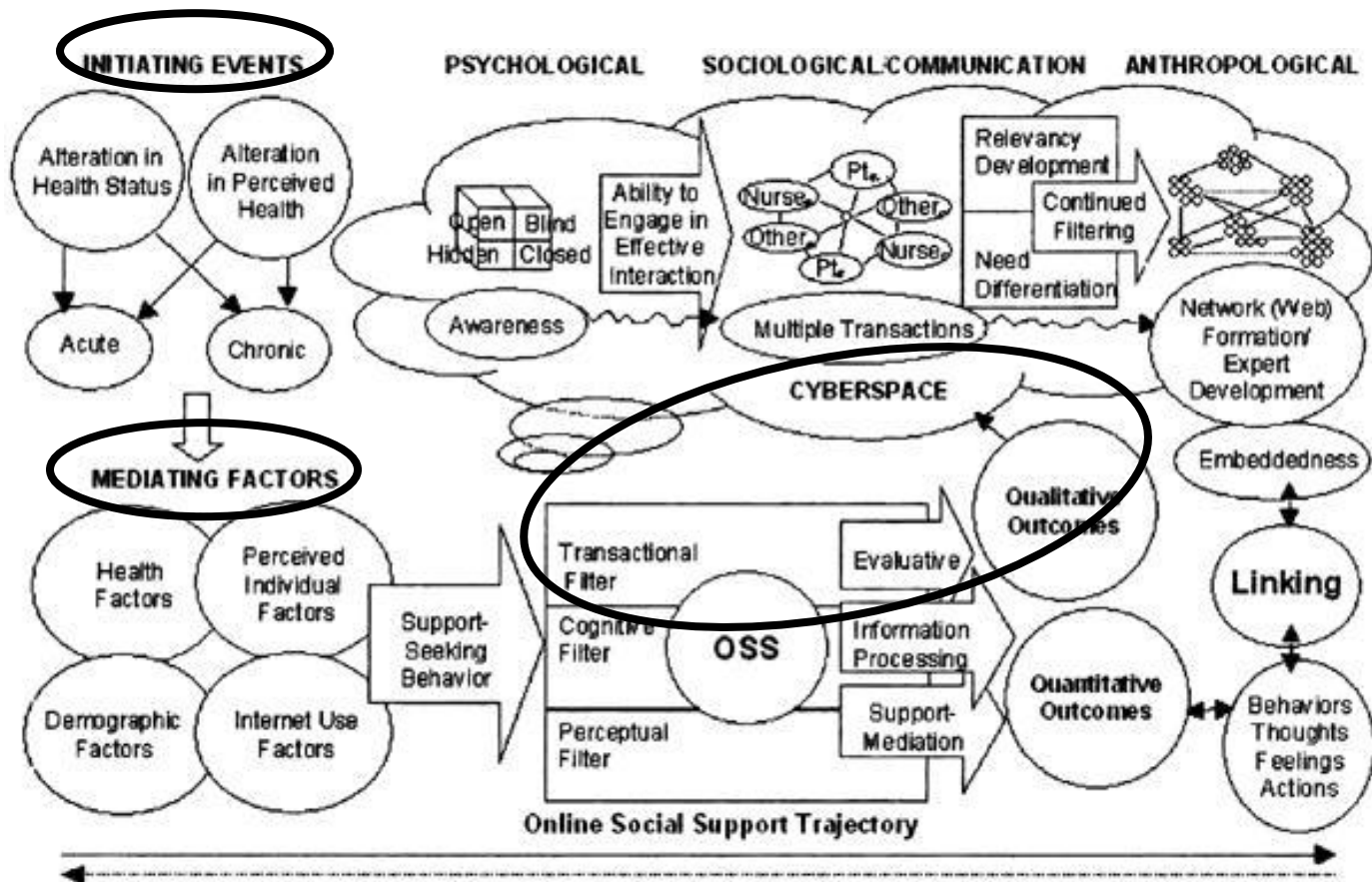


Figure 1. Theory of online social support (LaCoursiere, 2001, p. 63). The figure has been reprinted with the permission of the respective copyright holder.

2.2.3 Electronic social support mediums

Electronic social support can be obtained through the general Internet, as well as through electronic mediums, namely, phone, email and online chat. Studies related to phone, email and online chat provide information on their users, outcomes of use and how the users (recipients and providers) perceived these media.

Cancer patients who use the **Internet** to find cancer-related information are typically female, younger and well-educated (Blanch-Hartigan & Viswanath, 2015; Ludgate et al., 2011; Valero-Aguilera et al., 2014). The Internet is one source (Shea-Budgell et al., 2014) for seeking information, but it may not be the most trusted source (Balka et al., 2010; Bender et al., 2012), although most sites on which such information is available belong to professionally led non-profit cancer organisations (Alba-Ruiz et al., 2013). The reliability of information increases if it is endorsed by a professional body (Maddock et al., 2011), and nurses should guide their patients to reliable information sources (King et al., 2015; Nagler et al., 2010). Additionally, eHealth applications that monitor symptoms, offer personalised advice and tailored support have potential advantages for cancer patients, as well as for care providers (Lubberding et al., 2015).

The factors that influence the use of online cancer support groups are related to disease, background, culture, needs (Im, 2011) and Internet use (Im, 2011; Xu et al., 2014). The factors also include family environment (Yoo et al., 2014). Although these factors are presented as factors that influence participation in online support groups, some studies have found no associations among demographics, medical history, health status, psychological status and the intention to participate, for example, Xu et al. (2014). The outcomes of the use of online support interventions are mainly positive, but they are inconclusive in terms of online experiences and measures of different aspects of psychosocial well-being, such as quality of life (Hong et al., 2012; McAlpine et al., 2015). In addition, many interventions delivered via the Internet have yielded positive outcomes such as increased self-efficacy (Becker et al., 2013; Leykin et al., 2012), increased empowerment, improved physical activity (Kuijpers et al., 2013) and symptom management (Chan et al., 2014; Kuijpers et al., 2013). The reasons why some patients use Internet-based interventions minimally are related to connections with other in a similar situation, for example, difficulties in relating to others, wanting higher level of group interaction and communication, and cancer-

related issues. Moreover, problems related to individual expectations about a site, such as wanting greater facilitation and disliking online communication, and problems with sites (e.g. time commitment and problems with questionnaires) have been reported. (Gorlick et al., 2014)

The phone as a medium of electronic social support is well-accepted and useful means of communication (Ekberg et al., 2014; Ieropoli et al., 2011; Reid & Porter, 2011), especially in rural areas (Corboy et al., 2014) and in unique populations such as male breast cancer patients (Farrell et al., 2014). It can also be considered as a means to provide continued care to cancer patients (Beaver et al., 2010; Cox et al., 2008). Phone helplines are mainly used by female and younger cancer patients (Jefford et al., 2005; Reid & Porter, 2011), commonly to request support for breast cancer (Clinton-McHarg et al., 2014), pain or deterioration in condition (Reid & Porter, 2011). Perceived limitations in cancer care received from healthcare professionals, the convenience of helplines, anonymity and confidentiality, as well as the benefits of helplines for family members, have been reported as reasons for using cancer helplines (Ekberg et al., 2014). In addition to phone helplines, the phone has been used as a medium in interventions such as patient education (Garrett et al., 2013), support (Garrett et al., 2013; Harrison et al., 2011; Livingston et al., 2010; Salonen et al., 2009; Wenzel et al., 2015), peer support (Pistrang et al., 2012), change in health behaviour (Hawkes et al., 2015), and follow-up of cancer patients (Beaver et al., 2010; Cusack & Taylor, 2010; Kimman et al., 2011; McGrath, 2014). These studies show that phone interventions are a pleasant, well-accepted and convenient way of delivering care to cancer patients. Studies regarding phone interventions usually, with some exceptions (e.g. Wenzel et al., 2015), yield statistically non-significant findings between experimental and control groups (Leahy et al., 2013; Livingston et al., 2010; Sherman et al., 2012; White et al., 2012), but the experimental groups mainly score higher than the control groups (Harrison et al., 2011). Some studies show positive findings from the recipients' perspective (e.g. decreased isolation, increased hope, trust and mood) (Pistrang et al., 2012). Although the providers view phone interventions positively, they also see some challenges such as skill development and meeting the needs of patients (Beaver et al., 2010), as well as the fact that phone interventions are not suited for all patients (Beaver et al., 2010; McGrath, 2014). Phone interventions have also been found to be cost effective, the use of hospital resources is more effective and greater use of primary healthcare services than specialised care by patients involved in phone interventions (Cusack & Taylor, 2010; Harrison et al., 2011).

Literature searches revealed that almost 75% of cancer patients prefer to use **email** communication with their healthcare providers. Those patients tend to be younger, well-educated and wealthier. Cancer patients who use email but do not prefer to use it with healthcare providers presented reasons such as impersonal nature of communication, lack of willingness to discuss their disease and preference for face-to-face communication. (Dilts et al., 2009) Nurses have addressed both the pros and the cons of using email to communicate with cancer patients. The pros include posting messages at a mutually convenient time, the ability to read responses for clarity and accuracy before sending them, ability to replace phone communication to an extent and ability to edit information before replaying. Email may also help some people to disclose things they would rather not say face-to-face or over the phone. Moreover, links to different types of materials can be attached. The cons include confidentiality issues, lack of clear guidelines from employer/managers on using email communication with patients, possibility of new questions arising in response to each email reply or unreadable responses that need explanations and variable time delay from the persons receiving email responses. (Cornwall et al., 2008) In addition, email communication between peers has been studied, and it was found to be able to promote, for example, cancer screening (Cutrona et al., 2013).

To the researcher's knowledge, there exist no studies regarding social support for adult cancer patients' via **online chat** rooms with healthcare providers. However, there exist studies among children and youngsters with psychosocial problems and their use of online chat for social support from peer counsellors and professionally facilitated child helplines. These studies provide evidence that online chat services improved children's well-being, reduced the severity of their condition (Fukkink & Hermanns, 2009) and provided varied types of social support (Fukkink, 2011).

Findings from studies on social networking sites such as Facebook (Abramson et al., 2015; Bender et al., 2011) and Twitter (Attai et al., 2015; Himelboim & Han, 2014; Sugawara et al., 2012), as well as Internet web sites such as YouTube (Chou et al., 2011), blogs (Kim & Gillham, 2013; Ngwenya & Mills, 2014) and vlogs (Huh et al., 2014), have potential implications for health promotion through personal narratives (Chiu & Hsieh, 2013; Iredale et al., 2011).

2.2.4 Needed and received electronic social support

To facilitate the improvement of health, perceived health and psychological processing ability of cancer patients, there needs to be a match between the types of social support needed and the support received (Cutrona & Russell, 1990; Goldsmith, 2004). In literature searches, no studies were found that address *both* the needed and the received electronic support. Studies mainly provide insight into met or unmet needs of cancer patients, but rarely together in a single study in the electronic context. However, studies do provide information on factors that are associated with support needs and how the received support benefits cancer patients. In the following paragraphs, the support needs of cancer patients are described, along with the support the patients received or the support that was provided and their support needs that were not met. In addition, the factors related to support needs and the benefits of support are described.

Cancer patients' needs are most often related to information concerning the likelihood of cure, survival rates (Li et al., 2011), side effects (Grimsbo et al., 2012; Huber et al., 2011; Lavoie et al., 2012; Maddock et al., 2011; Schook et al., 2013; Sillence & Mo, 2014) and the disease itself and its treatments (Cox et al., 2008; Maddock et al., 2011; Reid & Porter, 2011; Schook et al., 2013; Sillence & Mo, 2014) to cope with their cancer (Schook et al., 2014). In addition to information, they need emotional support (Huber et al., 2011; Lobchuk et al., 2015) with issues such as making sense of feelings and concerns (Lobchuk et al., 2015), distress and adjusting to cancer (Chambers et al., 2012). Furthermore, issues regarding cancer advocacy have been reported (Lobchuk et al., 2015).

The support needed by cancer patients may depend on the type of cancer, associated survival rates and number of needs. Breast cancer patients have been found to be more concerned about the long-term effects of cancer and the impact of cancer on their families and personal life than, for example, urological cancer patients, whose needs are linked to short-term alternative treatments, sex life, keeping healthy and exercise (Valero-Aguilera et al., 2014). The differences between the need for social support types and cancer survival rates in electronic communities evidences that low-survival-rate cancer patients seek more informational support and less emotional support than high-survival-rate cancer patients (Buis & Whitten, 2011). Furthermore, patients who have greater unmet information needs spend more time seeking specialised health information on the Internet. Likewise, the higher the unmet need for emotional support, the more likely patients are to spend time seeking Internet social support services. (Lee & Hawkins, 2010)

Quite often, nurses are able to provide the support to cancer patients in the electronic environment (Andersen & Ruland, 2009; Cox et al., 2008; Grimsbo et al., 2012; Jefford et al., 2011; Reid & Porter, 2011) and patients are satisfied with email responses and the speed of email responses from nurses (Cornwall et al., 2008). For example, via email communication, nurses often provide both information about and support for (Grimsbo et al., 2012) issues such as living with symptoms, side effects and with a fear of relapse, everyday life concerns and unmet information needs from healthcare providers (Grimsbo et al., 2011). Additionally, patients have been found to receive the support they need from the Internet and from social media (Bender et al., 2012). However, there are also studies that state quite the opposite. In these studies patients have reported that they did not receive the support for their concerns about the future and worries of close ones, as well as for fear of cancer recurrence, loss of control and mood disturbances (Chambers et al., 2012). Furthermore, support needs related to body image, stress and survivorship and support needs related to financial issues have been reported as needs for which patients did not receive support (Bender et al., 2012). One reason why cancer patients do not receive the support they need is that a quarter of the information related to cancer on the Internet is not readable (Alba-Ruiz et al., 2013), that is, it is too difficult to understand (Alba-Ruiz et al., 2013; Sobota & Ozakinci, 2015) and may not serve as a resource to make well-informed decisions regarding, for example, treatment (Wasserman et al., 2014). Therefore, more comprehensive web sites that meet the needs of cancer patients are needed (Warren et al., 2014; Wasserman et al., 2014).

The matching type of electronic social support for cancer patients, professionally facilitated or otherwise, has shown several benefits. These benefits are likely to include increased hope and confidence, making sense of the illness experience and building up one's life (Pistrang et al., 2012), health promotion (Abramson et al., 2015), cancer screening (Chan & Vernon, 2008; Cutrona et al., 2013) and self-monitoring (Greaney et al., 2012). The received support may empower patients to influence and control care decisions (Balka et al., 2010; Dickerson et al., 2011; Dolce, 2011). However, patients may not always be able to make informed decisions based on the information they receive from the Internet (Kim & Kwon, 2010). From the organisational perspective, an electronic patient–nurse communication may have potential to supplement and improve the quality of healthcare (Andersen & Ruland, 2009; Grimsbo et al., 2012).

2.2.5 Measurement of electronic social support

To date, there is lack of an instrument to measure cancer patients' needed and received social support in electronic settings, that is, electronic social support. Using different combinations of the search terms social support, informational support, emotional support, tangible or instrumental support, cancer or cancer patients, online, Internet, web, electronic, email, electronic mail, telephone, phone, mobile, questionnaire, measure and scale and searching six different databases (Medic, Medline (Ovid), Pubmed, CINAHL, PsycINFO and Communication & Mass Media Complete) four studies were found that focused on electronic social support for cancer patients (Han et al., 2012; Im et al., 2011; Lepore et al., 2014; Setoyama et al., 2011). The search was limited to English language, abstract and full-text availability. These studies focused on peer support, and there was no one-to-one interaction between the participants of the support groups and the professional facilitators. The instruments were developed outside Europe, and two were in the field of nursing. Only one instrument was named precisely. Also, only one study focused on the types of social support provided, whereas the others focused on other categories of social support. Thus, there seems to be a research gap in this field. The instruments present some shortcomings. Three articles inadequately reported the validation measures; for example, no content validity parameters were reported, and only one article described validation measures other than face and content validation. The instruments, though, seem to have acceptable internal consistency. It is worth noting that Setoyama *et al.* also included conflict in their instrument because social support can sometimes be perceived negatively. The instruments used in the aforementioned are presented in Table 2.

The search also yielded five studies in which social support for cancer patients was examined in electronic settings using existing social support instruments (Appendix 1). The focus of these studies was often on evaluating interventions targeting support (Crane-Okada et al., 2012; Fogel et al., 2002; Owen et al., 2004; Ruland et al., 2013). The focus of one of these studies was on the description of the social and psychological characteristics that predict engagement with an online breast cancer support group (Han et al., 2012). The studies were performed mostly in English-speaking countries and mainly in the fields of nursing and psychology. In two of the studies, the Medical Outcomes Study Social Support Survey (MOS-SSS) instrument was used, which measures global functional social support (Sherbourne & Stewart, 1991). Other instruments that were used include Interpersonal Relationship Inventory (IPRI) short form (Tilden et al., 1994), Need for Information

Scale, Social Support Scale (Gustafson et al., 1993; Pingree & Hawkins, 1996) and The Interpersonal Support Evaluation List (ISEL) (Cohen & Hoberman, 1983). In these studies, the instruments were not adapted to fit the electronic environment. In some of the studies, the researchers did not report reliability measures for the subscales of the instruments (Rattray & Jones, 2007). Instrument validity is not a static condition (Streiner & Kottner, 2014; Tilden et al., 1994), but the researchers did not provide validation information in the articles.

Table 2. Instruments developed to measure cancer patients' electronic social support

Authors, year, discipline, country	Instrument/ subscales	Purpose of the instrument	Category of social support (Hupcey, 1998)	Items	Response format	Validity	Reliability
Han et al., 2014, Communication science USA	NR ¹ *emotional *instrumental	To assess perception of emotional and instrumental support	Recipient's perception of support	6	Likert (0=not at all, 4=very much)	NR ¹	$\alpha = .88$
Lepore et al., 2014, Public health USA	NR ¹ * helpfulness of received support * helpfulness of being able to provide support * helpfulness of hearing other women's experiences	To assess the perceived helpfulness of the intervention (enhanced prosocial Internet support group)	Recipient's perception of support, intentions and behaviors of the provider	9	Likert (1=not at all, 5=very much)	Face validation	For all subscales $\alpha = .91$
Im et al., 2011, Nursing science USA	Questions on the Use of Internet Cancer Support Groups (QOUICSG) *past use *usefulness of past use	To measure the use of Internet cancer support groups	Social network, recipient's perception of support	22	Dichotomous questions yes/no, Likert (1=less often, 5=once a week), Likert (1-4) ²	Face validation, criterion validation (t value = -15.66, $P < .00$), convergent validation between QOUICSG/HINTS ³ and QOUICSG/ The Support Care Needs Survey 34-	Kuder-Richardson 20 = 0.83, Spearman-Brown = 0.77

Authors, year, discipline, country	Instrument/subscales	Purpose of the instrument	Category of social support (Hupcey, 1998)	Items	Response format	Validity	Reliability
	*frequency of current use *likely of future use					Item Short Form, 0.50 (p<.00) and 0.27 (p=.02), respectively	
Setoyama et al., 2011, Nursing science Japan	NR ¹ *emotional support/helper therapy *emotional expression *advice *conflict *insight/universality	To measure received peer support for posters and lurkers in Japanese online breast cancer communities	Types of social support provided	29	Likert (5=strongly agree, 1=strongly disagree)	Face validation, content validation	For all subscales $\alpha > .65$

¹ Not reported, ² Verbal scaling was not reported, ³ Health Information National Trends Survey

2.3 Summary of the starting points

People who get cancer may face alterations in health status and/or in perceived health (LaCoursiere, 2001). Patients with cancer may perceive a wide range of alterations in physical, emotional and/or social health and well-being due to the disease and its treatments (Burles & Holtslander, 2013; Curtis et al., 2014; Pazar et al., 2015; Rowlands et al., 2015). Alteration in health status or in perceived health may lead to the search for different types of social support, especially in electronic environments (Andersen & Ruland, 2009; Dickerson et al., 2011; Shea-Budgell et al., 2014). In this study, the electronic environment consisted of the general Internet and the electronic counselling services (phone, email and online chat counselling) of non-profit cancer societies, therefore, the types of social support needed and received from these sources is called electronic social support. Because social support is a complex and multifaceted phenomenon, the focus of the present study is on the types of social support categorised by Hupcey (1998).

When cancer patients need different types of social support, they may turn to electronic sources to initiate, participate in and develop electronic interactions (LaCoursiere, 2001). In relationships with other patients (general Internet) and professionals (ECS), cancer patients may or may not receive the matching type of social support they have needed. If the type of electronic social support matches the needs of the patients, it is assumed that favourable outcomes in health status and/or perceived health occur. If not, there is a mismatch between the needed and received types of electronic social support and, as a result, unfavourable outcomes in health status and/or perceived health may occur. Therefore, the outcomes of the received electronic social support lead to a positive or negative feedback phenomenon. Positive supportive interactions increase positive outcomes and provide greater impetus to seek support when alterations in health demand (LaCoursiere, 2001), and the scenario is reversed if the feedback is negative (Rook, 1992).

Only a few instruments have been developed that take into account electronic environments. These instruments focus on peer support. A few researchers have used existing social support instruments, mostly without modifying them. All of the studies described have focused on the types of social support, on recipients' perceptions of support or on social networks. To date, there exists no instrument

for measuring the needed and received electronic social support in the context of non-profit cancer societies with a professional facilitator.

A summary of the starting points of the present study is shown in Figure 2.

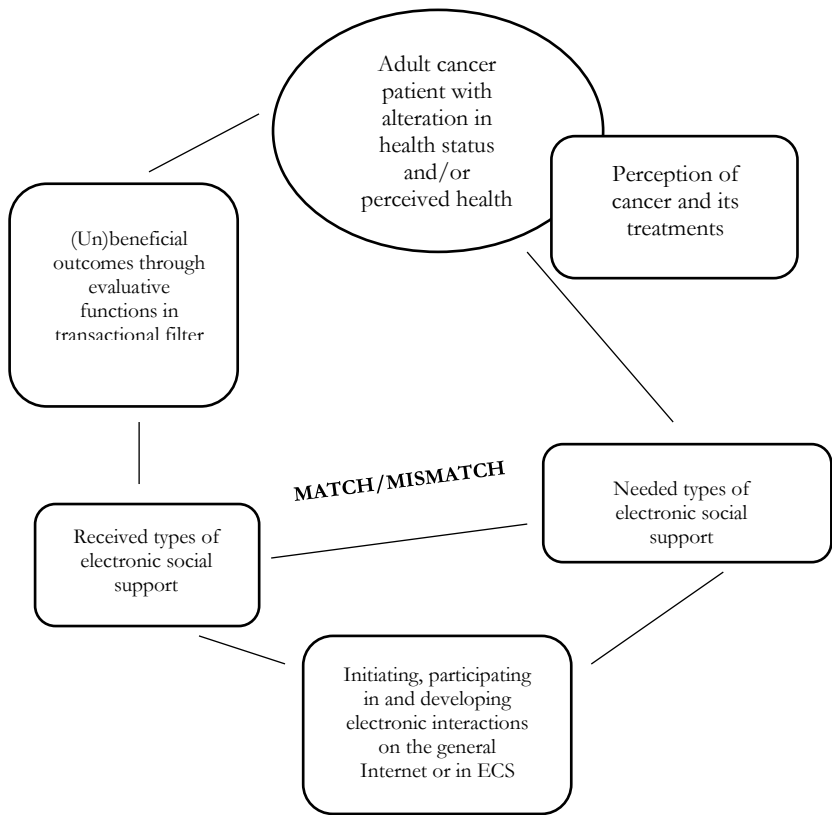


Figure 2. Starting points of the study

3 Purpose and aims of study

The purpose of the present study was to explore adult cancer patients' perception of electronic social support. Furthermore, the purpose was to develop and pre-test an instrument to measure the needed and received electronic social support from the ECS of non-profit cancer societies. The aim is to provide new information about the needed and received electronic social support for cancer patients. The results of the study can also be used to educate patients and nurses in different oncology settings.

The research phases are as follows:

1. To describe the current state of online social support for adult patients with cancer (articles I and II)
2. To describe adult cancer patients' and CNs' perceptions of electronic social support
 - Adult cancer patients' perceptions social support in ECS (article III)
 - The phases in the cancer trajectory when electronic social support was needed and the integration of the received support into cancer care in public healthcare (article IV)
 - The facilitators and barriers to electronic social support perceived by CNs (article V)
3. To develop an instrument to measure the needed and received electronic social support for adult cancer patients from non-profit ECS (Summary)
 - Development of an instrument based on previous phases of the study and its pre-testing
 - Measurement of the needed and received electronic social support for adult cancer patients who have used non-profit ECS

4 Empirical implementation of study

4.1 Methodological basis

In the present study, an exploratory sequential mixed methods research (MMR) design was used. In MMR, different research approaches are used in terms of questions, research methods, data collection, analysis procedures and inferences (Hesse-Biber, 2010; Johnson et al., 2007; Teddlie & Tashakkori, 2009), and MMR can be defined as a research design in which a researcher – or a team of researchers – combines elements of distinct research approaches for achieving the desired breadth and depth of understanding and corroboration (Johnson et al., 2007). The present MMR design is based on the philosophical orientation of pragmatism, which rejects the dogmatic either-or choice between constructivism and post-positivism and searches for practical answers to research questions of interest (Creswell & Tashakkori, 2007; Johnson et al., 2007; Muncey, 2009; Teddlie & Tashakkori, 2009). In this study, knowledge was constructed and based on the reality of the world that the study participants perceived and lived in, and both subjective and objective viewpoints were justified depending on the research phase. (Teddlie & Tashakkori, 2009)

The MMR design was considered justified because the purpose of the study and the research questions required a combination of different methods that would not individually address the primary purpose of the study, that is, a bottom-up approach (Creswell & Plano Clark, 2007; Curry & Nunez-Smith, 2015; Hesse-Biber, 2010; Teddlie & Tashakkori, 2010). In addition, the MMR design provides an opportunity to ask whether the findings of substudies are in agreement, that is, the results of the previous phases can be tested in subsequent phases (Hesse-Biber, 2010). Furthermore, the information available on the topic of the present study was insufficient (Curry & Nunez-Smith, 2015; Muncey, 2009), and the MMR design facilitated, first, identification of attributes of the types of electronic social support important to cancer patients and, second, development of a measure to establish perceptions of the types of support needed and received (Larkin et al., 2014). Here, the purpose of mixing was development (Greene et al., 1989). In sum, the combined use of different approaches within a single study yielded a better understanding of

the research purpose than that possible when using the approaches individually (Creswell & Plano Clark, 2007), which was also a sensible and ethical way to conduct the study (Gorard, 2010). The inductive phases of the study were considered core phases, because the theoretical structure of the study rests on these phases (Morse, 2010).

The study ran from 2010 to 2016 and it was divided into three phases (figure 3).

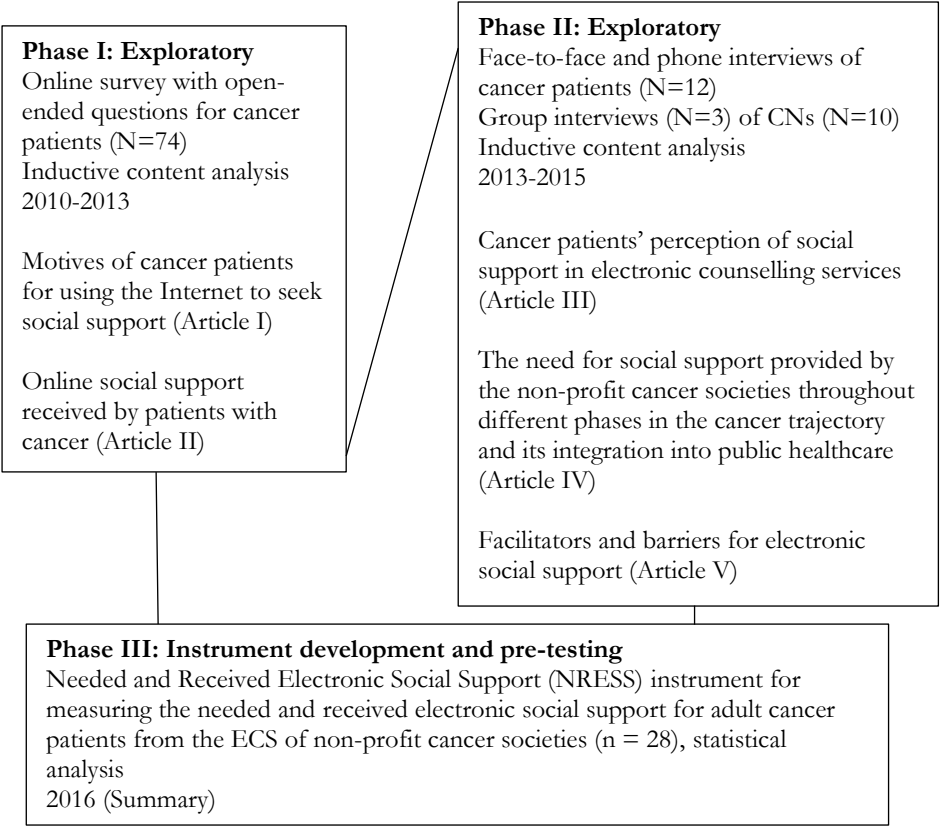


Figure 3. Study process

4.2 Development of NRESS instrument

The items comprising the Needed and Received Electronic Social Support (NRESS) instrument were generated from the categories formed as a result of inductive content analysis of the online survey (phase I) and the interviews (phase II) (Streiner et al., 2015). Altogether, 88 categories describing the types of social support were

generated. After careful consideration and removal of duplication, 37 categories were selected as base for the items. These 37 categories described the phenomenon under study, were within the research questions and were considered relevant for the target population. The categories were operationalised to correspond to every verbatim phrase within each chosen category that described the types of social support provided (Rattray & Jones, 2007). The operationalisation process yielded 38 items. The item pool consisted of four subscales, namely, network support (6 items), informational support (9 items), promotion of well-being (17 items) and customer service support (6 items). Based on reflective discussions with the dissertation committee and a statistician, the wording and sequence of the items were refined.

For the summary, the NRESS instrument was cross-translated by the researcher and a native Finnish speaker, who is an English teacher and was not involved in the original translation (Burns & Grove, 2005). The cross-translation process revealed two items with slight differences in wording but no difference in the meaning.

The items, needed and received support, were answered on a 5-point Likert scale (1=not at all, 2=quite a little, 3=some, 4=quite a lot, 5=very much) because the purpose of the scale was to measure respondents' perceptions about the phenomenon under study (DeVellis, 2012; Streiner et al., 2015). The literature suggests that the minimum number of response categories should be between five and seven. In this study, five categories were considered as appropriate because respondents seldom choose extreme positions on the scale, and the use of five response categories was thought to be convenient for participants to complete the survey. (Streiner et al., 2015) Furthermore, a response category 'does not apply to me' (0) was added. The intention was to add this category only as an option to the received support scale, but the online survey platform did not allow for this technically. Higher variable value indicated more needed and more received support. Moreover, the instrument included 15 background questions.

4.3 Samples and data collection

An independent multilevel mixed methods sampling scheme was used, that is, four distinct data were extracted sequentially from two different populations (adult cancer patients and CNs) to measure the same phenomenon but in different ways (Collins, 2010; Curry & Nunez-Smith, 2015). Purposive and convenience sampling techniques were used to address the research questions in each phase of the study (Teddlie & Tashakkori, 2009).

Data were collected using the between-strategies mixed methods data collection method. The interviews (phase II) were standardised open-ended interviews, in which the wording and the sequence of the questions were determined in advance, and all interviewees were asked the same questions in the same order (articles III and V). Two types of survey instruments were used: online survey with open-ended questions in phase I (articles I and II) and structured online survey with a five-point attitude scale in phase III (summary). (Streiner et al., 2015; Teddlie & Tashakkori, 2009)

4.3.1 Online survey with open-ended questions (phase I)

In phase I, convenience sampling (volunteer sampling) (Polit & Beck, 2010) was considered an appropriate sampling method because the purpose was to describe the phenomenon (Burns & Grove, 2005). An online survey with open-ended questions was administered for data collection. Online survey refers to a survey carried out via the Internet (Heikkilä, 2008). This survey type was considered justified because of the online context of the study. In addition, easy access to the participants who would otherwise be difficult to reach, rapid data collection (Duffy, 2002; Hunter, 2012), low costs compared to pen-and-paper data collection (Hunter, 2012; Scott et al., 2011) and a less intrusive data collection method (Holloway & Wheeler, 2010) were considered as advantages in favour of online data collection. The online survey operated by itself, and the answers were downloaded straight to the database in typed text form from where they could be extracted to other software applications (Holloway & Wheeler, 2010; Hunter, 2012). Furthermore, the manual saving of data was dispensed with to reduce errors (Hunter, 2012). (Articles I and II)

The online survey for this study was developed based on a theory of online social support (LaCoursiere, 2001). Of the four sections of this theory, three were used as base of the online survey, namely, initiating events, mediating factors and qualitative outcomes through evaluative functions in transactional filter (Figure 1, p. 35). The survey was administered in May 2010. A link to the survey was posted to four discussion forums on the web pages of the Cancer Society of Finland. Adult cancer patients visiting the discussion forums (posting messages or lurking) were eligible to participate. Altogether, 74 cancer patients participated in the study. (Articles I and II)

4.3.2 Individual and group interviews (phase II)

Purposive sampling (criterion sampling) and convenience sampling (volunteer sampling) (Polit & Beck, 2010) were used to recruit eligible participants. The semi-structured interview guide was influenced by phase I, the theory of online social support (LaCoursiere, 2001) (Figure 1, p. 35) and the researcher's discussions with representatives of the cancer societies involved in phases I and II of the study.

Adult cancer patients with experience of using ECS were eligible to participate in the study, and they were interviewed face-to-face or by phone. The interviews of cancer patients were conducted between May 2013 and May 2014. (Articles III and IV)

Group interviews (formal natural groups) were used to collect data from the CNs by purposive sampling (criterion sampling) (Green & Thorogood, 2009; Polit & Beck, 2010), and CNs who had experience with and were currently working in an ECS were eligible to participate. The group interviews were conducted in May 2014. (Article V)

4.3.3 Structured online survey (phase III)

Convenience sampling (Polit & Beck, 2010) was used to collect data via a structured online survey in order to pre-test the instrument. An Internet link to the structured online survey was posted to forums on the participating sites (Appendix 2). These forums were considered an appropriate 'home' for the structured online survey, and the Internet link provided immediate, easy and direct access to the survey (Santin et al., 2013). Adult cancer patients who had accessed and used the ECS of the participating non-profit cancer societies were eligible to participate.

For data collection, the e-form of the University of Tampere was used as a platform to construct an online version of the instrument. The NRESS instrument consists of 38 items. In addition, there are 15 background questions related to variables such as sociodemographic factors and ECS use. (Appendix 3.) In addition, a feedback field for participants' comments was included in the online survey. The pre-test was administered from the end of December 2015 to the end of August 2016 to adult cancer patients who had used ECS.

To pre-test the instrument, the desirable sample size was 10 subjects for each tested items (Burns & Grove, 2005). The accumulation of data was remarkably slow despite the fact that the Internet link was posted to three discussion forums on the site of cancer society 1, Facebook and Internet pages of 11 regional societies and five patient organisations. Additionally, paper invitations to participate in the study were available in the waiting rooms of the regional cancer societies. The invitation to participate in the study on Facebook page of association 2 was transferred to the top of the page timeline a few times, and a few regional societies even advertised the study.

4.4 Data analysis

The data analysis plan was guided by the overall purpose of the study, as well as by the study design. The data-sets used in the study were subjected to sequential mixed data analysis, that is, they were analysed in respectively (Creswell & Plano Clark, 2007). Analyses of the online survey with open-ended questions and the interviews were completed by the end of the initial phases to identify patterns that informed instrument design in the subsequent phase. In this stage, the data-sets were integrated by connecting them, such that one type of data built upon the other.

(Creswell & Plano Clark, 2007; Curry & Nunez-Smith, 2015; Teddlie & Tashakkori, 2009)

The data from the online survey with open-ended questions and the interviews were subjected to inductive content analysis from the manifest perspective through unitising and categorising processes (Teddlie & Tashakkori, 2009). After repeated reading of the data, units of information were identified, units of information that were related to the same content were grouped together, and based on similarity, internally consistent categories were developed (Polit & Beck, 2010; Teddlie & Tashakkori, 2009). (Articles I-V) The data from the structured online survey were analysed using statistical analysis techniques (Streiner et al., 2015).

4.4.1 Inductive content analysis (phases I and II)

Inductive content analysis was used because the purpose was to explore the phenomena under study (Flick, 2014; Kyngäs et al., 2011; Teddlie & Tashakkori, 2009). Content analysis was inductive, which meant that the analysis was derived directly from the data (Vaismoradi et al., 2013), and it proceeded from particulars to universals (Polit & Beck, 2010).

In phase I, the data were already in a typed format (articles I and II). In phase II, audio-taped interviews were transcribed verbatim (articles III-V). After checking the similarity of the audio-taped and transcribed data, the data were explored in greater detail, and sections relevant to the research questions were coded. (Dierckx de Casterle et al., 2012; Polit & Beck, 2010) The units of information consisted of expressions (words and sentences) relevant to the research questions. Based on their similarities and differences, these units were reduced and grouped into subcategories, categories, upper categories and main and/or core categories. (Flick, 2014) The manifest content of the data was of interest for developing categories (Graneheim & Lundman, 2004; Onwuegbuzie & Combs, 2010). (Articles I-V)

4.4.2 Statistical analysis (phase III)

Altogether, 42 adult cancer patients participated in the study. Thirteen cases (30%) were excluded because they did not meet the inclusion criteria, and one additional case (2%) was excluded due to empty questionnaire, leaving 28 (67%) eligible cases.

On the variable level, 71 variables (93%) had missing values ranging from one to five (4%-18%). On the case level, 16 cases (57%) had complete data.

The missing values were imputed because the sample was small, and, therefore, a mean/median replacement was used depending on the distribution of the variables (Munro, 2005). Mean/median substitution involved calculating mean/median values for each variable using the means/medians of age (as categorised into two groups) and gender. Owing to technical limitations of the platform of the e-form, the scaling response “*does not apply to me*” (0) had to be included in the *needed* electronic social support scaling response options, which was not the original intention. As a result of this, all responses in the “*does not apply to me*” category were converted to the “*not at all*” (1) response option.

Eight summated scales were formed that described the needed (four summated scales) and received (four summated scales) electronic social support. The lowest value (1) indicated no needed and received support, whereas the highest value (5) indicated the highest needed and received support. Based on skewness, kurtosis, histograms and one-sample Kolmogorov-Smirnov values, all summed scales could be considered normally distributed.

Background variables (N = 15) were based on the theory of online social support and literature, and they consisted of sociodemographic and ECS use factors. Sociodemographic factors (n = 12) were as follows: birth year, gender, highest education achieved, life situation, children living in the household and their year(s) of birth, living environment, cancer type, year of cancer diagnosis, phase of cancer, perceived current health, from whom the participants had received the most support and number of key supporters. The ECS use-related factors (n=3) were as follows: form of ECS used, frequency of contact and how the participants perceived phone/email/online chat as a means of communication. The participants had the possibility to give feedback about the online survey. The content of such feedback was analysed.

Five background variables were categorised. *Birth year* was first converted into age in years at the time of data collection (2016) and then categorised into two age groups: 33–64 years and 65–79 years. *Cancer type* was categorised into six groups: haematological, breast, gynaecological, urological, skin/mucosa and other cancers. *Year of the diagnosis* was also categorised into two groups: cancers diagnosed between 1989 and 2010 and between 2011 and 2015. *Most support received from* was categorised into six groups: family (spouse, siblings and children), healthcare professionals, peers (online and offline), friends, cancer societies and the Internet (not specified). (Appendix 4.) *Frequency of contact* was categorised into two groups: those who used

phone counselling 1–2 times or 3–30 times and those who used email counselling 1–2 times or 3–50 times (Table 3). The categorisation of age and year of the diagnosis was based on medians, and the categorisation of frequency of the contact was based on the cut-off point of frequency.

To describe the data, frequencies and percentages, measures of central tendency (mean and median), variability (standard deviation, range and lower and upper quartiles), symmetry (skewness) and peakedness (kurtosis) were used. The one-sample Kolmogorov-Smirnov test was used to assess the distribution of the variables. Because the sample size was small, nonparametric analysis techniques were used, such as the Mann-Whitney U test to compare the differences between two groups and the Kruskal-Wallis H test to examine if there were differences among three or more groups. The Spearman rank order correlation coefficient (r_s) was used to examine whether relationships exist between the *needed* and *received* electronic social support, and the Wilcoxon signed ranks test was used to describe the differences between the means of the items on the needed and the received scales. To assess instrument reliability, Cronbach's alpha coefficients (α) and item analysis in terms of corrected item-total correlations were used. Significance level for all tests was $p < 0.05$. (Burns & Grove, 2005; Munro, 2005) All statistical analyses were performed using IBM SPSS Statistics for Windows (version 23, Armonk, NY, IBM Corp.).

5 Results

The study process proceeded such that phase I (articles I and II) was conducted to gain a preliminary understanding of the current state of online (general Internet) social support for cancer patients. Phase II described adult cancer patients' and CNs' perceptions of electronic social support including adult cancer patients' perceptions of social support in ECS (article III), the phases in the cancer trajectory when support was needed and the integration of received support into cancer care in public healthcare (article IV). Furthermore, phase II described the facilitators and barriers to electronic social support perceived by CNs (article V). In phase III, the pre-test of the NRESS instrument was described first, followed by the results pertaining to the needed and received electronic social support from ECS provided by the non-profit cancer societies and the relationship of the background factors with the needed and received electronic social support (summary).

5.1 Participants

In phase I, the participants (N=74) were predominantly women and middle-aged. Most participants had at least a polytechnic/college or a vocational level of education. The most common cancer was breast cancer, and the majority of the cancers were diagnosed between 2004 and 2010 (at the time of data collection). Most participants perceived their health as good. (Articles I and II.)

In phase II, the participants consisted of adult cancer patients (N=12) and CNs (N=10). There were slightly more women than men with cancer participating in the study, and they were middle-aged with mainly vocational degrees as their education. The most common tumour sites were breast and prostate, and the years since diagnosis ranged from the year of the interview to 17 years. The use of phone counselling was predominant among these participants. The participants were in contact with an ECS mainly two to six times. (Articles III and IV) All CNs were female, and their mean age was 52 years. The CNs were either registered nurses or public health nurses or both, and they had additional training for the counselling

work, both formal and informal. The working history in the ESC was, on average, 9 years. (Article V)

In phase III, the rater panel consisted of five post-graduate nursing students and a social support researcher who assessed content validation of the developed instrument.

In pre-testing the instrument 28 adult cancer patients, who had accessed and made use of ECS provided by the cancer societies, participated in the study. The participants were predominantly women (n=21, 75%). The mean age of the participants was approximately 63 years, and 68% (n=19) of them had an education of bachelor's degree or higher. Over half of the participants were retired, and five participants had minors living in the same household. Nearly half of the participants lived in a city with a population of more than 100 000. There were altogether 36 cancers because six participants had two or three types of cancer. Half of the cancers were diagnosed over five years ago. Half of the participants were in the follow-up phase of their cancer care. The majority of the participants described their current health as moderate or higher, and none of the participants perceived their health as poor. Overall, the participants received the most support from their families, and they had four key supporters on average. (Appendix 5.)

None of the participants had used online chat counselling for electronic social support. Email was the most used form of ECS, and both phone and email as means of communication were perceived as easy by more than half of the participants. Although online chat was not used, only two participants reported difficulty in using online chat as a means of communication. (Table 3.)

Table 3. Participants' use of ECS in phase III

Variables	n	%	Md ¹	Q ₁ -Q ₃ ²
Phone counselling	28			
Have used	15	54		
Email counselling	28			
Have used	21	75		
Online chat counselling	28			
Have used	0	0		
Total number of phone contacts (n=14 participants)	76		1.0	.0-3.0
Frequency of phone contact	14			
1-2 contacts	6	43		
3-30 contacts	8	57		
Total number of email contacts (n=19 participants)	160		2.0	.0-3.5
Frequency of email contact	19			
1-2 contacts	10	53		
3-50 contacts	9	47		
Phone perceived as a means of communication	22			
Easy	14	63		
Not easy nor difficult	4	18		
Difficult	4	18		
Email perceived as a mean of communication	25			
Easy	20	80		
Not easy nor difficult	3	12		
Difficult	2	8		
Online chat perceived as a mean of communication ³	12			
Easy	4	33		
Not easy nor difficult	6	50		
Difficult	2	17		

¹ Median² Lower quartile-upper quartile³ None of the participants had used online chat but they nevertheless reported their perceptions

5.2 Current state of online social support for patients with cancer (phase I)

In this subchapter, the motives for seeking support from the Internet (article I) are first described, followed by descriptions of received support and the meaning of online social support for patients with cancer (article II).

Cancer patients' motives for using the Internet to seek social support consisted of the initial stimuli to seek social support from the Internet and the motives that drove them to seek further social support from the Internet. The need for information was the initial stimulus, as well as the motives to use Internet for support. The illness gave rise to information needs in different phases of the cancer trajectory. The need for emotional support provided another initial stimulus and motive to turn to the Internet. Patients sought peer support especially if they did not have peers in their circle of acquaintances. The lack of other sources of support outside the Internet was also a key reason to seek support from the Internet. The availability and ease of online communication were considered to be the initial stimuli and motives to turn to the Internet. (Article I)

The information received from the Internet was related to the illness, such as diagnosis, medical tests and treatments, disease progression, adverse effects and life expectancy. This information was desired from reliable sources such as research papers, peers, cancer societies and professionals at the hospital. In addition to the information, supportive interactions as a way of enhancing positive emotions consisted of interaction with peers, who helped manage issues related to their illness and its consequences. Practical tips for daily life with cancer, such as advice and instructions for searching information, advice on problems caused by the disease and coping with treatments, as well as instructions on personal rights, were reported. (Article II)

When exploring the meaning of online social support for patients with cancer, it was found that peers helped the participants to make their life easier by sharing the same experiences. The participants received empowerment through the Internet, including hope for recovery, expanded understanding on cancer-related issues and independence. In addition to the positive meanings of online support, the negative aspects of support were reported. (Article II)

5.3 Adult cancer patients' and CNs' perceptions of electronic social support (phase II)

In this subchapter, cancer patients' perceptions of social support through ECS (article III) are first described, followed by the phases of the cancer trajectory when support from ECS was needed and the integration of the received support with cancer care in public healthcare (article IV) are described. Finally, the facilitators of

and barriers to patients' electronic social support as perceived by CNs are described (article V).

The results on adult cancer patients' perceptions of ECS reveal two major themes. First, the cancer patients needed a contact person to ensure that they received personalized, matching type of support to enhance their ability to cope with cancer. The cancer patients reported a need for a contact person to turn to upon diagnosis to receive information and support for themselves and their families. Most often, the patients needed information related to their cancer, rehabilitation services and peer support to reduce uncertainty and obtain support for coping with their changed life situations. The support received had to be personalised for the cancer patients to benefit from it. Occasionally, the participants were in contact with ECS but reported that their needs were met outside ECS. Another major theme was that deficient resources in ECS may prevent the provision of matching types of support for patients' coping with cancer. Thus, there sometimes existed a mismatch between the needed and the received support from ECS. In such cases, the participants received support other than what they needed; for example, when they sought information, they received emotional support hindering their access to the desired information. The study participants suggested that ECS might not have sufficient resources to provide support, leading to mismatches between the needed and received electronic social support (article III).

The participants needed support from ECS in different phases of their cancer trajectories. Support was needed when emotional well-being was considered weakened. This happened when the participants were distressed and when they faced difficulties in interacting with healthcare providers, either in public healthcare or with previous contacts in ECS. The participants described that they needed support from ECS when their body broke. The body was considered broken when the participants were losing their physical integrity, their life was threatened or when the treatments or medication caused severe physical problems or fatigue. The participants of the present study also viewed the needs of support according to the traditional phases of cancer treatment. A few participants contacted ECS when they needed to strengthen their empowerment, for example, to complement their resources. The participants did not need support from ECS when their well-being was in balance. (Article IV.)

It was identified from the data that the way to integrate the support from ECS into cancer care in public healthcare involved supporting the patients emotionally. Additionally, ECS played an important role in developing the informational expertise of patients. One way to integrate the support from ECS into cancer care was to

expand the opportunities for support, in the present and in the future. In addition, the support from ECS assisted public healthcare by reducing its cancer care workload. However, it was not self-evident that the support from ECS was integrated into the cancer care in public healthcare. The integration required some prerequisites be fulfilled, such as the patient should actively find support services and initiate contact with said services. There were several reasons why the integration did not exist. These were related to the health status of the participants and the sufficiency of the participants' primary support sources. Furthermore, the integration of such support with the actual cancer care process was absent. (Article IV)

Studying electronic social support from the perspective of CNs led to the identification of several facilitators and barriers. First was the promotion of ECS accessibility, which required that ECS be diverse but uniform across the country while publicly available and accessible at any time. ECS also demanded collaboration between CNs and oncology nurses in hospitals. Second, facilitators of electronic social support for cancer patients included CNs' the well-organised work, functional working environments and the diverse competencies and experiences of CNs as part of the functioning structures of ECS. Third, use of individual CNs' strengths in ECS, such as their personal experiences, was considered to be a facilitator of patient support. Fourth, one of the most significant areas of counselling work was the promotion of life management by the cancer patients who contacted ECS. Fifth, the CNs also identified patient-related facilitators for support, such as competency and activity, necessary for patients to benefit from the support provided by ECS. Among other support facilitators, the counselling had to be patient centred and reliable. The CNs also reported barriers to patients' electronic social support, including the inaccessibility of ECS. Moreover, problems in mutual communication were seen as barriers; for example, it was difficult to support patients by writing, and some patients were uncomfortable talking on the phone. Occasionally, CNs and patients held different viewpoints, and in such cases, counselling could meet the needs of the cancer patients, or there was lack of a shared understanding. The ECS structures could also function as barriers to support. The barriers were the inverse of the facilitators (article V).

5.4 Pre-test of NRESS instrument (phase III)

5.4.1 Instrument validity

Instrument validity was based on content validation. A panel of five post-graduate nurse students and a senior nurse researcher with expertise in social support research rated the items on a 4-point scale for content relevance (1=not relevant, 2=somewhat relevant, 3=quite relevant, 4=highly relevant) (DeVellis, 2012; Lynn, 1986; Polit et al., 2007; Polit & Beck, 2006). The scale-level content validity index when using an averaging calculation method (S-CVI/Ave) was .91, which can be considered acceptable (Polit et al., 2007; Polit & Beck, 2006). The item-level content validity indices (I-CVI) (Polit et al., 2007; Polit & Beck, 2006) ranged from .33 to 1.00 (Appendix 4). Although there were five items that did not reach the acceptable item-level content validity .80 (Polit & Beck, 2006), they were not discarded at this early stage for three reasons. First, content validation applies to the scale as a whole, not to the individual items comprising the scale. The evidence of this was the overall scale content validity, which was at the acceptable level. (Streiner et al., 2015) Second, although the scale should be content valid mathematically, it should be meaningful conceptually as well (Lynn, 1986), which leads to the third reason, that is, the items were grounded in the data collected from the target population (Streiner et al., 2015). Data from the target population can also be seen as a part of content validation of an instrument (Imle & Atwood, 1988; Tilden et al., 1990). Therefore, at this early stage, it was decided not to put too much weight on the numbers alone and to acknowledge the underlying theory as well (DeVellis, 2012). Poor items can be detected and discarded later (Streiner et al., 2015).

Given the small sample size, construct validation of the instrument could not be performed in the present study.

5.4.2 Instrument reliability

Cronbach's alpha coefficients

To examine internal consistency as a form of instrument reliability, Cronbach's alpha coefficients were determined. The accepted lowest Cronbach's alpha coefficient value was set to $> .60$ (Knapp & Brown, 1995). Item analysis was used to select items

for *future* factor analysis, which provides a means for creating several composite variables and investigating item discriminating power. (Munro, 2005) To determine the item discriminating power, corrected item-total correlation levels > .30 were considered acceptable (Streiner et al., 2015).

The NRESS instrument showed acceptable internal consistency for both *needed* and *received* electronic social support. All subscales had Cronbach’s alpha coefficients > .60. The Cronbach’s alpha coefficients and 95% confidence intervals of alpha reliabilities are listed in Table 4.

Table 4. Cronbach’s alpha coefficients (α) and 95% confidence intervals of alpha reliabilities

	Needed support		Received support	
	α	Confidence intervals (95%)	α	Confidence intervals (95%)
NRESS (38)	.954	.926-.975	.942	.906-.969
Network support (6)	.724	.555-.852	.676	.477-.826
Informational support (9)	.923	.876-.959	.875	.798-.933
Promotion of well-being (17)	.965	.944-.981	.928	.884-.961
Customer service support (6)	.774	.635-.879	.673	.472-.824

Item analysis

The **overall** NRESS *needed* support scale had five items with corrected item-total correlations < .30. Four of these items, namely, “*A person you can turn to if you so wish*” ($r = .011$), “*Receiving assurance that your concern will be treated by the counselling service*” ($r = -.044$), “*Support from the counselling service when you do not want to seek help from the hospital personnel*” ($r = .132$) and “*Free counselling*” ($r = .045$) were in the Network support subscale. One item “*Support, no matter where you are located*” ($r = .261$) was in the Customer service support subscale. The removal of these items increased the Cronbach’s alpha coefficient of *needed* support to .955–.956. The corrected item-total correlations in overall *needed* scale ranged from -.044 to .829.

In the **overall** NRESS *received* support scale, three items had corrected item-total correlations < .30, namely, “*Guidance in terms of peer support*” ($r = .281$) in the Network support subscale and “*Support, no matter what time it is*” ($r = .149$) and “*Support, no matter where you are located*” ($r = .282$) in the Customer service support subscale. The removal of the items increased the Cronbach’s alpha coefficient to .943. The corrected item-total correlations in the overall *received* scale ranged from .149 to .806.

In the subscales of the NRESS instrument, only one item in the *needed* support subscale (Network support) did not reach the acceptable corrected item-total correlation level $> .30$. In the *received* support subscale, each subscale had one or two items that did not reach the desired level. These items, their corrected item-total correlations and Cronbach's alpha values if the item was deleted are presented in table 5.

Table 5. Items with corrected item-total correlations (ρ_{gXC}) $< .30$ in the needed and received support subscales and Cronbach's α if item deleted

Subscale/item	Needed support		Received support	
	ρ_{gXC}	α if item deleted	ρ_{gXC}	α if item deleted
Network support				
<i>Guidance in terms of peer support</i>	-.015	.798	.065	.744
Informational support				
<i>Information about the services that will be useful for you</i>			.281	.887
<i>Answers to the questions you have raised</i>			.224	.893
Promotion of well-being				
<i>Empathy from a counselling nurse</i>			.226	.936
Customer service support				
<i>The help of counselling services in explaining cancer-related topics in plain language</i>			.122	.713
<i>Finding the most suitable means of communication to suit your needs</i>			.226	.695

In addition, some items had better correlations to other subscales than their own. These items from the needed and received support subscales are presented in tables 6 and 7, respectively.

Table 6. Items in the needed support subscales that correlated better to other needed support subscales than their own

Needed support subscale/item	NS ρ_{gxc}^1	IS ρ_{gxc}^1	PW ² ρ_{gxc}^1	CS ρ_{gxc}^1
Network support (NS)				
<i>Guidance in terms of peer support</i>	-.015	.549	.257	.190
Informational support (IS)				
<i>Information about the services that will be useful for you</i>	.560	.514		
Customer service support (CS)				
<i>Counselling that is based on your specific needs</i>			.363	.392
<i>The help of counselling services in explaining cancer-related topics in plain language</i>			.681	.496

¹ Corrected item-total correlation, ² Promotion of well-being subscale

Table 7. Items in the received support subscales that correlated better to other received support subscales than their own

Received support subscale/item	NS ρ_{gxc}^1	IS ρ_{gxc}^1	PW ρ_{gxc}^1	CS ρ_{gxc}^1
Network support (NS)				
<i>Receiving assurance that your concern will be treated by the counselling service</i>	.563		.596	.739
<i>Guidance in terms of peer support</i>	.065	.324	.274	
<i>Support from the counselling service when you do not want to seek help from the hospital personnel</i>	.344		.466	.455
Informational support (IS)				
<i>Information about the services that will be useful for you</i>	.681	.281		
<i>Information about how your care could be organised elsewhere, outside of the public healthcare"</i>	.487	.378		
<i>Answers to the questions you have raised</i>	.500	.224		.331
Promotion of well-being (PW)				
<i>Counselling services to allow you to share any issues you do not wish to discuss with others</i>	.689		.681	
<i>Empathy from a counselling nurse</i>	.599		.226	.513
Customer service support (CS)				
<i>Counselling that is based on your specific needs</i>	.600			.421
<i>The help of counselling services in explaining cancer-related topics in plain language</i>	.291	.337		.122
<i>Finding the most suitable means of communication to suit your needs</i>	.272			.226

¹ Corrected item-total correlation

5.5 Needed and received electronic social support for adult cancer patients (phase III)

In this section, correlations between needed and received support are described and the most and least needed and received support are presented. Furthermore, the differences between needed and received support at the item level and the significant relationships between the summated NRESS scales and background variables are described. Finally, the participants' feedback on the survey instrument and the differences between the non-service-users and eligible participants are described. Non-service users completed the survey but did not use ECS.

A significant relationship between *needed* Network support and *received* Network support was detected by using bivariate analysis. Those with higher Network support needs tended to report an increase in received support ($r_s = .491$, $p = .008$). Between *needed* and *received* support in the other subscales, no statistically significant relationships were found, although the correlation in the Informational support subscale can be interpreted as moderate. (Table 8.)

Informational support was the most *needed* support (mean = 3.18, SD = 1.0), and Network support was the most *received* support (mean = 2.67, SD = 0.8). Promotion of well-being was the least *needed* support (mean = 2.64, SD = 1.08), and it was the least *received* support (mean = 1.64, SD = 0.74) as well.

Table 8. Correlations between needed and received electronic social support

Needed support		Received support			
		NS	IS	PW	CS
Network support (NS)	r_s	.491			
	Sig. (2-tailed)	.008*			
	N	28			
Informational support (IS)	r_s		.328		
	Sig. (2-tailed)		.088		
	N		28		
Promotion of well-being (PW)	r_s			.276	
	Sig. (2-tailed)			.155	
	N			28	
Customer service support (CS)	r_s				.247
	Sig. (2-tailed)				.205
	N				28

* Correlation is significant at the .01 level (2-tailed)

r_s = Spearman rank order correlation coefficient

The description of and the differences between the needed and received electronic social support on the item level are shown in Table 9. In general, adult cancer patients needed *some* electronic social support, while they received *quite a little* of it. A comparison of the means of the needed and received electronic social support on the item level showed that the participants needed more support than they received. There were four content areas in Network support, two in Informational support and one in Promotion of well-being where the amounts of needed and received support were approximately the same.

Relationships between background variables and summated scales

There were some statistically significant relationships between the background variables and the summated scales of the NRESS instrument (Table 10). Highest education achieved, children living in the same household, living environment, year of diagnosis, cancer type, support most received from, frequency of email contact and phone and email as a means of communication were the background variables that had statistically significant relationships with the summated scales.

Table 9. Description of and the differences between needed and received electronic social support at item level

Subscales and items	Needed support Percentages of response values ²						Received support Percentages of response values ²							p-value ¹
	Mean (SD)	1	2	3	4	5	Mean (SD)	0	1	2	3	4	5	
Network support	3.05 (.70)						2.67 (.79)							.015
A person you can turn to if you so wish	3.32 (.94)	-	18	46	21	14	3.29 (1.27)	-	11	14	32	21	21	1.000
Receiving assurance that your concern will be treated by the counselling service	3.00 (1.15)	11	21	36	21	11	3.00 (1.39)	4	11	21	29	18	18	.916
Guidance in terms of peer support	3.18 (.94)	4	14	54	18	11	2.61 (1.31)	7	18	11	39	21	4	.085
Filling in the gaps left by the lack of support provided by other healthcare professionals	3.11 (1.20)	11	18	36	21	14	2.14 (1.33)	7	29	29	21	7	7	.002
Support from the counselling service when you do not want to seek help from the hospital personnel	2.68 (1.19)	25	11	39	21	4	2.14 (1.38)	7	36	18	18	18	4	.008
Free counselling	3.00 (.98)	7	18	50	18	7	2.82 (.98)	-	11	21	46	18	4	.325
Informational support	3.18 (1.00)						2.22 (.90)							<.001

Subscales and items	Needed support Percentages of response values ²						Received support Percentages of response values ²							p- value ¹
	Mean (SD)	1	2	3	4	5	Mean (SD)	0	1	2	3	4	5	
Information about the services that will be useful for you	3.11 (1.03)	7	14	50	18	11	2.57 (1.17)	7	11	18	50	11	4	.058
Information about how your care could be organised elsewhere, outside of the public healthcare	2.04 (1.29)	50	18	18	7	7	1.25 (.75)	11	61	21	7	-	-	.006
Information about the nature of your cancer	3.75 (1.38)	11	11	11	29	39	2.43 (1.48)	7	25	21	21	14	11	.001
Information about the discomforts caused by your cancer	3.53 (1.29)	14	-	29	32	25	2.21 (1.47)	7	32	25	14	11	11	<.001
Information about the treatments for your cancer	3.46 (1.32)	14	4	29	29	25	2.39 (1.50)	11	18	29	18	14	11	<.001
Information about the adverse effects caused by your cancer treatments	2.96 (1.43)	21	14	32	11	21	1.96 (1.26)	11	29	29	21	7	4	<.001
Information that will help you to understand the treatment of your cancer as a whole	3.14 (1.41)	21	7	25	29	18	2.04 (1.29)	11	29	25	18	18	-	<.001
Answers to the questions you have raised	3.36 (1.10)	4	18	36	25	18	2.93 (1.25)	-	18	14	36	21	11	.059
Practical tips for daily living with cancer	3.25 (1.14)	4	29	21	32	14	2.21 (1.13)	4	18	54	7	14	4	.001

Subscales and items	Needed support Percentages of response values ²						Received support Percentages of response values ²							p- value ¹
	Mean (SD)	1	2	3	4	5	Mean (SD)	0	1	2	3	4	5	
Promotion of well-being	2.64 (1.08)						1.64 (.74)							<.001
Support if you are low in spirits	2.57 (1.37)	32	18	18	25	7	1.61 (1.23)	11	50	21	8	8	4	.001
Emotional support	2.75 (1.27)	21	21	25	25	7	1.71 (1.15)	11	43	18	21	7	-	.001
Support in adopting to the new life situation	2.93 (1.25)	18	14	36	21	11	2.07 (1.18)	7	36	7	43	7	-	.007
Alternative support if you are having difficulties in your interaction with the healthcare professionals participating in your cancer treatment	2.25 (1.17)	36	21	29	11	4	1.75 (1.27)	14	39	14	21	3	-	.030
Counselling services to allow you to share any issues you do not wish to discuss with others	2.36 (1.28)	36	18	29	11	7	1.89 (1.23)	7	43	18	18	14	-	.051
Counselling that takes into account those who are close to you	2.39 (1.26)	29	32	18	14	7	1.32 (1.06)	11	68	7	11	-	4	<.001
Support that will help you to face those who are close to you	2.25 (1.24)	36	25	25	7	7	1.39 (.99)	11	57	21	4	7	-	<.001
Support for your family's well-being	2.75 (1.40)	25	21	21	18	14	1.39 (.92)	11	54	25	7	4	-	<.001

Subscales and items	Needed support Percentages of response values ²						Received support Percentages of response values ²							p- value ¹
	Mean (SD)	1	2	3	4	5	Mean (SD)	0	1	2	3	4	5	
Support that includes the screening of your ability to manage your life	2.36 (1.50)	39	25	14	4	18	1.14 (.65)	11	68	18	4	-	-	<.001
Support that will strengthen your ability to cope with your own care for your cancer	2.75 (1.24)	21	14	43	11	11	1.85 (.97)	4	39	29	25	4	-	<.001
Confidence in your recovery from cancer	3.04 (1.48)	21	14	29	11	25	2.00 (1.31)	7	39	18	21	11	4	.001
Support after losing the physical integrity of your body	2.53 (1.45)	39	4	36	7	14	1.46 (1.07)	11	61	4	21	4	-	<.001
Support to help you to cope with what is happening to your body as a result of cancer treatment	2.68 (1.52)	32	18	18	14	18	1.39 (.83)	11	50	29	11	-	-	<.001
Support to help you to cope with the fear of your cancer spreading	2.68 (1.49)	32	14	25	11	18	1.29 (.98)	14	61	11	11	4	-	<.001
Support to help you to cope with the fear of death	2.64 (1.42)	39	21	21	14	14	1.29 (.94)	14	61	7	18	-	-	<.001
Support from the counselling nurse who discusses his/her own experiences with cancer-related topics	2.57 (1.40)	32	18	21	18	11	1.57 (1.07)	11	43	32	11	-	4	<.001

Subscales and items	Needed support Percentages of response values ²						Received support Percentages of response values ²							p- value ¹
	Mean (SD)	1	2	3	4	5	Mean (SD)	0	1	2	3	4	5	
Empathy from a counselling nurse	3.43 (1.14)	4	14	43	14	25	2.68 (1.36)	4	14	36	14	21	11	.041
Customer service support	2.84 (.85)						2.18 (.76)							.001
Counselling that is based on your specific needs	3.29 (1.08)	4	18	43	18	18	2.54 (1.37)	-	25	36	14	11	14	.022
Expert counselling	3.64 (1.03)	4	7	32	36	21	2.89 (1.29)	4	11	21	32	21	11	.013
The help of counselling services in explaining cancer-related topics in plain language	2.39 (1.45)	39	18	21	7	14	1.82 (1.12)	11	25	46	11	4	4	.042
Finding the most suitable means of communication to suit your needs	3.00 (1.22)	14	14	43	14	14	2.46 (1.35)	7	14	36	18	18	7	.040
Support, no matter what time it is	2.21 (1.26)	36	32	14	11	7	1.57 (1.17)	7	57	21	4	7	4	.014
Support, no matter where you are located	2.50 (1.37)	36	14	21	21	7	1.79 (1.23)	7	46	21	14	7	4	.001

¹ Wilcoxon signed ranks test

² Response values: 0 = does not apply to me, 1 = not at all, 2 = quite a little, 3 = some, 4 = quite a lot, 5 = very much

Table 10. Statistically significant relationships between summated scales of NRESS and background variables

Summated scale	Background variable	Groups	n	Md (Q ₁ -Q ₃)	p-value
Needed Network Support	Highest education achieved	Master's degree or higher	8	2.75 (2.17-3.08)	.038 ¹
		Batchelor's degree	11	3.33 (3.08-3.83)	
		Vocational degree	9	3.17 (2.50-3.17)	
	Phone as a means of communication	Easy	14	3.00 (2.33-3.17)	.042 ¹
		Not easy nor difficult	4	3.50 (2.92-4.00)	
		Difficult	4	3.67 (3.33-4.08)	
	Email as a means of communication	Easy	20	3.17 (3.00-3.58)	.030 ¹
		Not easy nor difficult	3	2.50 (2.08-2.67)	
		Difficult	2	2.42 (2.17-2.67)	
	Support most received from: healthcare professionals	Yes	11	2.83 (2.33-3.08)	.046 ²
		No	17	3.17 (3.00-3.67)	
Received Network Support	Cancer type: urological cancer	Yes	3	2.00 (1.67-2.08)	.040 ²
		No	25	2.67 (2.17-3.33)	
	Freq. of email contacts	1-2	10	2.42 (1.83-3.00)	.014 ²
		3-50	9	3.33 (2.67-3.67)	
	Email as a means of communication	Easy	20	2.83 (2.25-3.33)	.015 ¹
		Not easy nor difficult	3	1.83 (1.50-1.92)	
		Difficult	2	2.42 (2.17-2.67)	
	Support most received from: family	Yes	17	2.33 (2.00-3.00)	.047 ²
		No	11	3.00 (2.50-3.50)	
	Living environment	Large city	12	3.11 (3.00-3.50)	.033 ¹
		Medium-sized city or municipality	9	2.22 (2.00-3.00)	
		Smaller region or municipality	4	3.83 (3.17-4.28)	

Summated scale	Background variable	Groups	n	Md (Q ₁ -Q ₃)	p-value
	Year of the diagnosis	Rural area	3	5.00 (4.06-5.00)	.043 ²
		1989-2010	14	3.00 (2.22-3.22)	
		2011-2015	14	3.56 (3.11-4.56)	
Received Informational Support	Cancer type: other cancers	Yes	6	1.56 (1.33-1.89)	.034 ²
		No	22	2.22 (1.56-3.11)	
	Freq. of email contacts	1-2	10	1.78 (1.44-2.67)	.045 ²
		3-50	9	2.89 (2.22-3.67)	
Received Promotion of well-being	Freq. of email contacts	1-2	10	1.26 (1.18-1.65)	.029 ²
		3-50	9	2.47 (2.29-2.65)	
Needed Customer service support	Children living in the same household	Yes	5	3.33 (3.17-3.83)	.017 ²
		No	23	2.50 (2.08-3.08)	
	Support most received from: family	Yes	17	3.00 (2.17-3.83)	.040 ²
		No	11	2.50 (2.33-3.00)	
Received Customer service support	Children living in the same household	Yes	5	3.16 (3.00-3.33)	.002 ²
		No	23	2.00 (1.67-2.17)	

¹ Kruskal-Wallis H test

² Mann-Whitney U test

Participants' feedback on the survey instrument

The participants had the option to provide feedback about the survey instrument, and 14 participants did so. Based on the content analysis, the themes of the feedback were related to the survey instrument and the support services in general. Participants stated that there were many questions, that it was difficult to conceive the format of the questions that queried two issues at the same time (author's note: needed and received support), wished for a survey instrument for cancer patients in different phases of cancer care, and expressed the need for a survey instrument in Swedish. Moreover, one participant perceived the item "*Support from the counselling nurse who discusses his/her own experiences with cancer-related topics*" as poorly designed. Participants also gave positive feedback on the survey, such as thanks for the inquiry, good questions and questions ok.

The feedback regarding the services in general consisted of emotional support for cancer patients and their close ones, and proposals to develop support activities. The feedback on emotional support for cancer patients and their close ones included issues related to the lack of availability of emotional support in both non-profit cancer societies and public healthcare. Cancer societies and CNs were given a lot of thanks and credit. The latter were called 'angels in disguise'. Feedback related to proposals for developing support activities included statements regarding the need for expertise in cancer societies about general cancer care practices and the rights of cancer patients. Participants also expressed a need for a patient-safety ombudsman in healthcare. Greater engagement of the Board members of the cancer societies as support persons was suggested, as well as joint peer support for cancer patients and their close ones.

Non-service users

In this analysis, the main differences between the non-service users and the actual data are described. Altogether, the data of 13 participants were discarded from the study because of unmet inclusion criteria. In addition, one participant returned an empty questionnaire. Non-service users had fewer missing values on a variable ($n = 20$, 26%) and case levels ($n = 7$, 58%) than the participants in the actual data. The missing values on the variable level ranged from 1–2 (8%–17%).

Among the non-service users, there were fewer men than in the actual data ($n = 1$, 8% vs. $n = 6$, 21%). Moreover, the non-service users were younger (mean 58.5,

SD = 12.4 vs. mean 63.1, SD = 10.0), and a greater proportion of them had an education of vocational degree or less compared to the participants in the actual data ($n = 6$, 50% vs. $n = 9$, 32%). There were only minor differences in terms of life situation between the two groups. In the actual data, just over half of the participants were retired, while in the non-service users' group, 50% of the participants were retired. The non-service users more often had children living in the household than did the participants in the actual data ($n = 4$, 33% vs. $n = 5$, 18%). The same percentage (75%) of participants in both groups lived in a large or medium-sized city. None of the non-service users lived in rural areas, whereas in the actual data, three (11%) participants lived in rural areas.

Breast cancer was the most common cancer among the non-service users ($n = 5$, 42%), while the percentage of breast cancer patients in the actual data was 19% ($n = 7$). The year of diagnosis differed between the two groups. Fewer participants in the actual data were diagnosed within five years than in the non-service users' group ($n = 17$, 49% vs. $n = 8$, 67%). Furthermore, the phase of cancer differed between the groups. Approximately, every third non-service user was in the follow-up phase of their cancer care, whereas half of the participants in the actual data were in that phase of their cancer care. The participants who perceived their health as good or moderate in both groups did not differ much. Conversely, there were fewer non-service users who perceived their health as moderate or poor than in the actual data ($n = 4$, 33% vs. $n = 13$, 47%). Non-service users received the most support more often from the family than the participants in the actual data ($n = 16$, 53% vs. $n = 17$, 34%). Additionally, none of the non-service users mentioned cancer societies as places from where to receive most of their support. Furthermore, the non-service users had more key supporters than did the participants in the actual data ($Md = 7.0$, Q_1 - $Q_3 = 4.25$ - 10.75 vs. $Md = 4.0$, Q_1 - $Q_3 = 3.0$ - 7.8).

5.6 Summary of main results

The main results of the study are related to the development and pre-testing the NRESS instrument, the theoretical basis of which is based on phases I and II, as well as the results obtained using the instrument. Given the small sample size, the new instrument was validated by means of content validation. To evaluate the content validation, content relevance was examined by six raters and an acceptable CVI/Ave level was achieved. The new instrument showed acceptable internal consistency, and the items mainly correlated well to their subscales.

Based on the previous phases of the study, the needed and received types of electronic social support were related to network, information, promotion of well-being and customer service support. Network support was the only type of electronic social support in which the *needed* and *received* support matched each other. Differences were detected in *needed* and *received* support subscales in terms of education, children living in the same household, living environment, cancer type, time of diagnosis, support most received from, frequency of email counselling contact and perception of phone and email as means of communication. To initiate, participate in and develop electronic interactions in ECS and to facilitate *received* electronic social support in different phases of the cancer trajectory, cancer patients need to be familiar with the use of information and communication technology (ICT). Moreover, the structures of ECS need to be functional for cancer patients to receive the needed electronic social support. A summary of the main results is presented in Figure 4.

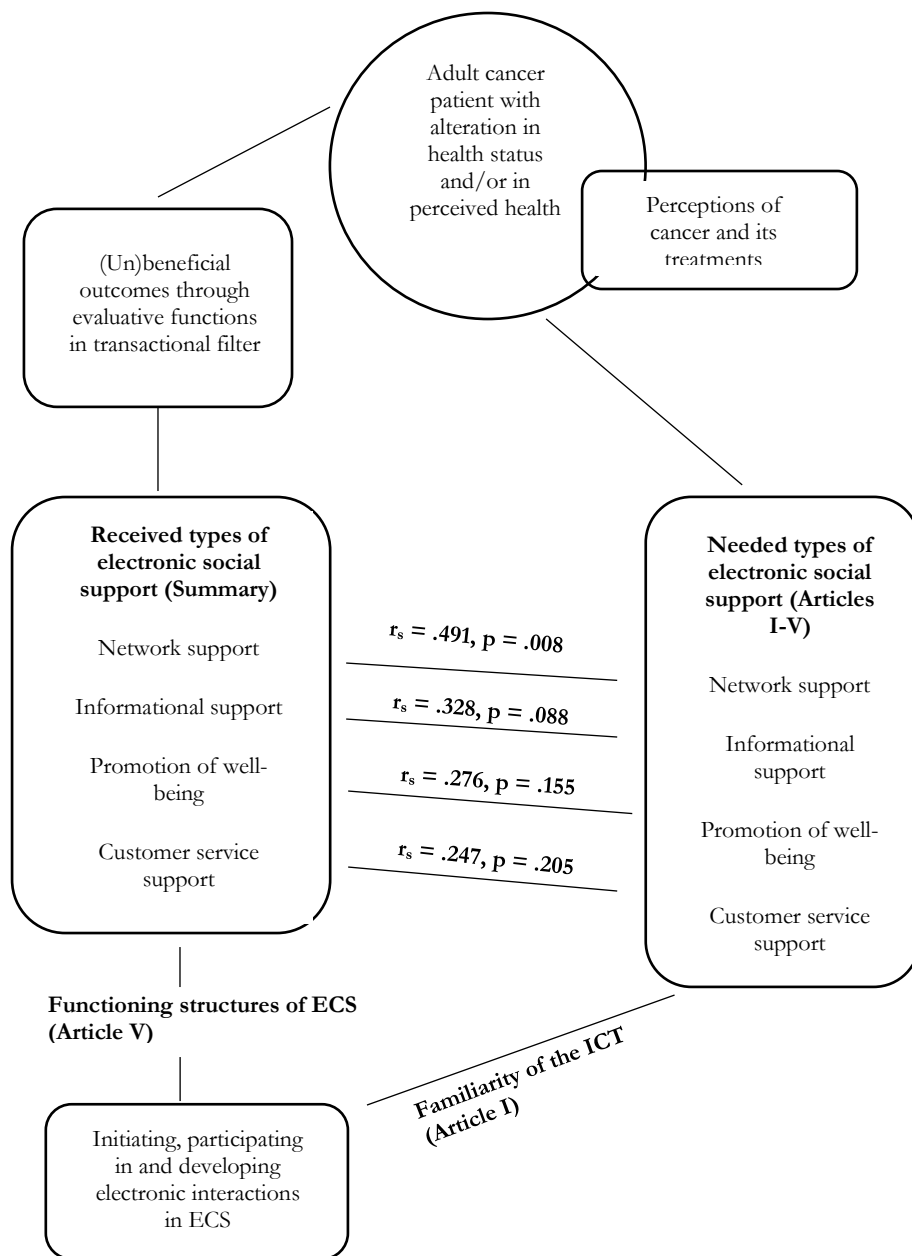


Figure 4. Summary of main results

6 Discussion

6.1 Ethical considerations

Study ethics should be taken into account throughout the study process to ensure the study is acceptable, reliable and its results are credible (TENK, 2012). Two phases of the present study (I and III) were conducted via the Internet. The researcher needed to consider a few ethical issues in this context. The most important issue was related to informed consent. Seeking informed consent involves providing information to support the participants' decision of whether to participate (Ellett et al., 2004). In this study, introductions of the online surveys contained information regarding researcher's research activities, assurance of anonymity and confidentiality, voluntary nature of participation, offer to answer questions raised by the participants as well as an option to withdraw from the study at any time (Burns & Grove, 2005). Informed consent was considered given if a participant pressed 'save' to forward his/her answers to the researcher. In phase II, written informed consent was received from all participants. This process is described in detail in article III because the verbal consent was sought before the phone interviews.

In phase I, approval to conduct the study was obtained from representatives of the Cancer Society of Finland. Favourable endorsement to conduct phase II of the study was obtained from the regional ethics committee of the hospital district (R12271H). In addition, study permits were obtained from each participating cancer society. In phase III, endorsement to conduct the study was obtained from the Ethics Committee of the Tampere region (24/2015), as well as from the participating societies and associations.

The risk-benefit ratio was weighed, and the researcher concluded that there was no potential harm to the participants. It was anticipated that the interviews were not stressful for the participants, because the topic of research was not considered sensitive. (Burns & Grove, 2005; Houghton et al., 2010) Confidentiality was maintained despite detailed descriptions of the participants and participating sites to illustrate the findings and to report the results (Houghton et al., 2010). The researcher removed all identifying information (e.g. names of the cancer societies

and cities) to protect the subjects' privacy. In addition, confidentiality was maintained when storing the data and the informed consent forms. (Burns & Grove, 2005)

A challenge that may affect the study is the nature of data collection involving interviews. The relationship between the researcher, participants and participating sites may raise ethical issues, for example, the ways the relationships were formed and managed, as well as power balance (Houghton et al., 2010). This was especially more of an issue in the interviews than in the online surveys because face-to-face contact required higher levels of interaction between the researcher and the participants (Teddle & Tashakkori, 2009). The researcher informed the participants and the participating sites about the study and about the researcher herself and her role as a nurse researcher in a transparent manner to build an equal relationship. (Houghton et al., 2010)

In addition to the ethics concerning the study participants, the researcher had responsibilities to those not participating in the study, that is, the people funding the study and to those who will use the results of the study. These parties have the right to expect that the research has been conducted in such a way that it was possible for the researcher to answer the questions asked. (Gorard, 2010)

6.2 Inference quality and inference transferability

An integrative framework for inference quality and inference transferability was used to assess the quality of the present mixed methods research design. Inference quality refers to evaluation of the quality of conclusions made on the basis of the results. Inference transferability is used to indicate the degree to which the conclusions may be applied to other specific contexts. (Tashakkori & Teddle, 2008; Teddle & Tashakkori, 2009)

6.2.1 Inference quality

The aspects of inference quality are related to the quality of design and interpretive rigor (Tashakkori & Teddle, 2008; Teddle & Tashakkori, 2009).

Design quality

Design quality is related to the quality of inputs to the research process, that is, the degree to which the researcher has selected the most appropriate procedures for answering the research purposes (Teddle & Tashakkori, 2009). In this section, design quality is assessed through design suitability, design fidelity, within-design consistency and analytic adequacy (Tashakkori & Teddle, 2008; Teddle & Tashakkori, 2009).

Design suitability. An explorative sequential design was considered appropriate because the overall purpose of the study was to explore adult cancer patients' perceptions of electronic social support, which informed the second purpose of the study, that is, to generalise the results to a larger group by developing and pre-testing an instrument (Creswell & Plano Clark, 2007; Morse, 2010; Nastasi et al., 2010). Moreover, the research purposes dictated the methods used in the study. The research questions were not the same in all phases of the study because the research questions were influenced by the researcher's discussions with the communities of practice. (Plano Clark & Badiee, 2010) Finally, the design also matched the selected paradigm, namely, pragmatism (O'Cathain, 2010). Although the methodology and methods were considered appropriate for answering the research questions, the small sample size in phase III may pose a question.

Design fidelity. The design components were implemented with quality and rigor to capture the meanings and the relationships. Data sampling and collection, as well as reconstruction of the data and the results according to the structure of the developed and used categories, were described as transparently as possible. Additionally, instrument development and pre-testing were reported in detail and truthfully. These issues help audit the research to yield consistent results. (Teddle & Tashakkori, 2009) In the data collection phase, different participants were recruited to collect the text data and the numerical data, which minimised the threat to design fidelity (Creswell & Plano Clark, 2007). The reports produced with links to the existing literature in peer-reviewed journals and in the summary strengthened the fidelity of the design. To achieve credible results, regular meetings conducted with co-doctoral students and academic supervisors revealed to disclose the researcher's 'blind spots'. (Flick, 2014; Lincoln & Guba, 1985) However, there exist some threats to design fidelity. First, the sampling was mostly conducted with convenience in mind (Burns & Grove, 2005) owing to the difficulties in reaching the participants, together with the issues related to the preconditions of the study permits. This may have led to selection bias during participants selection (Ahern, 2005), as a result, a

representative cross-section of the population may not have been selected (Burns & Grove, 2005; Jones et al., 2008). Second, the sample size for the numeric data was not adequate, and the sample type was not adequately representative. The planned sample size required to use rigorous procedures for validating the new instrument was not reached, which weakened design fidelity. (Creswell & Plano Clark, 2007) This also hinders generalisation of the results (Munro, 2005; Tashakkori & Teddlie, 2008). One reason for not reaching the required number of participants may be the fact that many studies on cancer patients were going on concurrently (Burns & Grove, 2005). Third, a member check might have strengthened the emic-perspective (phase II), although dependence on lay validity may keep the data shallow and detracted from the research (Meadows & Morse, 2001).

Within-design consistency. The phases of the study were connected logically and seamlessly to each other through the development of the instrument items (Creswell & Plano Clark, 2007). However, inconsistency occurred with the design during data collection in phase III given how one participant stated that the questions in the structured online survey were difficult to understand because two questions (needed and received support) were asked within each item at the same time (Teddlie & Tashakkori, 2009). This hinders the use of the instrument and warrants improvements to it in the future because readability can be identified as a component of content validation of the instrument (Burns & Grove, 2005; Tashakkori & Teddlie, 2008).

Analytic adequacy. Analytic adequacy was achieved by using appropriate analysis techniques in each phase of the study. The data analysis proceeded such that the text data were analysed sequentially followed by the numerical data. In phases I and II, the purpose was to explore the phenomenon; therefore, analysing the content of the text data by proceeding inductively from particulars to universals seemed adequate (Flick, 2014). A threat to the analytic adequacy of this study may be the vast and rich text data and whether the researcher succeeded in disclosing it sufficiently. In phase III, a threat to the analytic adequacy was small sample size, which hindered the use of more powerful statistical analysis techniques to draw generalised conclusions (Creswell & Plano Clark, 2007). Also, there were not enough data to test the validity of the items in order to decide how the items should be grouped together into subscales and which items should be discarded from the instrument entirely (Munro, 2005).

Interpretive rigor

Interpretive rigor is related to the integrity of the process of making meanings. This refers to the degree to which the researcher has succeeded in making credible interpretations on the basis of obtained results. (Teddle & Tashakkori, 2009) The quality of inferences is important to the users of the research. The users of the research must be able to rely on the credibility and trustworthiness of the results if they are going to take actions based on them. (O'Cathain, 2010) The aspects of interpretive rigor are related to interpretive consistency, theoretical consistency, interpretive agreement, interpretive distinctiveness, integrative efficacy and interpretive correspondence (Tashakkori & Teddle, 2008; Teddle & Tashakkori, 2009).

Interpretive consistency. The conclusions drawn were based on the findings. For example, no causal inferences between needed and received electronic social support were made based on correlation data. Moreover, the intensity of the conclusions was based on the magnitude of the results obtained. Because the sample size was small, strong generalisations were not made. (Creswell & Plano Clark, 2007; Tashakkori & Teddle, 2008) Instead, the context was taken into account.

Theoretical consistency. The results were reflected against those of previous studies, and deviations from previous findings are presented (Tashakkori & Teddle, 2008).

Interpretive agreement. The conclusions were reflected with the dissertation committee. A lack of member check can be considered a threat to interpretive agreement because the research purpose placed value on the perceptions of the participants. Therefore, the researcher was not aware whether the participants agreed with the researcher's interpretations. (O'Cathain, 2010; Tashakkori & Teddle, 2008) Publication of the results in peer-reviewed journals can be considered being in favour of the interpretive agreement of this study (Tashakkori & Teddle, 2008; Teddle & Tashakkori, 2009).

Interpretive distinctiveness. In the inductive content analysis of the text data, data reduction was based on the similarities and differences found in the data (Flick, 2014; Vaismoradi et al., 2013). To achieve consensus in terms of the content and category names and to eliminate other possible interpretations, the researcher had reflective discussions with senior nurse researchers (Tashakkori & Teddle, 2008). A threat to the interpretive distinctiveness of this study was related to the possible gap between the researcher's construction of reality and meanings and those of the informants because member check was not performed, as stated previously (Creswell & Plano

Clark, 2007). Also, strong conclusions could not be drawn due to the small numeric data sample (Tashakkori & Teddlie, 2008).

Integrative efficacy. The different phases of the study were integrated to draw meta-inferences in the discussion of the results, as well as in the Conclusions sections. The results of phases I and II were reflected against the results of phase III. The results obtained in phase III were not fully consistent with the results of previous phases, and this is presented in the Discussion section in a transparent manner. The inconsistency of the results was most likely related to problems in sampling (Teddlie & Tashakkori, 2009). Therefore, transferability of the findings and conclusions should be made with caution. Combination of the inferences from the different phases of the study also provided more general and meaningful meta-inferences than would have been possible on the basis of either set alone.

Interpretive correspondence. The meta-inferences drawn here can be considered to satisfy the initial purpose of using the MMR design, that is, to explore adult cancer patients' perceptions of electronic social support and to measure the needed and received electronic social support. Moreover, the conclusions made on the basis of the results correspond to the initial research tasks. (Teddlie & Tashakkori, 2009)

6.2.2 Inference transferability

Inference transferability denotes the degree to which the conclusions of a work can be applied to other entities (Teddlie & Tashakkori, 2009). Because the ecological and population transferability issues overlap (Teddlie & Tashakkori, 2009), they are not separated in this discussion.

Ecological/population and temporal transferability. The conclusions made in the study can be considered to be transferable partly to off-electronic settings, for example, to cancer care in public healthcare and to all types of adult cancer patients, albeit with serious cautions because the sample size in this study was small. This could also be a major issue when remote/eHealth services will become more common in the future.

6.3 Discussion of results

This study explored adult cancer patients' perceptions of electronic social support on the general Internet and through ECS of non-profit cancer societies. The types of social support needed and received were the focus of the present study. Based on the literature, there was limited and unclear information regarding the study topic, hindering the use of extant research results. Therefore, the types of social support were clarified using an online survey with open-ended questions in phase I. To further specify the types of social support in the non-profit context, adult cancer patients and CNs were interviewed in phase II.

The results of phase I revealed that adult cancer patients needed and were motivated to seek support on issues quite similar to those found in earlier research, and the types of support were informational, emotional and tangible (e.g. Buis & Whitten, 2011; Cutrona et al., 2013; Dolce, 2011). Phase II revealed more specifically the types of support needed and how these needs were met. In this area, there was a lack of clear evidence in the literature. Furthermore, the results of the present study provide new information about the phases in which various types of support are needed in the cancer trajectory, and these results differ clearly from our previous understanding of the matter. The results also provide new insights into cancer patients' perceptions of how the received types of support can be integrated with their cancer care in public healthcare under certain circumstances and with some exceptions. Additionally, organisational, individual and counselling process related facilitators of and barriers to electronic social support were identified.

Based on the types of social support identified in phases I and II, a cancer-specific NRESS instrument was developed and pre-tested, and the results are discussed below. First, the validity and reliability of the instrument are discussed, followed by the results obtained using the instrument.

To assess the content validation of the instrument, a panel of six raters was employed. The content validity index when using an averaging calculation method was at an acceptable level of .91 (Polit et al., 2007; Polit & Beck, 2006).

The lowest acceptable reliability coefficient level was set rather low (.60) in the study because the instrument was newly developed and because there are very few items in the instrument (Knapp & Brown, 1995; Streiner et al., 2015). Nevertheless, the NRESS and its subscales showed acceptable Cronbach's alpha coefficient values. However, the literature suggests that slightly higher (.70) level of reliability is recommended for newly developed instruments (Burns & Grove, 2005; Tavakol & Dennick, 2011). The received Customer service support subscale was the only one

with reliability score of $< .70$. However, it is worth mentioning that the total scores may be more reliable than the subscores in determining reliability. Moreover, after *future* factor analysis performance, items with low factor weights can be deleted. (Burns & Grove, 2005) The total NRESS reliability scores ($> .90$) suggest that the instrument may have some overlapping and redundant items and that it may need to be shortened in length (Streiner et al., 2015; Tavakol & Dennick, 2011). Owing to the small sample size, confidence intervals of alpha reliabilities were displayed (Streiner et al., 2015).

The number of responses in phase III was surprisingly low, possibly because the survey was administered only via the Internet. However, in phase I, the online survey with open-ended questions produced a substantial number of responses within a short time-period. Moreover, today, Internet use is somewhat more common than five years ago, especially among the older age groups (Statistics Finland, 2015). Therefore, a greater number of responses were expected, although evidence to this end from extant research is not clear when surveying people online. Studies have reported lower rate of use of online questionnaires compared to telephone interviews or mailed questionnaires (Christie et al., 2014; Couturier et al., 2015; Jones et al., 2008; Reinisch et al., 2016). Especially, low response rates have been reported in psychosocial cancer care research (Santin et al., 2013). In contrast, some studies state that the number of respondents could be higher when using an online questionnaire (Horevoorts et al., 2015; Hunter, 2012). In retrospect, participant recruitment in phase III may have benefitted from email invitations (this would have required interventions on part of the CNs) and email or text message reminders, monetary or other incentives, such as a possibility for participants to require a mailed questionnaire and greater emphasis on the participants' potential contribution to the research (Cunningham et al., 2015; Horevoorts et al., 2015; Hunter, 2012; Short et al., 2015).

There were some interesting issues regarding the background factors in phase III. One issue was related to the participants' age. The participants in the study were approaching retirement age, and more than half of them were retired. Extant research states that those who use electronic services are typically younger and employed (Blanch-Hartigan & Viswanath, 2015; Corboy et al., 2011), although dissenting voices have been presented (e.g. Kim & Kwon, 2010). This may simply be due to the fact that cancer is more common in older age groups (NORDCAN, 2014), and cancer survivors may access the Internet at a lower rate than the general population (Chou et al., 2011). Another interesting issue was related to the participants' living environment. The number of participants from rural areas was

expected to be higher because evidence suggests that Internet- and phone-based services are the most-used types of support in rural areas (Corboy et al., 2011; Corboy et al., 2014; Kratzke et al., 2013). However, the majority of the participants in the present study lived in large or medium-sized cities, where the services of cancer societies are more accessible face-to-face and, for example, interviewees in phase II expressed their desire for face-to-face contact as well. Other background factors were similar to those in extant research (Blanch-Hartigan & Viswanath, 2015; Dilts et al., 2009; Ludgate et al., 2011; Reid & Porter, 2011; Valero-Aguilera et al., 2014).

Informational support was the most needed type of electronic social support, especially the nature of disease, and the result is in accordance with the results of earlier research (Dickerson et al., 2011; Dolce, 2011; Grant & Wiegand, 2013; Kent et al., 2012; Kim & Kwon, 2010; Lee & Hawkins, 2010; Lobchuk et al., 2015; Love et al., 2012; Paul et al., 2011). The result also agrees with the earlier phases of this very study. However, informational support was not the most received support, and participants rated that they needed *some* informational support on average, not *very much*. Explanations for this may be, alongside with the Act on the status and rights of patients (Finlex, 785/1992), the Kanta.fi (National Health Archive) portal on which healthcare units enter patient records from their own data systems and in which patients can monitor their medical records without geographical restrictions (Hordern et al., 2011; Kanta, 2016). These actions will increase patients' access to their medical information and may decrease the need for additional information. Moreover, the participants of the study were well educated, which may have had an impact on their need for additional information. However, evidence suggests that cancer patients with higher levels of education tend to use electronic sources of information more prolifically than those with lower levels of education (Blanch-Hartigan & Viswanath, 2015; Lee et al., 2012). Nevertheless, it is worth mentioning that factors other than sociodemographic (Chou et al., 2011) may be associated with the use of electronic informational services, such as the level of social support, symptom distress, depression and health-related quality of life (Børøsund et al., 2013), as well as psychosocial determinants such as attitude and self-efficacy (Smith-McLallen et al., 2011). This study also revealed differences between participants' living environment and the needed informational support. The majority of the participants lived in urban areas, and the results of previous studies argue that there are no widespread differences between rural and non-rural patients, for example, in the use of mental health services (Andrykowski & Burris, 2010), and it is not the distance from service centres but attitudes toward different types of services and support services in general (Corboy et al., 2011; Corboy et al., 2014; Sabesan & Kelly,

2014) and gender (Goldner et al., 2013) that may predict the use of electronic services.

Surprisingly, promotion of well-being was the least needed and received type of electronic social support. This is not in line with the results of phases I and II of the present study because the promotion of well-being was strongly pointed out in these phases. Neither is it in accordance with the results of earlier research because psychological needs have shown to be the major unmet supportive care needs (Chambers et al., 2012; Ekberg et al., 2014; Lee & Hawkins, 2010). Moreover, the low needed and received support was unexpected because electronic interventions have shown to have many positive effects on psychological well-being, such as improved quality of life (Badger et al., 2013; Bouma et al., 2015; Osei et al., 2013), adaptation to and coping with the illness (Cleary & Stanton, 2015; Schook et al., 2014), and improvements in unmet supportive care needs (Lee & Hawkins, 2010; Liao et al., 2014; White et al., 2012). The lack of needed promotion of well-being may be due to the fact that the participants reported getting most support from their family and healthcare professionals, which has been reported in earlier studies as well (Hill, 2015; Merluzzi et al., 2015). The most needed support in the promotion of well-being area was empathy from the CN, but the participants reported not receiving as much empathy as they needed. In the previous phases of the study, the participants reported that they needed to feel that the CN cared for them, but a few participants also expressed that they were left without encouragement and answers to their emails were almost similar to automatic, standard responses to certain types of questions. However, CNs found it utmost important to show the patients understanding in many different ways to facilitate social support. An earlier study revealed that empathy reception lowers cancer-related concerns (Han et al., 2011), and it has also been evidenced that the effectiveness of information seeking affects patients' perceived empathy in electronic communities. Therefore, electronic communities, such as ECS, need to develop tools that will make information seeking more effective to increase patients' perceived empathy. (Nambisan, 2011)

Network support was the most received type of electronic social support. "*A person you can turn to if you so wish*" was the most *needed* and *received* network support. The result agrees with the results of the previous phases of the study because the participants stated that it was of utmost importance to know that there was a person to turn to in times of need, also for future problems. In addition, network support was the only type of support with a match between the needed and received support. The occasions when patients had to turn to ECS may be related to dissatisfaction with healthcare professionals in primary cancer care in terms of information and

support provision (Dolce, 2011; Grimsbo et al., 2011; Tustin, 2010). The participants of the present study reported that guidance to ECS should be a natural part of supportive cancer care in public healthcare, and it should not be solely nurse-dependent because not every patient is aware of non-profit ECS. Education and phone and email as means of communication were associated with the needed network support. This agrees with earlier findings because higher education has found to be associated with a positive attitude to electronic social support (Girault et al., 2015; Jansen et al., 2015), and positive perceptions of the use of electronic devices for health activities (Girault et al., 2015).

Customer service support in the form of *“Expert counselling”* was the most needed and received electronic social support. This partly agrees and disagrees with the results of previous phases of the study. In previous phases of the study, participants wanted multidimensional information especially from a professional body, and there were circumstances in which this did not happen. In addition to family, professionals have been reported to be one of the major sources of social support for adult cancer patients, especially for medical advice regarding cancer and overall health and well-being (Kim & Kwon, 2010; Wong et al., 2014). The results revealed a significant relationship between the needed and received customer service support and the participants with children living in the same household. At first glance, it seemed strange that the participants with children needed and received this kind of support and not, for example, promotion of well-being. However, it is rational because participants with children living in their household may need the most suitable means of communication to address their needs, that is, support based on their specific needs and support without time and geographic restrictions because they may have difficulties in finding time and resources to participate in offline supportive services owing to their responsibilities and guilt about prioritizing care for self when they have dependent children (Ahmad et al., 2015). Moreover, cancer patients with children have increased levels of needs related to daily living activities and dissatisfied needs in terms of patient care and support (Griesser et al., 2011). Therefore, it is important in ECS to screen the life-management of patients and involve family in the counselling in order to promote the life-management of patients, as was stated by CNs in their interviews.

Frequency of email contacts was associated significantly with received electronic social support in every other support area but customer service support. It seems logical but inconclusive that more frequent contact leads to the provision of more support. This can also reflect the fact that one contact may be all that is needed to obtain the support not available from other structures of social support, rather than

lack of satisfaction with the support obtained (Queenan et al., 2010). This agrees with the results of the earlier phases of this study because most participants contacted ECS only a few times.

6.4 Importance of the study

The present study raises awareness within and adds new research-based information to the body of nursing knowledge on adult cancer patients' perceptions of electronic social support in non-profit contexts. This study adopts a new perspective because so far, studies have not provided insights into the phases of support needs during the cancer trajectory from the perspective of cancer patients. The present study also contributed new information on the ways that the received electronic social support is integrated into cancer care in public healthcare. Furthermore, facilitators of and barriers to electronic social support from the perspective of support providers and the needed and received electronic social support recorded in a single study were reported. The study also produced a cancer-specific electronic social support instrument whose theoretical base lies in the perceptions of both actors, cancer patients and CNs, in the electronic social support process. The development and pre-testing of the instrument established as a baseline for its refinement and, hopefully, greater understanding of adult cancer patients' electronic social support. As well, the study's theoretical framework incorporated the theory of online social support, which has not been implemented in research or practice. Thus, the study provided new information about the application of this theory.

The present study also has implications for formal nursing education. This research informs nursing education about adult cancer patients' perceptions of electronic social support and associated knowledge, which stresses the importance of psychosocial aspects in comprehensive cancer nursing, for example, when teaching about issues pertinent to the rehabilitation of cancer patients. There is a risk that psychosocial nursing education can be neglected in favour of somatic nursing education, which might also be the situation in cancer nursing practice.

The different types of electronic social support identified in the study might have yet to be noticed in primary cancer care and therefore, can be used as basis of education for cancer patients and nurses caring for cancer patients. These findings might provide, for example, reminders of issues to upraise with patients. Furthermore, the results can be used as a framework for continuous education in psychosocial cancer nursing. Adult cancer patients seemed to prefer personalised

support targeted specifically at their needs over general cancer information found on various web pages. These results show that, in the future, there might be a need for email contact with patients in public healthcare. Therefore, it is suggested that nurses be trained in various aspects of email communication with patients, such as information provision and empathic/caring writing.

The study results can also benefit management. The results clearly show the importance of co-operation among the various actors in cancer care. Management ought to take this need seriously as ECS have the potential to provide services not possible through public healthcare systems with limited resources. Therefore, ECS should be seen as a complementary service targeting the same aims in cancer patients' care. Collaboration among the actors in cancer care and low-threshold services is still needed to offer services that the public sector does not address adequately. The role of the non-profit sector as a more flexible, functional service producer which improves patients' well-being, reduces regional health inequalities and supports patients' social involvement. The on-going social and healthcare reforms should acknowledge these benefits of the non-profit sector's involvement.

6.5 Conclusions

The following conclusions can be drawn from the results of the present study:

1. On the Internet, adult cancer patients seek information from reliable sources, emotional support from peers to make their lives easier and tangible support to manage their daily life with cancer.
2. ECS have the potential to provide personalised, matching type of support to enhance patients' coping abilities, but the limited resources of ECS can hinder the provision of this care.
3. Adult cancer patients need electronic social support in various phases of their cancer trajectory, which are different from the support phases as traditionally understood by healthcare systems.
4. The support received from ECS can be integrated into cancer care in public healthcare under certain circumstances and with some exceptions.

5. The facilitators of and barriers to electronic social support for adult cancer patients were related to organisations, individuals and the counselling process.
6. The NRESS instrument and its subscales were internally consistent. Although a few items correlated better to other subscales, it would be premature to remove them from the instrument without further evidence.
7. Network support as a type of electronic social support matched the needed and received support. The most needed electronic social support was informational support, but there was a mismatch between the needed and received informational support.
8. Patients' education level, living environment, cancer type, other supporters, year of diagnosis and the presence of minors living in the patient's household influenced electronic social support.
9. Email was the most-used means of communication between adult cancer patients and CNs.

6.6 Implications for further research

In the future, cancer patients' perceptions of the extent to which ECS fulfil their needs should be examined in research with a longitudinal design. This research could improve cancer care processes and patient outcomes and contribute new information about the use of aspects of online social support theory not applied in the present study, particularly quantitative outcomes through perceptual and cognitive filters which do not occur in cyberspace. The use of other aspects of the theory also enables the synthesis of quantitative and qualitative outcomes (linking) resulting in a more comprehensive understanding of electronic social support.

The NRESS instrument allows measuring cancer-specific needed and received electronic social support nationally and, partly, internationally in non-profit contexts. However, the instrument requires further testing with a larger sample before it can be administered in practice. Content validation might need to be re-evaluated by an expert panel comprised of members other than post-graduate students (e.g. CNs). Exploratory factor analysis should be conducted to examine the relationships among

the various items in the instrument and criterion validation (convergent validation) should assess the degree of similarity of operationalisations that theory indicates should be similar.

7 References

- Abramson, K., Keefe, B., & Chou, W. S. (2015). Communicating about cancer through facebook: A qualitative analysis of a breast cancer awareness page. *Journal of Health Communication, 20*(2), 237-243. Doi:10.1080/10810730.2014.927034
- Ahern, N. R. (2005). Using the internet to conduct research. *Nurse Researcher, 13*(2), 55-70.
- Ahmad, S., Fergus, K., & McCarthy, M. (2015). Psychosocial issues experienced by young women with breast cancer: The minority group with the majority of need. *Current Opinion in Supportive & Palliative Care, 9*(3), 271-278.
- Alba-Ruiz, R., Bermudez-Tamayo, C., Pernet, J. J., Garcia-Gutierrez, J. F., Cozar-Olmo, J. M., & Valero-Aguilera, B. (2013). Adapting the content of cancer web sites to the information needs of patients: Reliability and readability. *Telemedicine Journal & E-Health, 19*(12), 956-966.
- Alfano, C. M., Lichstein, K. L., Vander Wal, G., S., Smith, A. W., Reeve, B. B., McTiernan, A., Bernstein, L., Baumgartner, K. B., & Ballard-Barbash, R. (2011). Sleep duration change across breast cancer survivorship: Associations with symptoms and health-related quality of life. *Breast Cancer Research & Treatment, 130*(1), 243-254.
- Andersen, T., & Ruland, C. M. (2009). Cancer patients' questions and concerns expressed in an online nurse-delivered mail service: Preliminary results. *Studies in Health Technology & Informatics, 146*, 149-153.
- Andrews, G., Tennant, C., Hewson, D., & Schonell, M. (1978). The relation of social factors to physical and psychiatric illness. *American Journal of Epidemiology, 108*(1), 27-35.
- Andrykowski, M. A., & Burris, J. L. (2010). Use of formal and informal mental health resources by cancer survivors: Differences between rural and nonrural survivors and a preliminary test of the theory of planned behavior. *Psycho-Oncology, 19*(11), 1148-1155. Doi:10.1002/pon.1669
- Antonucci, T. C. (1985). Social support: Theoretical advances, recent findings and pressing issues. In I. G. Sarason, & B. R. Sarason (Eds.), *Social support: Theory, research and applications* (pp. 21-37). Boston, MA: Nijhoff.
- Antonucci, T. C., & Jackson, J. S. (1990). The role of reciprocity in social support. In B. R. Sarason, I. G. Sarason & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 173-198). New York, NY: A Wiley-Interscience Publication.
- Arving, C., Brandberg, Y., Feldman, I., Johansson, B., & Glimelius, B. (2014). Cost-utility analysis of individual psychosocial support interventions for breast cancer patients in a randomized controlled study. *Psycho-Oncology, 23*(3), 251-258. Doi:10.1002/pon.3411
- Attai, D. J., Cowher, M. S., Al-Hamadani, M., Schoger, J. M., Staley, A. C., & Landercasper, J. (2015). Twitter social media is an effective tool for breast cancer patient education and support: Patient-reported outcomes by survey. *Journal of Medical Internet Research, 17*(7), e188. Doi:10.2196/jmir.4721

- Azzani, M., Roslani, A. C., & Su, T. T. (2015). The perceived cancer-related financial hardship among patients and their families: A systematic review. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 23(3), 889-898. Doi:10.1007/s00520-014-2474-y
- Badger, T., Segrin, C., Pasvogel, A., & Lopez, A. M. (2013). The effect of psychosocial interventions delivered by telephone and videophone on quality of life in early-stage breast cancer survivors and their supportive partners. *Journal of Telemedicine and Telecare*, 19(5), 260-265. Doi:10.1177/1357633X13492289
- Balka, E., Krueger, G., Holmes, B. J., & Stephen, J. E. (2010). Situating internet use: Information-seeking among young women with breast cancer. *Journal of Computer-Mediated Communication*, 15(3), 389-411. Doi:<http://dx.doi.org/10.1111/j.1083-6101.2010.01506.x>
- Beaver, K., Williamson, S., & Chalmers, K. (2010). Telephone follow-up after treatment for breast cancer: Views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing*, 19(19-20), 2916-2924. Doi:<http://helios.uta.fi:2142/10.1111/j.1365-2702.2010.03197.x>
- Becker, H., Mackert, M., & Kang, S. J. (2013). Using an e-health intervention to promote the health of cancer survivors with preexisting disabling conditions. *CIN: Computers, Informatics, Nursing*, 31(3), 107-114.
- Belkora, J., Stupar, L., O'Donnell, S., Loucks, A., Moore, D., Jupiter, C., Johnson, N., & Wilson, L. (2012). Decision support by telephone: Randomized controlled trial in a rural community setting. *Patient Education and Counseling*, 89(1), 134-142. Doi:10.1016/j.pec.2012.06.009
- Bender, J. L., Jimenez-Marroquin, M., & Jadad, A. R. (2011). Seeking support on facebook: A content analysis of breast cancer groups. *Journal of Medical Internet Research*, 13(1), 18-18. Doi:10.2196/jmir.1560
- Bender, J. L., Wiljer, D., To, M. J., Bedard, P. L., Chung, P., Jewett, M. A., Matthew, A., Moore, M., Warde, P., & Gospodarowicz, M. (2012). Testicular cancer survivors' supportive care needs and use of online support: A cross-sectional survey. *Supportive Care in Cancer*, 20(11), 2737-2746.
- Bergénmar, M., Johansson, H., & Sharp, L. (2014). Patients' perception of information after completion of adjuvant radiotherapy for breast cancer. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*, 18(3), 305-309. Doi:10.1016/j.ejon.2014.02.002
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, 51(6), 843-857. Doi:[http://helios.uta.fi:2161/10.1016/S0277-9536\(00\)00065-4](http://helios.uta.fi:2161/10.1016/S0277-9536(00)00065-4)
- Blanch-Hartigan, D., & Viswanath, K. (2015). Socioeconomic and sociodemographic predictors of cancer-related information sources used by cancer survivors. *Journal of Health Communication*, 20(2), 204-210. Doi:10.1080/10810730.2014.921742
- Børøsund, E., Cvancarova, M., Ekstedt, M., Moore, S. M., & Ruland, C. M. (2013). How user characteristics affect use patterns in web-based illness management support for patients with breast and prostate cancer. *Journal of Medical Internet Research*, 15(3), 15-33. Doi:<http://dx.doi.org.helios.uta.fi/10.2196/jmir.2285>
- Bouma, G., Admiraal, J. M., de Vries, E. G., Schroder, C. P., Walenkamp, A. M., & Reyners, A. K. (2015). Internet-based support programs to alleviate psychosocial and physical

- symptoms in cancer patients: A literature analysis. *Critical Reviews in Oncology/Hematology*, 95(1), 26-37. Doi:10.1016/j.critrevonc.2015.01.011
- Brant, J. M., Beck, S., Dudley, W. N., Cobb, P., Pepper, G., & Miaskowski, C. (2011). Symptom trajectories in posttreatment cancer survivors. *Cancer Nursing*, 34(1), 67-77.
- Braybrooke, J. P., Mimoun, S., Zarca, D., Elia, D., Pinder, B., Lloyd, A. J., Breheny, K., Lomazzi, M., & Borisch, B. (2015). Patients' experiences following breast cancer treatment: An exploratory survey of personal and work experiences of breast cancer patients from three European countries. *European Journal of Cancer Care*, 24(5), 650-661. Doi:10.1111/ecc.12222
- Buis, L. R., & Whitten, P. (2011). Comparison of social support content within online communities for high- and low-survival-rate cancers. *CIN: Computers, Informatics, Nursing*, 29(8), 461-467.
- Burles, M., & Holtslander, L. (2013). "Cautiously optimistic that today will be another day with my disease under control": Understanding women's lived experiences of ovarian cancer. *Cancer Nursing*, 36(6), 436-444. Doi:http://helios.uta.fi:2132/10.1097/NCC.0b013e318277b57e
- Burns, N., & Grove, S. (2005). *The practice of nursing research. Conduct, critique and utilization*. (5th ed.). Philadelphia, PA: Elsevier Saunders.
- Callahan, C., & Brintzenhofesoc, K. (2015). Financial quality of life for patients with cancer: An exploratory study. *Journal of Psychosocial Oncology*, 33(4), 377-394. Doi:10.1080/07347332.2015.1045679
- Cancer Society of Finland. (2016). The cancer society. Retrieved from <https://www.cancersociety.fi/organisation/the-cancer-society/>
- Chambers, S. K., Girgis, A., Occhipinti, S., Hutchison, S., Turner, J., Morris, B., & Dunn, J. (2012). Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *European Journal of Cancer Care*, 21(2), 213-223.
- Chan, E. C., & Vernon, S. W. (2008). Implementing an intervention to promote colon cancer screening through e-mail over the internet: Lessons learned from a pilot study. *Medical Care*, 46(9 Suppl 1), S117-22.
- Chan, M. E., Ang, N. K., Cho, A. A., Chow, Y. L., & Taylor, B. (2014). Online chemotherapy symptom care and patient management system: An evaluative study. *CIN: Computers, Informatics, Nursing*, 32(2), 75-83.
- Chiu, Y. C., & Hsieh, Y. L. (2013). Communication online with fellow cancer patients: Writing to be remembered, gain strength, and find survivors. *Journal of Health Psychology*, 18(12), 1572-1581.
- Chou, W. Y., Liu, B., Post, S., & Hesse, B. (2011). Health-related Internet use among cancer survivors: Data from the health information national trends survey, 2003-2008. *Journal of Cancer Survivorship: Research and Practice*, 5(3), 263-270. Doi:10.1007/s11764-011-0179-5
- Chou, W. Y. S., Hunt, Y., Folkers, A., & Augustson, E. (2011). Cancer survivorship in the age of YouTube and social media: A narrative analysis. *Journal of Internet Medical Research*, 13(1), e7. Doi:10.2196/jmir.1569
- Christie, A., D., H., Dale, O., Schulz, T., & Hagen, K. B. (2014). Collection of patient-reported outcomes; Text messages on mobile phones provide valid scores and high response rates. *BMC Medical Research Methodology*, 14, 52.
- Cleary, E. H., & Stanton, A. L. (2015). Mediators of an Internet-based psychosocial intervention for women with breast cancer. *Health Psychology: Official Journal of the*

- Division of Health Psychology, American Psychological Association*, 34(5), 477-485.
Doi:10.1037/hea0000170
- Clinton-McHarg, T., Paul, C., Boyes, A., Rose, S., Vallentine, P., & O'Brien, L. (2014). Do cancer helplines deliver benefits to people affected by cancer? A systematic review. *Patient Education & Counseling*, 97(3), 302-309.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, 38(5), 300-314.
- Cobb, S. (1979). Social support and health through the life course. In M. W. Riley (Ed.), *Aging from birth to death: Interdisciplinary perspectives* (pp. 93-106). Boulder, CO: Westview Press.
- Cohen, S., Gottlieb, B. H., & Underwood, L. G. (2000). Social relationships and health. In B. H. Gottlieb, L. G. Underwood & S. Cohen (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 3-25). Oxford: Oxford University Press.
- Cohen, S., & Hoberman, H. M. (1983). Positive events and social support as buffers of life change stress. *Journal of Applied Social Psychology*, 13(2), 99-125.
- Cohen, S., & McKay, G. (1984). Social support, stress and the buffering hypothesis: A theoretical analysis. In A. Baum, J. E. Singer & S. E. Taylor (Eds.), *Handbook of psychology and health (vol 4)* (). Hillsdale, NJ: Erlbaum.
- Cohen, S., Mermelstein, R., Karmarck, T., & Hoberman, H. M. (1985). Measuring the functional components of social support. In I. G. Sarason, & B. R. Sarason (Eds.), *Social support: Theory, research and application* (pp. 77-94). Boston, MA: Nijhoff.
- Cohen, S., & Syme, L. (1985). Issues in the study and application of social support. In S. Cohen, & L. Syme (Eds.), *Social support and health* (pp. 3-22). Orlando, FL: Academic Press, INC.
- Cohen, S., & Wills, T. A. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357.
- Collins, K. M. T. (2010). Advanced sampling designs in mixed research. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 353-377). Thousand Oaks, CA: SAGE Publishing, Inc.
- Cooney, M. A., Galvin, R., & Stokes, E. K. (2015). Do women with breast cancer report treatment after-effects to healthcare professionals, and who provides the intervention? *International Journal of Rehabilitation Research*, 38(1), 20-26.
- Corboy, D., McLaren, S., Jenkins, M., & McDonald, J. (2014). The relationship between geographic remoteness and intentions to use a telephone support service among Australian men following radical prostatectomy. *Psycho-Oncology*, 23(11), 1259-1266.
Doi:10.1002/pon.3559
- Corboy, D., McLaren, S., & McDonald, J. (2011). Predictors of support service use by rural and regional men with cancer. *Australian Journal of Rural Health*, 19(4), 185-190.
Doi:10.1111/j.1440-1584.2011.01210.x
- Cornwall, A., Moore, S., & Plant, H. (2008). Embracing technology: Patients', family members' and nurse specialists' experience of communicating using e-mail. *European Journal of Oncology Nursing*, 12(3), 198-208.
- Couturier, B., Carrat, F., Hejblum, G., & SENTIPAT Study Group. (2015). Comparing patients' opinions on the hospital discharge process collected with a self-reported questionnaire completed via the Internet or through a telephone survey: An ancillary

- study of the SENTIPAT randomized controlled trial. *Journal of Medical Internet Research*, 17(6), e158.
- Cox, A., Bull, E., Cockle-Hearne, J., Knibb, W., Potter, C., & Faithfull, S. (2008). Nurse led telephone follow up in ovarian cancer: A psychosocial perspective. *European Journal of Oncology Nursing*, 12(5), 412-417. Doi:<http://helios.uta.fi:2142/10.1016/j.ejon.2008.06.002>
- Crane-Okada, R., Freeman, E., Kiger, H., Ross, M., Elashoff, D., Deacon, L., & Giuliano, A. E. (2012). Senior peer counseling by telephone for psychosocial support after breast cancer surgery: Effects at six months. *Oncology Nursing Forum*, 39(1), 78-89.
- Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: SAGE Publications, Inc.
- Creswell, J. W., & Tashakkori, A. (2007). Differing perspectives on mixed methods research. *Journal of Mixed Methods Research*, 1(4), 303-308. Doi:10.1177/1558689807306132
- Cunningham, C. T., Quan, H., Hemmelgarn, B., Noseworthy, T., Beck, C. A., Dixon, E., Samuel, S., Ghali, W. A., Sykes, L. L., & Jette, N. (2015). Exploring physician specialist response rates to web-based surveys. *BMC Medical Research Methodology*, 15, 32.
- Current Care Guidelines. (2014). Guidelines. Retrieved from http://www.kaypahoito.fi/web/kh/suositikset?p_auth=E6WtZUIK&p_p_id=KH2014suositukset_WAR_KH2014suosituksetportlet&p_p_lifecycle=1&p_p_state=normal&p_p_mode=view&p_p_col_id=column-1&p_p_col_count=1
- Curry, L., & Nunez-Smith, M. (2015). *Mixed methods in health sciences research. A practical primer*. Thousand Oaks, CA: SAGE Publications, Inc.
- Curtis, R., Groarke, A., McSharry, J., & Kerin, M. (2014). Experience of breast cancer: Burden, benefit, or both? *Cancer Nursing*, 37(3), E21-30.
- Cusack, M., & Taylor, C. (2010). A literature review of the potential of telephone follow-up in colorectal cancer. *Journal of Clinical Nursing*, 19(17-18), 2394-2405. Doi:<http://helios.uta.fi:2142/10.1111/j.1365-2702.2010.03253.x>
- Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 319-366). New York, NY: A Wiley-Interscience Publication.
- Cutrona, S. L., Roblin, D. W., Wagner, J. L., Gaglio, B., Williams, A. E., Torres Stone, R., Field, T. S., & Mazor, K. M. (2013). Adult willingness to use email and social media for peer-to-peer cancer screening communication: Quantitative interview study. *JMIR Research Protocols*, 2(2), e52.
- DeVellis, R. F. (2012). *Scale development. Theory and applications*. (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Devitt, B., Hatton, A., Baravelli, C., Schofield, P., Jefford, M., & Mileschkin, L. (2010). What should a support program for people with lung cancer look like? Differing attitudes of patients and support group facilitators. *Journal of Thoracic Oncology: Official Publication of the International Association for the Study of Lung Cancer*, 5(8), 1227-1232.
- Dickerson, S. S., Reinhart, A., Boehmke, M., & Akhu-Zaheya, L. (2011). Cancer as a problem to be solved: Internet use and provider communication by men with cancer. *CIN: Computers, Informatics, Nursing*, 29(7), 388-395.
- Dierckx de Casterle, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, 49(3), 360-371.

- Dilts, D., Ridner, S. H., Franco, A., & Murphy, B. (2009). Patients with cancer and e-mail: Implications for clinical communication. *Supportive Care in Cancer*, 17(8), 1049-1056.
- Dolce, M. C. (2011). The Internet as a source of health information: Experiences of cancer survivors and caregivers with healthcare providers. *Oncology Nursing Forum*, 38(3), 353-359.
- Drageset, J., Corbett, A., Selbaek, G., & Husebo, B. (2014). Cancer-related pain and symptoms among nursing home residents: A systematic review. *Journal of Pain & Symptom Management*, 48(4), 699-710.
- Duffy, M. E. (2002). Methodological issues in web-based research. *Journal of Nursing Scholarship*, 34(1), 83-88.
- Dunkel-Schetter, C., & Skokan, L. A. (1990). Determinants of social support provision in personal relationships. *Journal of Social & Personal Relationships*, 7(4), 437-450.
- Dunn, J., Ng, S. K., Holland, J., Aitken, J., Youl, P., Baade, P. D., & Chambers, S. K. (2013). Trajectories of psychological distress after colorectal cancer. *Psycho-Oncology*, 22(8), 1759-1765. Doi:<http://helios.uta.fi:2132/10.1002/pon.3210>
- Ekberg, K., McDermott, J., Moynihan, C., Brindle, L., Little, P., & Leydon, G. M. (2014). The role of helplines in cancer care: Intertwining emotional support with information or advice-seeking needs. *Journal of Psychosocial Oncology*, 32(3), 359-381. Doi:10.1080/07347332.2014.897294
- Ellett, M. L., Lane, L., & Keffer, J. (2004). Ethical and legal issues of conducting nursing research via the Internet. *Journal of Professional Nursing*, 20(1), 68-74.
- Ernst, J. C., Beierlein, V., Romer, G., Möller, B., Koch, U., & Bergelt, C. (2013). Use and need for psychosocial support in cancer patients. *Cancer*, 119(12), 2333-2341. Doi:<http://helios.uta.fi:2141/10.1002/cncr.28021>
- Ezer, H., Chachamovich, J. R., Saad, F., Aprikian, A., & Souhami, L. (2012). Psychosocial adjustment of men during the first year of prostate cancer. *Cancer Nursing*, 35(2), 141-147.
- Farrell, E., Borstelmann, N., Meyer, F., Partridge, A., Winer, E., & Ruddy, K. (2014). Male breast cancer networking and telephone support group: A model for supporting a unique population. *Psycho-Oncology*, 23(8), 956-958. Doi:10.1002/pon.3519
- Farrelly, A., White, V., Young, M. A., Jefford, M., Ieropoli, S., Duffy, J., Winship, I., & Meiser, B. (2015). Implementing a telephone based peer support intervention for women with a BRCA1/2 mutation. *Familial Cancer*, 14(3), 373-382. Doi:10.1007/s10689-015-9797-9
- Finlex. (785/1992). Act on the status and rights of patients. Retrieved from <http://www.finlex.fi/en/laki/kaannokset/1992/19920785>
- Finnish Cancer Registry. (2013). Cancer statistics. Retrieved from <http://www.cancer.fi/syoparekisteri/en/statistics/cancer-statistics/koko-maa/>
- Finnish Cancer Registry. (2016). Cancer statistics. Retrieved from <http://www.cancer.fi/syoparekisteri/en/statistics/cancer-statistics/koko-maa/>
- Flick, U. (2014). *An introduction to qualitative research* (5th ed.). London: Sage Publications Ltd.
- Fogel, J., Albert, S. M., Schnabel, F., Ditkoff, B. A., & Neugut, A. I. (2002). Internet use and social support in women with breast cancer. *Health Psychology*, 21(4), 398-404. Doi:<http://helios.uta.fi:2132/10.1037/0278-6133.21.4.398>
- Fukkink, R. (2011). Peer counseling in an online chat service: A content analysis of social support. *Cyberpsychology, Behavior and Social Networking*, 14(4), 247-251.

- Fukkink, R. G., & Hermanns, J. M. (2009). Children's experiences with chat support and telephone support. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 50(6), 759-766.
- Garrett, K., Okuyama, S., Jones, W., Barnes, D., Tran, Z., Spencer, L., Lewis, K., Maroni, P., Chesney, M., & Marcus, A. (2013). Bridging the transition from cancer patient to survivor: Pilot study results of the cancer survivor telephone education and personal support (C-STEPS) program. *Patient Education & Counseling*, 92(2), 266-272.
- Geller, B. M., Vacek, P. M., Flynn, B. S., Lord, K., & Cranmer, D. (2014). What are cancer survivors' needs and how well are they being met? *The Journal of Family Practice*, 63(10), E7-16. Doi:jfp_6310i
- Genc, F., & Tan, M. (2011). Symptoms of patients with lung cancer undergoing chemotherapy and coping strategies. *Cancer Nursing*, 34(6), 503-509.
- Girault, A., Ferrua, M., Lalloue, B., Sicotte, C., Fourcade, A., Yatim, F., Hebert, G., Di Palma, M., & Minvielle, E. (2015). Internet-based technologies to improve cancer care coordination: Current use and attitudes among cancer patients. *European Journal of Cancer (Oxford, England: 1990)*, 51(4), 551-557. Doi:10.1016/j.ejca.2014.12.001
- Goldner, M., Hale, T. M., Cotten, S. R., Stern, M. J., & Drentea, P. (2013). The intersection of gender and place in online health activities. *Journal of Health Communication*, 18(10), 1235-1255. Doi:10.1080/10810730.2013.778364
- Goldsmith, D. J. (2004). *Communicating social support*. Cambridge: Cambridge University Press.
- Gorard, S. (2010). Research design, as independent of methods. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 237-251). Thousand Oaks, CA: SAGE Publications, Inc.
- Gordon, L. G., Beesley, V. L., & Scuffham, P. A. (2011). Evidence on the economic value of psychosocial interventions to alleviate anxiety and depression among cancer survivors: A systematic review. *Asia-Pacific Journal of Clinical Oncology*, 7(2), 96-105. Doi:10.1111/j.1743-7563.2011.01395.x
- Gordon, L. G., Patrao, T., Kularatna, S., & Hawkes, A. L. (2015). A telephone-delivered multiple health behaviour change intervention for colorectal cancer survivors: Making the case for cost-effective healthcare. *European Journal of Cancer Care*, 24(6), 854-861. Doi:10.1111/ecc.12345
- Gorlick, A., Bantum, E. O., & Owen, J. E. (2014). Internet-based interventions for cancer-related distress: Exploring the experiences of those whose needs are not met. *Psycho-Oncology*, 23(4), 452-458. Doi:10.1002/pon.3443
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.
- Grant, M. S., & Wiegand, D. L. (2013). Conversations with strangers. *Journal of Hospice & Palliative Nursing*, 15(5), 278-285. Doi:10.1097/NJH.Ob013e31827f1da9
- Greaney, M. L., Sprunck-Harrild, K., Bennett, G. G., Puleo, E., Haines, J., Viswanath, K. V., & Emmons, K. M. (2012). Use of email and telephone prompts to increase self-monitoring in a web-based intervention: Randomized controlled trial. *Journal of Medical Internet Research*, 14(4), e96.
- Green, J., & Thorogood, N. (2009). *Qualitative methods for health research* (2nd ed.). London: SAGE.

- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation & Policy Analysis*, 11(3), 255-274.
- Griesser, A. C., Vlastos, G., Morel, L., Beaume, C., Sappino, A. P., & Haller, G. (2011). Socio-demographic predictors of high support needs in newly diagnosed breast cancer patients. *European Journal of Cancer Care*, 20(4), 466-474.
- Grimsbo, G. H., Finset, A., & Ruland, C. M. (2011). Left hanging in the air: Experiences of living with cancer as expressed through E-mail communications with oncology nurses. *Cancer Nursing*, 34(2), 107-116.
- Grimsbo, G. H., Ruland, C. M., & Finset, A. (2012). Cancer patients' expressions of emotional cues and concerns and oncology nurses' responses, in an online patient-nurse communication service. *Patient Education & Counseling*, 88(1), 36-43.
- Guidry, J. J., Aday, L. A., Zhang, D., & Winn, R. J. (1997). The role of informal and formal social support networks for patients with cancer. *Cancer Practice*, 5(4), 241-246.
- Gustafson, D. H., Wise, M., McTavish, F., Taylor, J. O., Wolberg, W., Stewart, J., Smalley, R., & Bosworth, K. (1993). Development and pivotal evaluation of a computer-based support system for women with breast cancer. *Journal of Psychosocial Oncology*, 11(4), 69-93. Doi: 10.1300/J077V11N04_05
- Hagedoorn, M., Kreicbergs, U., & Appel, C. (2011). Coping with cancer: The perspective of patients' relatives. *Acta Oncologica*, 50(2), 205-211.
- Hall, D. L., Mishel, M. H., & Germino, B. B. (2014). Living with cancer-related uncertainty: Associations with fatigue, insomnia, and affect in younger breast cancer survivors. *Supportive Care in Cancer*, 22(9), 2489-2495.
- Hall, A. E., Sanson-Fisher, R. W., Lynagh, M. C., Tzelepis, F., & D'Este, C. (2015). What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs. *BMC Research Notes*, 8, 221-015-1188-7. Doi:10.1186/s13104-015-1188-7
- Han, J. Y., Kim, J., Yoon, H. J., Shim, M., McTavish, F. M., & Gustafson, D. (2012). Social and psychological determinants of levels of engagement with an online breast cancer support group: Posters, lurkers, and nonusers. *Journal of Health Communication*, 17(3), 356-371. Doi:<http://dx.doi.org/10.1080/10810730.2011.585696>
- Han, J. Y., Shah, D. V., Kim, E., Namkoong, K., Lee, S. -, Moon, T. J., Cleland, R., Bu, Q. L., McTavish, F. M., & Gustafson, D. H. (2011). Empathic exchanges in online cancer support groups: Distinguishing message expression and reception effects. *Health Communication*, 26(2), 185-197.
- Han, X., Lin, C. C., Li, C., de Moor, J. S., Rodriguez, J. L., Kent, E. E., & Forsythe, L. P. (2015). Association between serious psychological distress and health care use and expenditures by cancer history. *Cancer*, 121(4), 614-622. Doi:10.1002/cncr.29102
- Hanly, P., Koopmanschap, M., & Sharp, L. (2015a). Valuing productivity costs in a changing macroeconomic environment: The estimation of colorectal cancer productivity costs using the friction cost approach. *The European Journal of Health Economics: HEPAC: Health Economics in Prevention and Care*, Doi:10.1007/s10198-015-0698-5
- Hanly, P., Soerjomataram, I., & Sharp, L. (2015b). Measuring the societal burden of cancer: The cost of lost productivity due to premature cancer-related mortality in Europe. *International Journal of Cancer: Journal International Du Cancer*, 136(4), E136-45. Doi:10.1002/ijc.29105

- Harrison, J. D., Durcinoska, I., Butow, P. N., White, K., Solomon, M. J., & Young, J. M. (2014). Localized versus centralized nurse-delivered telephone services for people in follow up for cancer: Opinions of cancer clinicians. *Asia-Pacific Journal of Clinical Oncology*, 10(2), 175-182. Doi:10.1111/ajco.12082
- Harrison, J. D., Young, J. M., Solomon, M. J., Butow, P. N., Secomb, R., & Masya, L. (2011). Randomized pilot evaluation of the supportive care intervention "CONNECT" for people following surgery for colorectal cancer. *Diseases of the Colon & Rectum*, 54(5), 622-631.
- Hawkes, A. L., Patrao, T. A., Baade, P., Lynch, B. M., & Courneya, K. S. (2015). Predictors of physical activity in colorectal cancer survivors after participation in a telephone-delivered multiple health behavior change intervention. *Journal of Cancer Survivorship: Research and Practice*, 9(1), 40-49. Doi:10.1007/s11764-014-0389-8
- Heikkilä, T. (2008). *Tilastollinen tutkimus*. Helsinki: Edita Prima Oy.
- Heinze, J. E., Kruger, D. J., Reischl, T. M., Cupal, S., & Zimmerman, M. A. (2015). Relationships among disease, social support, and perceived health: A lifespan approach. *American Journal of Community Psychology*, Doi:10.1007/s10464-015-9758-3
- Heller, K., Swindle, R. W., & Dusenbury, L. (1986). Component social support processes: Comments and integration. *Journal of Consulting and Clinical Psychology*, 54(4), 466-470. Doi:<http://dx.doi.org/helios.uta.fi/10.1037/0022-006X.54.4.466>
- Henselmans, I., Helgeson, V. S., Seltman, H., de Vries, J., Sanderman, R., & Ranchor, A. V. (2010). Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. *Health Psychology*, 29(2), 160-168.
- Hesse-Biber, S. N. (2010). *Mixed methods research merging theory with practice*. New York: Guilford Press.
- Hill, E. M. (2015). Quality of life and mental health among women with ovarian cancer: Examining the role of emotional and instrumental social support seeking. *Psychology, Health & Medicine*, 1-11. Doi:10.1080/13548506.2015.1109674
- Himmelboim, I., & Han, J. Y. (2014). Cancer talk on twitter: Community structure and information sources in breast and prostate cancer social networks. *Journal of Health Communication*, 19(2), 210-225. Doi:10.1080/10810730.2013.811321
- Hirschman, K. B., & Bourjolly, J. N. (2005). How do tangible supports impact the breast cancer experience? *Social Work in Health Care*, 41(1), 17-32.
- Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and healthcare* (3rd ed.). Oxford: Wiley-Blackwell.
- Holt, K. A., Hansen, H. P., & Mogensen, O. (2014). Supportive care needs for women with gynecological cancer and their relatives during the prediagnostic period. *Cancer Nursing*, 37(6), 457-467.
- Hong, Y., Pena-Purcell, N. C., & Ory, M. G. (2012). Outcomes of online support and resources for cancer survivors: A systematic literature review. *Patient Education & Counseling*, 86(3), 288-296.
- Hordern, A., Georgiou, A., Whetton, S., & Prgomet, M. (2011). Consumer e-health: An overview of research evidence and implications for future policy. *Health Information Management Journal*, 40(2), 6-14.
- Horevoorts, N. J., Vissers, P. A., Mols, F., Thong, M. S., & van de Poll-Franse, L. V. (2015). Response rates for patient-reported outcomes using web-based versus paper questionnaires: Comparison of two invitational methods in older colorectal cancer patients. *Journal of Medical Internet Research*, 17(5), e111.

- Houghton, C. E., Casey, D., Shaw, D., & Murphy, K. (2010). Ethical challenges in qualitative research: Examples from practice. *Nurse Researcher*, 18(1), 15-25.
- House, J. S., & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen, & L. S. Syme (Eds.), *Social support and health* (pp. 83-108). Orlando, FL: Academic Press, Inc.
- Huang, S. M., Tai, C. J., Lin, K. C., Tai, C. J., Tseng, L. M., & Chien, L. Y. (2013). A comparative study of symptoms and quality of life among patients with breast cancer receiving target, chemotherapy, or combined therapy. *Cancer Nursing*, 36(4), 317-325.
- Huber, J., Ihrig, A., Peters, T., Huber, C. G., Kessler, A., Hadaschik, B., Pahernik, S., & Hohenfellner, M. (2011). Decision-making in localized prostate cancer: Lessons learned from an online support group. *BJU International*, 107(10), 1570-1575.
- Hughes, S., Jaremka, L. M., Alfano, C. M., Glaser, R., Povoski, S. P., Lipari, A. M., Agnese, D. M., Farrar, W. B., Yee, L. D., Carson, W. E., 3rd, Malarkey, W. B., & Kiecolt-Glaser, J. K. (2014). Social support predicts inflammation, pain, and depressive symptoms: Longitudinal relationships among breast cancer survivors. *Psychoneuroendocrinology*, 42, 38-44. Doi:10.1016/j.psyneuen.2013.12.016
- Huh, J., Liu, L. S., Neogi, T., Inkpen, K., & Pratt, W. (2014). Health vlogs as social support for chronic illness management. *ACM Transactions on Computer-Human Interaction: A Publication of the Association for Computing Machinery*, 21(4), 23.
- Hunter, L. (2012). Challenging the reported disadvantages of e-questionnaires and addressing methodological issues of online data collection. *Nurse Researcher*, 20(1), 11-20.
- Hupcey, J. E., & Morse, J. M. (1997). Can a professional relationship be considered social support? *Nursing Outlook*, 45(6), 270-276.
- Hupcey, J. E. (1998). Clarifying the social support theory-research linkage. *Journal of Advanced Nursing*, 27(6), 1231-1241.
- Ieropoli, S. C., White, V. M., Jefford, M., & Akkerman, D. (2011). What models of peer support do people with colorectal cancer prefer? *European Journal of Cancer Care*, 20(4), 455-465.
- Im, E. O., Lee, B., & Chee, W. (2011). The questions on the use of internet cancer support groups: Instrument development. *CIN: Computers, Informatics, Nursing*, 29(6), 344-351.
- Im, E. O. (2011). Online support of patients and survivors of cancer. *Seminars in Oncology Nursing*, 27(3), 229-236.
- Imle, M. A., & Atwood, J. R. (1988). Retaining qualitative validity while gaining quantitative reliability and validity: Development of the transition to parenthood concerns scale. *Advances in Nursing Science*, 11(1), 61-75.
- Iredale, R., Mundy, L., & Hilgart, J. (2011). An online resource of digital stories about cancer genetics: Qualitative study of patient preferences and information needs. *Journal of Medical Internet Research*, 13(3), e78.
- Isola, J., & Kallioniemi, A. (2013). Syövän synty, kasvu ja leviäminen: Määritelmä, jaottelu ja näkemykset syntymekanismeista. In H. Joensuu, P. J. Roberts, P. Kellokumpu-Lehtinen, S. Jyrkkiö, M. Kouri & L. Teppo (Eds.), *Syöpätaudit* (5. uudistettu painos ed., pp. 9-28). Helsinki: Kustannus Oy Duodecim.
- Isshiki, T. (2014). Outpatient treatment costs and their potential impact on cancer care. *Cancer Medicine*, 3(6), 1539-1543. Doi:10.1002/cam4.308
- Jacobson, D. E. (1986). Types and timing of social support. *Journal of Health and Social Behavior*, 27(3), 250-264. Doi:<http://helios.uta.fi:2141/10.2307/2136745>

- Jansen, F., van Uden-Kraan, C. F., van Zwieten, V., Witte, B. I., & Verdonck-de Leeuw, I. M. (2015). Cancer survivors' perceived need for supportive care and their attitude towards self-management and eHealth. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 23(6), 1679-1688. Doi:10.1007/s00520-014-2514-7
- Jefford, M., Black, C., Grogan, S., Yeoman, G., White, V., & Akkerman, D. (2005). Information and support needs of callers to the cancer helpline, the cancer council victoria. *European Journal of Cancer Care*, 14(2), 113-123.
- Jefford, M., Lotfi-Jam, K., Baravelli, C., Grogan, S., Rogers, M., Krishnasamy, M., Pezaro, C., Milne, D., Aranda, S., King, D., Shaw, B., & Schofield, P. (2011). Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. *Cancer Nursing*, 34(3), E1-10.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133.
- Jones, S., Murphy, F., Edwards, M., & James, J. (2008). Doing things differently: Advantages and disadvantages of web questionnaires. *Nurse Researcher*, 15(4), 15-26.
- Kanatas, A., Humphris, G., Lowe, D., & Rogers, S. N. (2015). Further analysis of the emotional consequences of head and neck cancer as reflected by the patients' concerns inventory. *The British Journal of Oral & Maxillofacial Surgery*, 53(8), 711-718. Doi:10.1016/j.bjoms.2015.02.026
- Kanta. (2016). My kanta pages. Retrieved from <http://www.kanta.fi/en/omakanta>
- Kent, E. E., Arora, N. K., Rowland, J. H., Bellizzi, K. M., Forsythe, L. P., Hamilton, A. S., Oakley-Girvan, I., Beckjord, E. B., & Aziz, N. M. (2012). Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. *Patient Education and Counseling*, 89(2), 345-352. Doi:<http://dx.doi.org/helios.uta.fi/10.1016/j.pec.2012.08.014>
- Kim, B., & Gillham, D. M. (2013). The experience of young adult cancer patients described through online narratives. *Cancer Nursing*, 36(5), 377-384.
- Kim, K., & Kwon, N. (2010). Profile of e-patients: Analysis of their cancer information-seeking from a national survey. *Journal of Health Communication*, 15(7), 712-733. Doi:<http://helios.uta.fi/2135/10.1080/10810730.2010.514031>
- Kimman, M. L., Dirksen, C. D., Voogd, A. C., Falger, P., Gijsen, B. C., Thuring, M., Lenssen, A., van der Ent, F., Verkeyn, J., Haekens, C., Hupperets, P., Nuytinck, J. K., van Riet, Y., Brenninkmeijer, S. J., Scheijmans, L. J., Kessels, A., Lambin, P., & Boersma, L. J. (2011). Nurse-led telephone follow-up and an educational group programme after breast cancer treatment: Results of a 2 x 2 randomised controlled trial. *European Journal of Cancer (Oxford, England: 1990)*, 47(7), 1027-1036. Doi:10.1016/j.ejca.2010.12.003
- King, A. J., Evans, M., Moore, T. H., Paterson, C., Sharp, D., Persad, R., & Huntley, A. L. (2015). Prostate cancer and supportive care: A systematic review and qualitative synthesis of men's experiences and unmet needs. *European Journal of Cancer Care*, 24(5), 618-634. Doi:10.1111/ecc.12286
- Knapp, T. R., & Brown, J. K. (1995). Ten measurement commandments that often should be broken. *Research in Nursing & Health*, 18, 465-469.
- Koutsopoulou, S., Papathanassoglou, E. D. E., Katapodi, M. C., & Patiraki, E. I. (2010). A critical review of the evidence for nurses as information providers to cancer patients. *Journal of Clinical Nursing*, 19(5-6), 749-765. Doi:10.1111/j.1365-2702.2009.02954.x

- Kratzke, C., Wilson, S., & Vilchis, H. (2013). Reaching rural women: Breast cancer prevention information seeking behaviors and interest in internet, cell phone, and text use. *Journal of Community Health: The Publication for Health Promotion and Disease Prevention*, 38(1), 54-61. Doi:<http://dx.doi.org/helios.uta.fi/10.1007/s10900-012-9579-3>
- Kreps, G. L., & Neuhauser, L. (2010). Editors' introduction: Ehealth and the delivery of health care. *Journal of Computer-Mediated Communication*, 15(3), 364-366. Doi:10.1111/j.1083-6101.2010.01524.x
- Kroenke, K., Theobald, D., Wu, J., Loza, J. K., Carpenter, J. S., & Tu, W. (2010). The association of depression and pain with health-related quality of life, disability, and health care use in cancer patients. *Journal of Pain & Symptom Management*, 40(3), 327-341.
- Kuijpers, W., Groen, W. G., Aaronson, N. K., & van Harten, W. H. (2013). A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: Relevance for cancer survivors. *Journal of Medical Internet Research*, 15(2), e37. Doi:10.2196/jmir.2281
- Kullberg, A., Sharp, L., Johansson, H., & Bergenmar, M. (2015). Information exchange in oncological inpatient care--patient satisfaction, participation, and safety. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*, 19(2), 142-147. Doi:10.1016/j.ejon.2014.10.005
- Kyngäs, H., Elo, S., Pölkki, T., Kääriäinen, M., & Kanste, O. (2011). Sisällönanalyysi suomalaisessa hoitotieteellisessä tutkimuksessa. *Hoitotiede*, 23, 138-148.
- LaCoursiere, S. P. (2001). A theory of online social support. *Advances in Nursing Science*, 24(1), 60-77.
- Larkin, P. M., Begley, C. M., & Devane, D. (2014). Breaking from binaries - using a sequential mixed methods design. *Nurse Researcher*, 21(4), 8-12.
- Lavoie, S. E. M., Skalla, K., Li, Z., Onega, T., Rhoda, J., Gates, C., Litterini, A., & Scott, M. R. (2012). Assessing cancer survivors' needs using web-based technology: A pilot study. *CIN: Computers, Informatics, Nursing*, 30(2), 71-81.
- Leahy, M., Krishnasamy, M., Herschtal, A., Bressel, M., Dryden, T., Tai, K. H., & Foroudi, F. (2013). Satisfaction with nurse-led telephone follow up for low to intermediate risk prostate cancer patients treated with radical radiotherapy. A comparative study. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*, 17(2), 162-169. Doi:10.1016/j.ejon.2012.04.003
- Lee, C. J., Ramírez, A. S., Lewis, N., Gray, S. W., & Hornik, R. C. (2012). Looking beyond the Internet: Examining socioeconomic inequalities in cancer information seeking among cancer patients. *Health Communication*, 27(8), 806-817. Doi:10.1080/10410236.2011.647621
- Lee, S. Y., & Hawkins, R. (2010). Why do patients seek an alternative channel? The effects of unmet needs on patients' health-related internet use. *Journal of Health Communication*, 15(2), 152-166. Doi:10.1080/10810730903528033
- Lehto, U., Tenhola, H., Taari, K., & Aromaa, A. (2013). Eturauhassyövän hoitojen haitat ja potilaiden tyytyväisyys. *Suomen Lääkärilehti - Finlands Läkartidning*, 68(46), 2997-3005.
- Leino, K. (2011). *Pirstaloitumisesta kohti naisena eheytymistä. Substantiivinen teoria rintasyöpäpotilaan sosiaalisesta tuesta hoitoprosessin aikana* (Doctoral dissertation). Available from Acta Electronica Universitatis Tampereensis. <http://urn.fi/urn:isbn:978-951-44-8555-8>
- Lepore, S. J., Buzaglo, J. S., Lieberman, M. A., Golant, M., Greener, J. R., & Davey, A. (2014). Comparing standard versus prosocial internet support groups for patients with breast

- cancer: A randomized controlled trial of the helper therapy principle. *Journal of Clinical Oncology*, 32(36), 4081-4089.
- Leykin, Y., Thekdi, S. M., Shumay, D. M., Munoz, R. F., Riba, M., & Dunn, L. B. (2012). Internet interventions for improving psychological well-being in psycho-oncology: Review and recommendations. *Psycho-Oncology*, 21(9), 1016-1025. Doi:10.1002/pon.1993
- Li, P. W., So, W. K., Fong, D. Y., Lui, L. Y., Lo, J. C., & Lau, S. F. (2011). The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. *Cancer Nursing*, 34(1), 49-57.
- Liao, M. N., Chen, S. C., Lin, Y. C., Chen, M. F., Wang, C. H., & Jane, S. W. (2014). Education and psychological support meet the supportive care needs of Taiwanese women three months after surgery for newly diagnosed breast cancer: A non-randomised quasi-experimental study. *International Journal of Nursing Studies*, 51(3), 390-399. Doi:<http://dx.doi.org/helios.uta.fi/10.1016/j.ijnurstu.2013.07.007>
- Lin, N., Simeone, R. S., Ensel, W. M., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and an empirical test. *Journal of Health and Social Behavior*, 17, 108-119.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, London, New Delhi: Sage Publications Inc.
- Livingston, P. M., White, V. M., Hayman, J., Maunsell, E., Dunn, S. M., & Hill, D. (2010). The psychological impact of a specialist referral and telephone intervention on male cancer patients: A randomised controlled trial. *Psycho-Oncology*, 19(6), 617-625. Doi:<http://helios.uta.fi/2142/10.1002/pon.1609>
- Lobchuk, M., McClement, S., Rigney, M., Copeland, A., & Bayrampour, H. (2015). A qualitative analysis of "naturalistic" conversations in a peer-led online support community for lung cancer. *Cancer Nursing*, 38(5), E21-31.
- Loscalzo, M., Clark, K., Pal, S., & Pirl, W. F. (2013). Role of biopsychosocial screening in cancer care. *Cancer Journal*, 19(5), 414-420.
- Love, B., Crook, B., Thompson, C. M., Zaitchik, S., Knapp, J., LeFebvre, L., Jones, B., Donovan-Kicken, E., Eargle, E., & Rechis, R. (2012). Exploring psychosocial support online: A content analysis of messages in an adolescent and young adult cancer community. *Cyberpsychology, Behavior, and Social Networking*, 15(10), 555-559. Doi:<http://dx.doi.org/helios.uta.fi/10.1089/cyber.2012.0138>
- Lowery, A. E., Krebs, P., Coups, E. J., Feinstein, M. B., Burkhalter, J. E., Park, B. J., & Ostroff, J. S. (2014). Impact of symptom burden in post-surgical non-small cell lung cancer survivors. *Supportive Care in Cancer*, 22(1), 173-180.
- Lubberding, S., Uden-Kraan, C. F., Te Velde, E. A., Cuijpers, P., Leemans, C. R., & Verdonck-de Leeuw, I. M. (2015). Improving access to supportive cancer care through an eHealth application: A qualitative needs assessment among cancer survivors. *Journal of Clinical Nursing*, 24(9-10), 1367-1379. Doi:<http://dx.doi.org/helios.uta.fi/10.1111/jocn.12753>
- Ludgate, M. W., Sabel, M. S., Fullen, D. R., Frohm, M. L., Lee, J. S., Couper, M. P., Johnson, T. M., Bichakjian, C. K., & Sabel, M. S. (2011). Internet use and anxiety in people with melanoma and nonmelanoma skin cancer. *Dermatologic Surgery*, 37(9), 1252-1259.
- Lynn, M. R. (1986). Determination and quantification of content validity. *Nursing Research*, 35(6), 382-385.

- Maddock, C., Lewis, I., Ahmad, K., & Sullivan, R. (2011). Online information needs of cancer patients and their organizations. *Ecancermedicalscience*, 5, 235.
- Maguire, R., Kotronoulas, G., Simpson, M., & Paterson, C. (2015). A systematic review of the supportive care needs of women living with and beyond cervical cancer. *Gynecologic Oncology*, 136(3), 478-490. Doi:10.1016/j.ygyno.2014.10.030
- Majumder, K., Brandberg, Y., Johansson, H., Nilsson, S., & Bergenmar, M. (2014). Less satisfaction with information in patients with prostate cancer treated with surgery and salvage radiotherapy compared with patients treated with curative radiotherapy alone, despite similar health-related quality of life. *Clinical Genitourinary Cancer*, 12(3), e71-82. Doi:10.1016/j.clgc.2013.11.001
- Mäklin, S., & Rissanen, P. (2006). *Syöpien aiheuttamat kustannukset, hoito- ja tuottavuuskustannusten kehitys vuosina 1996-2004 ja ennuste niiden muutoksista vuoteen 2015. Suomen syöpäyhdistyksen julkaisuja nro 67*. Helsinki: Syöpäsäätiö.
- Matthews, E. E., Schmiede, S. J., Cook, P. F., & Sousa, K. H. (2012). Breast cancer and symptom clusters during radiotherapy. *Cancer Nursing*, 35(2), E1-11.
- Mattila, E. (2011). *Aikuispotilaan ja perheenjäsenen emotionaalinen ja tiedollinen tuki sairaalahoiton aikana* (Doctoral dissertation). Available from Acta Electronica Universitatis Tamperensis. <http://urn.fi/urn:isbn:978-951-44-8541-1>
- McAlpine, H., Joubert, L., Martin-Sanchez, F., Merolli, M., & Drummond, K. J. (2015). A systematic review of types and efficacy of online interventions for cancer patients. *Patient Education and Counseling*, 98(3), 283-295. Doi:10.1016/j.pec.2014.11.002
- McGrath, P. (2014). Patient perspectives on the usefulness of routine telephone follow-up as psychosocial support for hematologic malignancies: Australian findings. *Oncology Nursing Forum*, 41(1), 40-44. Doi:10.1188/14.ONF.40-44
- Meadows, L. M., & Morse, J. M. (2001). Constructing evidence within the qualitative project. In J. M. Morse, J. M. Swanson & A. J. Kuzel (Eds.), *The nature of qualitative evidence* (pp. 187-200). Thousand Oaks, CA: SAGE Publications.
- Merluzzi, T. V., Philip, E. J., Yang, M., & Heitzmann, C. A. (2015). Matching of received social support with need for support in adjusting to cancer and cancer survivorship. *Psycho-Oncology*, Doi:10.1002/pon.3896
- Mewes, J. C., Steuten, L. M., Groeneveld, I. F., de Boer, A. G., Frings-Dresen, M. H., IJzerman, M. J., & van Harten, W. H. (2015). Return-to-work intervention for cancer survivors: Budget impact and allocation of costs and returns in the Netherlands and six major EU-countries. *BMC Cancer*, 15(1), 899-015-1912-7. Doi:10.1186/s12885-015-1912-7
- Morrison, V., Henderson, B. J., Zinovieff, F., Davies, G., Cartmell, R., Hall, A., & Gollins, S. (2012). Common, important, and unmet needs of cancer outpatients. *European Journal of Oncology Nursing*, 16(2), 115-123. Doi:<http://helios.uta.fi:2141/10.1016/j.ejon.2011.04.004>
- Morse, J. (2010). Procedures and practice of mixed method design. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 339-352). Thousand Oaks, CA: SAGE Publications, Inc.
- Moye, J., June, A., Martin, L. A., Gosian, J., Herman, L. I., & Naik, A. D. (2014). Pain is prevalent and persisting in cancer survivors: Differential factors across age groups. *Journal of Geriatric Oncology*, 5(2), 190-196. Doi:10.1016/j.jgo.2013.12.006

- Muncey, T. (2009). Does mixed methods constitute a change in paradigm. In S. Andrews, & E. J. Halcomb (Eds.), *Mixed methods research for nursing and the health sciences* (pp. 13-30). Chichester: Wiley-Blackwell.
- Munro, B. H. (2005). *Statistical methods for health care research* (Fifth ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Mystakidou, K., Parpa, E., Tsilika, E., Panagiotou, I., Galanos, A., & Gouliamos, A. (2013). The influence of distressing symptoms to levels of depression in cancer patients. *Journal of B.U.On*, 18(3), 751-759.
- Nagler, R. H., Romantan, A., Kelly, B. J., Stevens, R. S., Gray, S. W., Hull, S. J., Ramirez, A. S., & Hornik, R. C. (2010). How do cancer patients navigate the public information environment? Understanding patterns and motivations for movement among information sources. *Journal of Cancer Education*, 25(3), 360-370. Doi:<http://dx.doi.org.helios.uta.fi/10.1007/s13187-010-0054-5>
- Nambisan, P. (2011). Evaluating patient experience in online health communities: Implications for health care organizations. *Health Care Management Review*, 36(2), 124-133.
- Nastasi, B. K., Hitchcock, J. H., & Brown, L. M. (2010). An inclusive framework for conceptualising mixed methods design typologies. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 305-338). Thousand Oaks, CA: SAGE Publications, Inc.
- National Institution for Health and Welfare. (2014). *Syövän ehkäisy, varhaisen toteamisen ja kuntoutumisen tuen kehittäminen vuosina 2014-2025. kansallisen syöpäsunnitelman II osa [development of cancer prevention, early detection and rehabilitative support 2014-2025. National cancer plan, part II]*. (No. 6/2014). Tampere: Terveysten- ja hyvinvoinnin laitos.
- Ngwenya, N. B., & Mills, S. (2014). The use of weblogs within palliative care: A systematic literature review. *Health Informatics Journal*, 20(1), 13-21. Doi:10.1177/1460458213475894
- Norbeck, J. S. (1988). Social support. *Annual Review of Nursing Research*, 6, 85-109.
- NORDCAN. (2014). Incidence/mortality data. Retrieved from <http://www-dep.iarc.fr/NORDCAN/English/frame.asp>
- O'Cathain, A. (2010). Assessing the quality of mixed methods research. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 531-555). Thousand Oaks, CA: SAGE Publications, Inc.
- Onwuegbuzie, A. J., & Combs, J. P. (2010). Emergent data analysis techniques in mixed methods research. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 397-430). Thousand Oaks, CA: SAGE Publications, Inc.
- Osei, D. K., Lee, J. W., Modest, N. N., & Pothier, P. K. T. (2013). Effects of an online support group for prostate cancer survivors: A randomized trial. *Urologic Nursing*, 33(3), 123-133. Doi:10.7257/1053-816X.2013.33.3.123
- Owen, J. E., Klapow, J. C., Roth, D. L., Nabell, L., & Tucker, D. C. (2004). Improving the effectiveness of adjuvant psychological treatment for women with breast cancer: The feasibility of providing online support. *Psycho-Oncology*, 13(4), 281-292.
- Paterson, C., Robertson, A., Smith, A., & Nabi, G. (2015). Identifying the unmet supportive care needs of men living with and beyond prostate cancer: A systematic review. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society*, 19(4), 405-418. Doi:10.1016/j.ejon.2014.12.007

- Patterson, P., Millar, B., Desille, N., & McDonald, F. (2012). The unmet needs of emerging adults with a cancer diagnosis: A qualitative study. *Cancer Nursing*, 35(3), E32-40.
- Paul, C. L., Carey, M. L., Hall, A. E., Lynagh, M. C., Sanson-Fisher, R. W., & Henskens, F. A. (2011). Improving access to information and support for patients with less common cancers: Hematologic cancer patients' views about web-based approaches. *Journal of Medical Internet Research*, 13(4), 399-409. Doi:<http://dx.doi.org/helios.uta.fi/10.2196/jmir.1894>
- Pazar, B., Yava, A., & Basal, S. (2015). Health-related quality of life in persons living with a urostomy. *Journal of Wound, Ostomy, & Continence Nursing*, 42(3), 264-270.
- Pedersen, B., Koktved, D. P., & Nielsen, L. L. (2013). Living with side effects from cancer treatment - a challenge to target information. *Scandinavian Journal of Caring Sciences*, 27(3), 715-723.
- Peters, M. E., Goedendorp, M. M., Verhagen, C. A., van der Graaf, W. T., & Bleijenberg, G. (2014). Severe fatigue during the palliative treatment phase of cancer: An exploratory study. *Cancer Nursing*, 37(2), 139-145.
- Pieterse, Q. D., Kenter, G. G., Maas, C. P., de Kroon, C. D., Creutzberg, C. L., Trimbos, J. B., & Ter Kuile, M. M. (2013). Self-reported sexual, bowel and bladder function in cervical cancer patients following different treatment modalities: Longitudinal prospective cohort study. *International Journal of Gynecological Cancer*, 23(9), 1717-1725.
- Pingree, S., & Hawkins, R. P. (1996). Will the disadvantaged ride the information highway? Hopeful answers from a computer-based. *Journal of Broadcasting & Electronic Media*, 40(3), 331.
- Pistrang, N., Jay, Z., Gessler, S., & Barker, C. (2012). Telephone peer support for women with gynaecological cancer: Recipients' perspectives. *Psycho-Oncology*, 21(10), 1082-1090. Doi:<http://helios.uta.fi:2142/10.1002/pon.2005>
- Plano Clark, V. L., & Badiie, M. (2010). Research questions in mixed methods research. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social & behavioral research* (Second ed., pp. 275-304). Thousand Oaks, CA: SAGE Publishing, Inc.
- Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research. Appraising evidence for nursing practice* (7th ed.). Philadelphia, PA: Wolters Kluwer, Lippincott Williams & Wilkins.
- Polit, D. F., Beck, C. T., & Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, 30(4), 459-467.
- Polit, D. F., & Beck, C. T. (2006). The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health*, 29(5), 489-497. Doi:10.1002/nur.20147
- Popat, K., McQueen, K., & Feeley, T. W. (2013). The global burden of cancer. *Best Practice & Research.Clinical Anaesthesiology*, 27(4), 399-408. Doi:10.1016/j.bpa.2013.10.010
- Power, S., & Hegarty, J. (2010). Facilitated peer support in breast cancer: A pre- and post-program evaluation of women's expectations and experiences of a facilitated peer support program. *Cancer Nursing*, 33(2), E9-16.
- Preyde, M., Chevalier, P., Hatton-Bauer, J., & Barksey, M. (2010). Exploratory survey of patients' needs and perceptions of psychosocial oncology. *Journal of Psychosocial Oncology*, 28(3), 320-333. Doi:<http://helios.uta.fi:2141/10.1080/07347331003689128>

- Procidano, M. E., & Heller, K. (1983). Measures of perceived social support from friends and from family: Three validation studies. *American Journal of Community Psychology*, (11), 1-24.
- Queenan, J., Feldman-Stewart, D., Brundage, M., & Groome, P. (2010). Social support and quality of life of prostate cancer patients after radiotherapy treatment. *European Journal of Cancer Care*, 19(2), 251-259. Doi:10.1111/j.1365-2354.2008.01029.x
- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16(2), 234-243.
- Reichardt, P., Leahy, M., Garcia Del Muro, X., Ferrari, S., Martin, J., Gelderblom, H., Wang, J., Krishna, A., Eriksson, J., Staddon, A., & Blay, J. Y. (2012). Quality of life and utility in patients with metastatic soft tissue and bone sarcoma: The sarcoma treatment and burden of illness in North America and Europe (SABINE) study. *Sarcoma*, 2012, 740279.
- Reid, J., & Porter, S. (2011). Utility, caller, and patient profile of a novel chemotherapy telephone helpline service within a regional cancer centre in Northern Ireland. *Cancer Nursing*, 34(3), E27-32.
- Reinisch, J. F., Yu, D. C., & Li, W. Y. (2016). Getting a valid survey response from 662 plastic surgeons in the 21st century. *Annals of Plastic Surgery*, 76(1), 3-5.
- Robinson, J. D., & Tian, Y. (2009). Cancer patients and the provision of informational social support. *Health Communication*, 24(5), 381-390. Doi:10.1080/10410230903023261
- Rogus-Pulia, N. M., Pierce, M. C., Mittal, B. B., Zecker, S. G., & Logemann, J. A. (2014). Changes in swallowing physiology and patient perception of swallowing function following chemoradiation for head and neck cancer. *Dysphagia*, 29(2), 223-233.
- Rook, K. S. (1992). Detrimental aspects of social relationships: Taking stock of an emerging literature. In H. O. F. Veiel, & U. Baumann (Eds.), *The meaning and the measurement of social support* (pp. 157-169). New York, NY: Hemisphere Publishing Corporation.
- Rook, K. S. (1987). Reciprocity of social exchange and social satisfaction among older women. *Journal of Personality and Social Psychology*, 52(1), 145-154. Doi:<http://helios.uta.fi:2173/10.1037/0022-3514.52.1.145>
- Rowlands, I. J., Lee, C., Beesley, V. L., Janda, M., Nagle, C. M., & Webb, P. M. (2015). Women's perceptions of their lifestyle and quality of life several years after a diagnosis of endometrial cancer. *Cancer Nursing*, 38(1), E21-8.
- Ruland, C. M., Andersen, T., Jeneson, A., Moore, S., Grimsbo, G. H., Borosund, E., & Ellison, M. C. (2013). Effects of an internet support system to assist cancer patients in reducing symptom distress: A randomized controlled trial. *Cancer Nursing*, 36(1), 6-17.
- Sabesan, S., & Kelly, J. (2014). Are teleoncology models merely about avoiding long distance travel for patients? *European Journal of Cancer Care*, 23(6), 745-749.
- Saied, A., Sherry, S. J., Castricone, D. J., Perry, K. M., Katz, S. C., & Somasundar, P. (2014). Age-related trends in utilization of the internet and electronic communication devices for coordination of cancer care in elderly patients. *Journal of Geriatric Oncology*, 5(2), 185-189.
- Salonen, P. (2011). *Quality of life in patients with breast cancer. A prospective intervention study* (Doctoral dissertation). Available from Acta Electronica Universitatis Tampereensis. <http://urn.fi/urn:isbn:978-951-44-8549-7>

- Salonen, P., Tarkka, M. T., Kellokumpu-Lehtinen, P. L., Astedt-Kurki, P., Luukkaala, T., & Kaunonen, M. (2009). Telephone intervention and quality of life in patients with breast cancer. *Cancer Nursing*, 32(3), 177-190.
- Santin, O., Mills, M., Treanor, C., McDonald, G., & Donnelly, M. (2013). Web psychosocial surveys in cancer survivorship—A methodological note. *Journal of Psychosocial Oncology*, 31(5), 556-564. Doi:<http://helios.uta.fi:2141/10.1080/07347332.2013.822050>
- Schook, R. M., Linssen, C., Festen, J., Schramel, F. M., Lammers, E., Zaanen, P., & Postmus, P. E. (2013). Website visitors asking questions online to lung cancer specialists: What do they want to know? *Interactive Journal of Medical Research*, 2(2), e15.
- Schook, R. M., Linssen, C., Schramel, F. M., Festen, J., Lammers, E., Smit, E. F., Postmus, P. E., & Westerman, M. J. (2014). Why do patients and caregivers seek answers from the internet and online lung specialists? A qualitative study. *Journal of Medical Internet Research*, 16(2), e37.
- Scott, A., Jeon, S., Joyce, C. M., Humphreys, J. S., Kalb, G., Witt, J., & Leahy, A. (2011). A randomised trial and economic evaluation of the effect of response mode on response rate, response bias, and item non-response in a survey of doctors. *BMC Medical Research Methodology*, 11, 126-137.
- Setoyama, Y., Yamazaki, Y., & Namayama, K. (2011). Benefits of peer support in online Japanese breast cancer communities: Differences between lurkers and posters. *Journal of Medical Internet Research*, 13(4), e122.
- Shea-Budgell, M. A., Kostaras, X., Myhill, K. P., & Hagen, N. A. (2014). Information needs and sources of information for patients during cancer follow-up. *Current Oncology*, 21(4), 165-173.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, 32(6), 705-714.
- Sherman, D. W., Haber, J., Hoskins, C. N., Budin, W. C., Maislin, G., Shukla, S., Cartwright-Alcarese, F., McSherry, C. B., Feurbach, R., Kowalski, M. O., Rosedale, M., & Roth, A. (2012). The effects of psychoeducation and telephone counseling on the adjustment of women with early-stage breast cancer. *Applied Nursing Research: ANR*, 25(1), 3-16. Doi:10.1016/j.apnr.2009.10.003
- Shiba, K., Kondo, N., & Kondo, K. (2016). Informal and formal social support and caregiver burden: The AGES caregiver survey. *Journal of Epidemiology*, 26(12), 622-628.
- Shiozaki, M., Hirai, K., Koyama, A., Inui, H., Yoshida, R., & Tokoro, A. (2011). Negative support of significant others affects psychological adjustment in breast cancer patients. *Psychology & Health*, 26(11), 1540-1551.
- Short, C. E., Rebar, A. L., & Vandelanotte, C. (2015). Do personalised e-mail invitations increase the response rates of breast cancer survivors invited to participate in a web-based behaviour change intervention? A quasi-randomised 2-arm controlled trial. *BMC Medical Research Methodology*, 15, 66-015-0063-5. Doi:10.1186/s12874-015-0063-5
- Shumaker, S. A., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. *Journal of Social Issues*, 40(4), 11-36.
- Sillence, E., & Mo, P. K. (2014). Communicating health decisions: An analysis of messages posted to online prostate cancer forums. *Health Expectations*, 17(2), 244-253.
- Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., & Ozakinci, G. (2013). Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *Journal of Cancer Survivorship*, 7(3), 300-322.

- Skolarus, T. A., Zhang, Y., & Hollenbeck, B. K. (2012). Understanding fragmentation of prostate cancer survivorship care: Implications for cost and quality. *Cancer*, 118(11), 2837-2845. Doi:10.1002/cncr.26601
- Smith-McLallen, A., Fishbein, M., & Hornik, R. C. (2011). Psychosocial determinants of cancer-related information seeking among cancer patients. *Journal of Health Communication*, 16(2), 212-225. Doi:10.1080/10810730.2010.522227
- So, W. K., Chan, C. W., Choi, K. C., Wan, R. W., Mak, S. S., & Chair, S. Y. (2013). Perceived unmet needs and health-related quality of life of Chinese cancer survivors at 1 year after treatment. *Cancer Nursing*, 36(3), E23-32.
- Sobota, A., & Ozakinci, G. (2015). The quality and readability of online consumer information about gynecologic cancer. *International Journal of Gynecological Cancer*, 25(3), 537-541.
- Sohl, S. J., Levine, B., Case, L. D., Danhauer, S. C., & Avis, N. E. (2014). Trajectories of illness intrusiveness domains following a diagnosis of breast cancer. *Health Psychology*, 33(3), 232-241. Doi:<http://helios.uta.fi:2132/10.1037/a0032388>
- Soltow, D., Given, B. A., & Given, C. W. (2010). Relationship between age and symptoms of pain and fatigue in adults undergoing treatment for cancer. *Cancer Nursing*, 33(4), 296-303.
- Statistics Finland. (2015). Use of information and communication technology by individuals. Retrieved from http://tilastokeskus.fi/til/sutivi/index_en.html
- Stickel, A., Gropper, S., Pallauf, A., & Goerling, U. (2015). Patients' knowledge and attitudes towards cancer peer support programs. *Oncology*, 89(4), 242-244. Doi:10.1159/000430918
- Streiner, D. L., Norman, G. R., & Cairney, J. (2015). *Health measurement scales. A practical guide to their development and use* (Fifth edition ed.). Oxford: Oxford University Press.
- Streiner, D. L., & Kottner, J. (2014). Recommendations for reporting the results of studies of instrument and scale development and testing. *Journal of Advanced Nursing*, 70(9), 1970-1979.
- Sugawara, Y., Narimatsu, H., Hozawa, A., Shao, L., Otani, K., & Fukao, A. (2012). Cancer patients on twitter: A novel patient community on social media. *BMC Research Notes*, 5, 699-0500-5-699. Doi:10.1186/1756-0500-5-699
- Sun, V., Borneman, T., Koczywas, M., Cristea, M., Piper, B. F., Uman, G., & Ferrell, B. (2012). Quality of life and barriers to symptom management in colon cancer. *European Journal of Oncology Nursing*, 16(3), 276-280.
- Tashakkori, A., & Teddlie, C. (2008). Quality inferences in mixed methods research. In M. Bergman (Ed.), *Advances in mixed methods research: Theories and applications* (pp. 101-119). London: SAGE.
- Taubert, M., Watts, G., Bolland, J., & Radbruch, L. (2014). Palliative social media. *BMJ Supportive & Palliative Care*, 4(1), 13-18. Doi:10.1136/bmjspcare-2013-000584
- Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, 2, 53-55. Doi:10.5116/ijme.4dfb.8dfd
- Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Thousand Oaks, CA: SAGE Publications, Inc.
- Teddlie, C., & Tashakkori, A. (2010). Overview of contemporary issues in mixed methods research. In A. Tashakkori, & C. Teddlie (Eds.), *Sage handbook of mixed methods in social*

- & behavioral research* (Second ed., pp. 1-41). Thousand Oaks, CA: Sage Publications, Inc.
- TENK. (2012). Finnish advisory board on research integrity. Retrieved from <http://www.tenk.fi/en/frontpage>
- Thoits, P. A. (1985). Social support and psychological well-being: Theoretical possibilities. In I. G. Sarason, & B. R. Sarason (Eds.), *Social support: Theory, research and applications* (pp. 51-72). Boston, PA: Nijhoff.
- Thoits, P. A. (1992). Social support functions and network structures: A supplemental view. In H. O. F. Veiel, & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 57-62). New York, NY: Hemisphere Publishing Corporation.
- Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health & Social Behavior*, 52(2), 145-161.
- Tilden, V. P., Hirsch, A. M., & Nelson, C. A. (1994). The interpersonal relationship inventory: Continued psychometric evaluation. *Journal of Nursing Measurement*, 2(1), 63-78.
- Tilden, V. P., Nelson, C. A., & May, B. A. (1990). Use of qualitative methods to enhance content validity. *Nursing Research*, 39(3), 172-175.
- Tilden, V. P. (1986). New perspectives on social support. *Nurse Practitioner*, 11(8), 60.
- Tipsmark, L. S., Bunger, C. E., Wang, M., Morgen, S. S., Dahl, B., & Sogaard, R. (2015). Healthcare costs attributable to the treatment of patients with spinal metastases: A cohort study with up to 8 years follow-up. *BMC Cancer*, 15, 354. Doi:10.1186/s12885-015-1357-z
- Torvinen, S., Farkkila, N., Sintonen, H., Saarto, T., Roine, R. P., & Taari, K. (2013). Health-related quality of life in prostate cancer. *Acta Oncologica*, 52(6), 1094-1101.
- Trudel-Fitzgerald, C., Savard, J., & Ivers, H. (2013). Evolution of cancer-related symptoms over an 18-month period. *Journal of Pain & Symptom Management*, 45(6), 1007-1018.
- Tustin, N. (2010). The role of patient satisfaction in online health information seeking. *Journal of Health Communication*, 15(1), 3-17. Doi:10.1080/10810730903465491
- Uchino, B. N. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*, 29(4), 377-387.
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405.
- Valero-Aguilera, B., Bermudez-Tamayo, C., Garcia-Gutierrez, J. F., Jimenez-Pernett, J., Cozar-Olmo, J. M., Guerrero-Tejada, R., & Alba-Ruiz, R. (2014). Information needs and Internet use in urological and breast cancer patients. *Supportive Care in Cancer*, 22(2), 545-552.
- Vaux, A. (1988). *Social support - theory, research and intervention*. New York, NY: Praeger.
- Vaux, A. (1992). Assessment of social support. In H. O. F. Veiel, & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 193-216). New York, NY: Hemisphere Publishing Corporation.
- Veiel, H. O. F., & Baumann, U. (1992). The many meanings of social support. In H. O. F. Veiel, & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 1-12). New York, NY: Hemisphere Publishing Corporation.

- Vivar, C. G., & McQueen, A. (2005). Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing*, 51(5), 520-528. Doi:10.1111/j.1365-2648.2005.03524.x
- Waldrop, D. P., O'Connor, T. L., & Trabold, N. (2011). "Waiting for the other shoe to drop:" Distress and coping during and after treatment for breast cancer. *Journal of Psychosocial Oncology*, 29(4), 450-473.
- Walling, A. M., Weeks, J. C., Kahn, K. L., Tisnado, D., Keating, N. L., Dy, S. M., Arora, N. K., Mack, J. W., Pantoja, P. M., & Malin, J. L. (2015). Symptom prevalence in lung and colorectal cancer patients. *Journal of Pain & Symptom Management*, 49(2), 192-202.
- Warren, E., Footman, K., Tinelli, M., McKee, M., & Knai, C. (2014). Do cancer-specific websites meet patient's information needs? *Patient Education & Counseling*, 95(1), 126-136.
- Wasserman, M., Baxter, N. N., Rosen, B., Burnstein, M., & Halverson, A. L. (2014). Systematic review of Internet patient information on colorectal cancer surgery. *Diseases of the Colon & Rectum*, 57(1), 64-69.
- Weiss, R. S. (1974). The provision of social relationships. In Z. Rubin (Ed.), *Doing unto others* (pp. 17-26). Englewood Cliffs, NJ: Prentice-Hall.
- Wenzel, L., Osann, K., Hsieh, S., Tucker, J. A., Monk, B. J., & Nelson, E. L. (2015). Psychosocial telephone counseling for survivors of cervical cancer: Results of a randomized biobehavioral trial. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 33(10), 1171-1179. Doi:10.1200/JCO.2014.57.4079
- Wesselmann, E. D., Day, M., Graziano, W. G., & Doherty, E. F. (2015). Religious beliefs about mental illness influence social support preferences. *Journal of Prevention & Intervention in the Community*, 43(3), 165-174.
- White, V. M., Macvean, M. L., Grogan, S., D'Este, C., Akkerman, D., Ieropoli, S., Hill, D. J., & Sanson-Fisher, R. (2012). Can a tailored telephone intervention delivered by volunteers reduce the supportive care needs, anxiety and depression of people with colorectal cancer? A randomised controlled trial. *Psycho-Oncology*, 21(10), 1053-1062. Doi:10.1002/pon.2019
- Wilcox, B., & Vernberg, E. (1985). Conceptual and theoretical dilemmas facing social support. In I. G. Sarason, & B. R. Sarason (Eds.), *Social support: Theory, research and applications* (pp. 3-20). Boston, MA: Martinus Nijhoff Publishers.
- Wong, A. G., Ki, P., Maharaj, A., Brown, E., Davis, C., & Apolinsky, F. (2014). Social support sources, types, and generativity: A focus group study of cancer survivors and their caregivers. *Social Work in Health Care*, 53(3), 214-232. Doi:10.1080/00981389.2013.873515
- Wortman, C. B. (1984). Social support and the cancer patient. Conceptual and methodologic issues. *Cancer*, 53(10 Suppl), 2339-2362.
- Wright, K. B., Johnson, A. J., Bernard, D. R., & Averbek, J. (2011). Computer-mediated social support. Promises and pitfalls for individuals coping with health concerns. In T. L. Thompson, R. Parrott & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (Second ed.,) pp. 349-362. New York, NY: Routledge.
- Wu, H. S., Natavio, T., Davis, J. E., & Yarandi, H. N. (2013). Pain in outpatients treated for breast cancer: Prevalence, pharmacological treatment, and impact on quality of life. *Cancer Nursing*, 36(3), 229-235.

- Xu, Y., Testerman, L. S., Owen, J. E., Bantum, E. O., Thornton, A. A., & Stanton, A. L. (2014). Modeling intention to participate in face-to-face and online lung cancer support groups. *Psycho-Oncology*, 23(5), 555-561. Doi:10.1002/pon.3449
- Yanez, B., Pearman, T., Lis, C. G., Beaumont, J. L., & Cella, D. (2013). The FACT-G7: A rapid version of the functional assessment of cancer therapy-general (FACT-G) for monitoring symptoms and concerns in oncology practice and research. *Annals of Oncology*, 24(4), 1073-1078.
- Yoo, W., Shah, D. V., Shaw, B. R., Kim, E., Smaglik, P., Roberts, L. J., Hawkins, R. P., Pingree, S., McDowell, H., & Gustafson, D. H. (2014). The role of the family environment and computer-mediated social support on breast cancer patients' coping strategies. *Journal of Health Communication*, 19(9), 981-998.
- Zhang, N., Fielding, R., Soong, I., Chan, K. K., Tsang, J., Lee, V., Lee, C., Ng, A., Sze, W. K., Tin, P., & Lam, W. W. (2015). Illness perceptions among cancer survivors. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, Doi:10.1007/s00520-015-2914-3
- Zucca, A. C., Boyes, A. W., Linden, W., & Girgis, A. (2012). All's well that ends well? Quality of life and physical symptom clusters in long-term cancer survivors across cancer types. *Journal of Pain & Symptom Management*, 43(4), 720-731.

Appendix 1. Studies measuring cancer patients' electronic social support

Author et al., Title, Journal, Year, Discipline, Country	Purpose of study, sample	Social support measure	Rating	Reliability	Validity	Results related to social support
Ruland CM et al. Effects of an internet support system to assist cancer patients in reducing symptom distress: a randomized controlled trial <i>Cancer Nursing</i> 2013 Nursing Norway	To examine the effects of WebChoice on symptom distress (primary outcome), depression, self-efficacy, health-related quality of life, and social support (secondary outcomes), Prostate and breast cancer patients, 110 patients in intervention group and 135 patients in control group	Subdimensions of the Medical Outcomes Study Social Support Survey *instrumental support *emotional support	Agreement with statements	$\alpha=0.81$ (at baseline)	Not reported	No significant between-group differences on social support
Crane-Okada R et al. Senior peer counseling by telephone for psychosocial support after breast cancer surgery: effects at six months <i>Oncology Nursing Forum</i> 2012 Nursing USA	To evaluate the efficacy of senior peer counseling by telephone for supplemental psychosocial support of older women after breast cancer surgery, 142 women newly diagnosed and scheduled for surgery for stage 0-III breast cancer	Interpersonal Relationship Inventory short form	Not reported	$\alpha=0.70-0.89$ in previous studies, internal consistency calculation not presented in the article	Not reported	A significant main effect of age on social support at baseline and six months Younger participants reported higher social support than older participants regardless of intervention Social support was stable over time on sample
Han JY et al. Social and psychological determinants of levels of engagement with an online breast cancer	To explore how various social and psychological characteristics predict different levels	Health Information Competence Scale (women's perception)	Agreement with statements	$\alpha=0.74$	Not reported	Non-users and lurkers' social support level was significantly greater than that of posters

Author et al., Title, Journal, Year, Discipline, Country	Purpose of study, sample	Social support measure	Rating	Reliability	Validity	Results related to social support
support group: Posters, lurkers, and nonusers <i>Journal of Health Communication</i> 2012 Communication USA	of engagement with an online breast cancer support group: posters, lurkers, and nonusers, 231 recently diagnosed breast cancer patients	that she could get and use health information)				Nonusers' competence in health information was greater than that of posters Posters' need for information was greater than that of lurkers' at pretest
Owen JE et al. Improving the effectiveness of adjuvant psychological treatment for women with breast cancer: the feasibility of providing online support <i>Psycho-Oncology</i> 2004 Psychology USA	To evaluate the relationship between stage, time since diagnosis, age and interest in an internet-based adjuvant psychological therapy (APT), the accessibility of APT, perceived benefits and barriers to participation in APT, the efficiency of different recruitment strategies in making a clinical trial of an internet-based APT available to participants, 136 women with breast cancer	Medical Studies Outcomes Social Support Survey *tangible support *affectionate support *positive social interaction *emotional, informational support	Agreement with statements	$\alpha=0.97$ in the original study, internal consistency calculations not presented in the article	High convergent validity for correlations with loneliness, family functioning, and psychological well-being in the original study	Among the psychological factors hypothesized to predict interest in participation, outcome expectancies mediated the effects of social support, preference for face-to-face psychosocial care, and perceived difficulty sharing feelings on the Internet
Fogel J et al. Internet use and social support in women with breast cancer <i>Health Psychology</i> 2002 Psychology Canada	To investigate the potential psychological benefits of Internet use for medical information by breast cancer patients, 188 breast cancer patients	Interpersonal Support Evaluation List	Agreement with statements (T/F)	$\alpha=0.93$	Not reported	Internet use for breast health issues was associated with greater social support than Internet use for other purposes or non-use

Appendix 2. Data collection sites in phase III

Settings of data collection	Placement of the online survey	Data collection period
Cancer Society 1	Online discussion forums (forums for female/male cancer patients, general cancer forum)	28.12.2015-9.2.2016
Association 2	Web pages of the association, Facebook (FB)	29.2.-31.8.2016
Association 3	Web pages of the association, FB	18.4. -31.8.2016
Association 4	Web pages of the association, FB	21.4. -31.8.2016
Association 5	Web pages of the association	19.5. -31.8.2016
Cancer Society 6	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	29.4. -31.8.2016
Cancer Society 7	Web pages of the society, a paper invitation to participate in the research in the office waiting room	18.4. -31.8.2016
Cancer Society 8	Web pages of the society, a paper invitation to participate in the research in the office waiting room	9.4. -31.8.2016
Cancer Society 9	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	18.4. -31.8.2016
Cancer Society 10	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	FB + paper invitations sent 26.5. -31.8.2016
Cancer Society 11	Web pages of the society, FB	20.5. -31.8.2016
Cancer Society 12	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	23.5. -31.8.2016
Cancer Society 13	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	Paper invitations sent 19.5. -31.8.2016 Web pages + FB 7.6. - 31.8.2016
Cancer Society 14	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	19.5. -31.8.2016
Cancer Society 15	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	19.5. -31.8.2016
Cancer Society 16	Web pages of the society, FB, a paper invitation to participate in the research in the office waiting room	19.5. -31.8.2016
Association 17	Web pages of the society	A link to questionnaire sent 18.5.2016

Appendix 3. NRESS instrument and background variables

	Item	Not at all	Quite a little	Some	Quite a lot	Very much	Does not apply to me
	© Tiina Yli-Uotila	(1)	(2)	(3)	(4)	(5)	(0)
1	A person you can turn to if you so wish Have you needed? Have you received?						
2	Receiving assurance that your concern will be treated by the counselling service Have you needed? Have you received?						
3	Guidance in terms of peer support Have you needed? Have you received?						
4	Filling in the gaps left by the lack of support provided by other healthcare professionals Have you needed? Have you received?						
5	Support from the counselling service when you do not want to seek help from the hospital personnel Have you needed? Have you received?						
6	Free counselling Have you needed? Have you received?						
7	Information about the services that will be useful for you (e.g., the services/benefits of the Social Insurance Institution of Finland, assistance for rehabilitation that is offered by the cancer societies) Have you needed? Have you received?						
8	Information about how your care could be organised elsewhere, outside of the public healthcare Have you needed? Have you received?						
9	Information about the nature of your cancer						

Item		Not at all	Quite a little	Some	Quite a lot	Very much	Does not apply to me
© Tiina Yli-Uotila		(1)	(2)	(3)	(4)	(5)	(0)
	Have you needed? Have you received?						
10	Information about the discomforts caused by your cancer Have you needed? Have you received?						
11	Information about the treatments for your cancer Have you needed? Have you received?						
12	Information about the adverse effects caused by your cancer treatments Have you needed? Have you received?						
13	Information that will help you to understand the treatment of your cancer as a whole Have you needed? Have you received?						
14	Answers to the questions you have raised Have you needed? Have you received?						
15	Practical tips for daily living with cancer Have you needed? Have you received?						
16	Support if you are low in spirits Have you needed? Have you received?						
17	Emotional support Have you needed? Have you received?						
18	Support in adapting to the new life situation Have you needed? Have you received?						
19	Alternative support if you are having difficulties in your interaction with the healthcare professionals participating in your cancer treatment Have you needed?						

Item	Not at all	Quite a little	Some	Quite a lot	Very much	Does not apply to me
© Tiina Yli-Uotila	(1)	(2)	(3)	(4)	(5)	(0)
Have you received?						
20 Counselling services to allow you to share any issues you do not wish to discuss with others						
Have you needed?						
Have you received?						
21 Counselling that takes into account those who are close to you						
Have you needed?						
Have you received?						
22 Support that will help you to face those who are close to you						
Have you needed?						
Have you received?						
23 Support for your family's well-being						
Have you needed?						
Have you received?						
24 Support that includes the screening of your ability to manage your life						
Have you needed?						
Have you received?						
25 Support that will strengthen your ability to cope with your own care for your cancer						
Have you needed?						
Have you received?						
26 Confidence in your recovery from cancer						
Have you needed?						
Have you received?						
27 Support after losing the physical integrity of your body (e.g., loss of a breast or loss of hair)						
Have you needed?						
Have you received?						
28 Support to help you to cope with what is happening to your body as a result of cancer treatment (e.g., pain, diarrhea)						
Have you needed?						
Have you received?						

Item		Not at all	Quite a little	Some	Quite a lot	Very much	Does not apply to me
© Tiina Yli-Uotila		(1)	(2)	(3)	(4)	(5)	(0)
29	Support to help you to cope with the fear of your cancer spreading Have you needed? Have you received?						
30	Support to help you to cope with the fear of death Have you needed? Have you received?						
31	Support from the counselling nurse who discusses his/her own experiences with cancer-related topics Have you needed? Have you received?						
32	Empathy from a counselling nurse Have you needed? Have you received?						
33	Counselling that is based on your specific needs Have you needed? Have you received?						
34	Expert counselling Have you needed? Have you received?						
35	The help of counselling services in explaining cancer-related topics in plain language Have you needed? Have you received?						
36	Finding the most suitable means of communication to suit your needs Have you needed? Have you received?						
37	Support, no matter what time it is Have you needed? Have you received?						
38	Support, no matter where you are located Have you needed? Have you received?						

Background variables:

1. In what year were you born?
2. Your gender?
 - a. Female
 - b. Male
3. What is the highest level of education you achieved?
 - a. Master's degree or higher
 - b. Bachelor's degree
 - c. Vocational degree
 - d. No vocational degree
4. Which one of the following options describe best your life situation? Please, select the most appropriate option.
 - a. Employed
 - b. Unemployed
 - c. Student
 - d. Retired
 - e. Taking care of a household
 - f. Other, please specify?
5. Do you have children living in your household?
 - a. Yes, if so, please give year birth of your child(ren)
 - b. No
6. Which one of the following options describe your current living environment?
 - a. Big city (over 100,000 inhabitants)
 - b. Small or medium-sized city or municipality (20,000-100,000 inhabitants)
 - c. Smaller region or municipality (less than 20,000 inhabitants)
 - d. Rural area
7. What is your cancer type? (e.g., breast cancer)
8. In what year was your cancer diagnosed?
9. What is the current phase of your cancer?
 - a. Cancer confirmed but diagnosis not specified yet
 - b. The phase between the specified diagnosis and the onset of cancer treatment
 - c. The phase involving surgery, chemotherapy, radiation therapy and/or hormonal therapy
 - d. The follow-up phase (the end of treatment up to five years afterwards)
 - e. Chronic cancer
 - f. Something else, please specify?

Continues

© Tiina Yli-Uotila

10. How would you describe your current health?
 - a. Good
 - b. Fair
 - c. Moderate
 - d. Quite poor
 - e. Poor
11. From whom do you think you have received the most support during your illness?
(e.g., spouse, parents, children, friends, healthcare professionals, Internet)?
12. How many key supporters do you have?
13. What kind of counselling services have you used from the cancer societies?
 - a. Phone counselling
 - i. I have used this
 1. How often?
 2. How do you perceive a phone call as a means of communication?
 - a. Easy
 - b. Neither easy nor difficult
 - c. Difficult
 - ii. I have not used this
 - b. Email counselling
 - i. I have used this
 1. How often?
 2. How do you perceive email as a means of communication?
 - a. Easy
 - b. Neither easy nor difficult
 - c. Difficult
 - ii. I have not used this
 - c. Online chat counselling
 - i. I have used this
 1. How often?
 2. How do you perceive online chat as a means of communication?
 - a. Easy
 - b. Neither easy nor difficult
 - c. Difficult
 - ii. I have not used this

Appendix 4. Content validity indices

Table 1. Ratings on a 38-item scale by six raters: Items rated 3 or 4 on 4-point relevance scale (ratings 1 or 2 = -)

Item	Rater 1	Rater 2	Rater 3	Rater 4	Rater 5	Rater 6	Raters in agreement	I- CVI ¹
1	3	4	4	4	4	4	6	1.00
2	3	4	4	3	4	4	6	1.00
3	3	4	4	4	4	4	6	1.00
4	4	4	3	3	3	4	6	1.00
5	4	4	4	4	4	3	6	1.00
6	4	4	-	4	4	3	5	.83
7	4	4	3	4	4	4	6	1.00
8	-	4	3	4	-	4	4	.67
9	-	4	3	4	-	4	4	.67
10	4	4	3	4	4	4	6	1.00
11	4	4	3	4	-	4	5	.83
12	4	4	3	4	4	4	6	1.00
13	4	4	4	4	4	4	6	1.00
14	-	3	4	3	-	4	4	.67
15	4	4	4	4	4	4	6	1.00
16	-	4	4	4	4	4	5	.83
17	3	4	4	4	4	4	6	1.00
18	4 ²	4 ²	4	4	4	4	6	1.00
19	-	4	-	3	4	4	4	.67
20	3	4	4	4 ²	4	4	6	1.00
21	4	4	4	4	4	4	6	1.00
22	4	4 ²	3	3	4	4	6	1.00
23	4	4	4	4	4	4	6	1.00
24	-	4	4	4	4	4	5	.83
25	3	4	4	3	4	4	6	1.00
26	3	4	4	4	4	4	6	1.00
27	3	4	4	4	4	4	6	1.00
28	-	4	4	4	4	4	5	.83
29	3	4	4	4	4	4	6	1.00
30	3	4	4	4	4	4	6	1.00
31	-	4	-	-	-	4	2	.33
32	3	4	4	3	4	4	6	1.00
33	4	4	4	4	4	4	6	1.00

Item	Rater 1	Rater 2	Rater 3	Rater 4	Rater 5	Rater 6	Raters in agreement	I- CVI ¹
34	3	4	4	-	4	4	5	.83
35	3	4	4	3	4	4	6	1.00
36	-	4	4	4	4	3	5	.83
37	3	3	4	4	4	4	6	1.00
38	3	-	4	4	4	4	5	.83
Proportion relevant	.76	.97	.92	.95	.87	1.00		
Sum							25	34.65

¹ Item level content validity index

² Missing information, which was replaced by average rating of the item (rounded to the nearest integer)

Table 2. CVI values for the overall scale

S-CVI/Ave ³	.91
S-CVI/UA ⁴	.66

³ Scale level content validity index, averaging calculation method (average of the I-CVIs for all items on the scale)

⁴ Scale level content validity index, universal agreement calculation method (proportion of items on a scale that achieves a relevance rating of 3 or 4 by all raters)

Appendix 5. Participants in phase III

Variable	N	%	Mean	SD ¹	Md ²	Q ₁ -Q ₃ ³	Range
Gender	27						
*Female	21	75					
*Male	6	21					
*Unreported	1	4					
Age	28		63.1	10.0			33-74
Education	28						
*Master's degree or higher	8	29					
*Batchelor's degree	11	39					
*Vocational degree	9	32					
Life situation	28						
*Employed	4	14					
*Unemployed	2	7					
*Student	1	4					
*Retired	16	57					
*Taking care of the household	1	4					
*Other	3	11					
Children living in the household	28						
*Yes	5	18					
*No	23	82					
Birth years of the children	6						1998-2012
Living environment	28						
*Large city (> 100 000 inhabitants)	12	43					
*Medium-sized city or municipality (20 000-100 00 inhabitants)	9	32					
*Smaller region or municipality (< 20 000 inhabitants)	4	14					
*Rural area	3	11					
Cancer type	36						
*Haematological cancers	11	31					
*Breast cancers	7	19					
*Gynaecological cancers	4	11					
*Urological cancers	4	11					
*Skin/mucosa cancers	4	11					
* Others (lung cancer, bone cancer, thyroid cancer, gastro-intestinal cancer)	6	17					
Year of the diagnosis	35						
*1989-2010	18	51					
*2011-2015	17	49					
Current phase of the cancer	28						
*The phase involving surgery, chemotherapy, radiation	7	25					

Variable	N	%	Mean	SD ¹	Md ²	Q ₁ -Q ₃ ³	Range
*The follow-up phase (the end of treatment up to five years afterwards)	14	50					
*Chronic cancer	7	25					
Perceived current health	28						
*Good	3	11					
*Fair	12	43					
*Moderate	8	29					
*Quite poor	5	18					
Most support received from	50						
*Family (spouse, children, siblings)	17	34					
*Healthcare professionals	11	22					
*Peers (online and offline)	9	18					
*Friends	9	18					
*Cancer societies	2	4					
*Internet (not specified)	2	4					
The number of key supporters	177				4.0	3.0-7.8	1-30

¹ Standard deviation

² Median

³ Lower quartile-upper quartile

Motives of cancer patients for using the internet to seek social support

T. YLI-UOTILA, MNSC, *Nursing Science, School of Health Sciences, University of Tampere, Tampere*,
A. RANTANEN, PHD, *Nursing Science, School of Health Sciences, University of Tampere, Tampere*, &
T. SUOMINEN, PHD, PROFESSOR, *Nursing Science, School of Health Sciences, University of Tampere, Tampere, Finland*

YLI-UOTILA T., RANTANEN A., & SUOMINEN T. (2013) *European Journal of Cancer Care* **22**, 261–271
Motives of cancer patients for using the internet to seek social support

The purpose of the study was to describe why Finnish cancer patients choose the internet as a source of social support. The data were collected in May 2010, using an online questionnaire with open-ended questions, through four discussion forums on the websites of the non-profit Cancer Society of Finland. Seventy-four adult patients with cancer participated. The data were analysed using inductive content analysis. The mean age of the participants was 53 years and they were predominantly women. The most common cancer was breast cancer and more than three quarters of the participants had suffered from cancer for less than 5 years. The initial stimuli to use the internet as a source of social support were the ease of communication and access to information as well as the need for emotional and informational support. The actual motives that drove the use of the internet as a source of social support were the requirements for information and peer support, internet technology, a lack of support outside the internet and the negative experiences caused by the illness. The fact that there is an enormous need for information as well as for emotional support and that cancer treatment in Finland is concentrated in major hospitals, to which cancer patients may travel a considerable distance, suggests that nurses should learn to make more frequent virtual contact with their patients.

Keywords: social support, internet, cancer.

INTRODUCTION

Use of the internet is ever increasing. Currently, as many as 86% of Finns are users of the internet and 72% use the internet daily or almost daily. The activities that are pursued most commonly online are making contact with friends and acquaintances, managing private finances, making purchases and following the mass media. Internet usage is fairly similar for men and women, but there are some differences. Women prefer to look for specific information by browsing internet pages or use the web

for social communication. Male-dominated activities are connected to the downloading of files, and the purchasing and selling products on online sales or auction sites for private purposes (Statistics Finland 2010).

It is well known that social support has been found to have positive effects on cancer patients' health and well-being (e.g. Klemm 2012; Pinar *et al.* 2012). Social support is a complex concept but basically it encompasses informational, emotional and practical types of support (Cohen & Syme 1985) and social support as a problem must be seen in terms of an interactional exchange between donors and recipients (Pearlin 1985, p. 48). The internet offers virtually unlimited possibilities for finding health information and support, from both lay and expert perspectives. Patients seek information on the internet when they cannot get the answers that they require from health professionals. On the internet, patients do not have to settle for a single source of information. The internet can

Correspondence address: Tiina Yli-Uotila, Nursing Science, School of Health Sciences, University of Tampere, Tampere 33014, Finland (e-mail: tiina.yli-uotila@uta.fi).

Accepted 16 October 2012

DOI: 10.1111/ecc.12025

European Journal of Cancer Care, 2013, **22**, 261–271

be accessed at home or at work, and this ease of access might facilitate everyday health management (Kivits 2004, 2006).

Almost half of patients with cancer use the internet to search for medical information and nearly as many search for emotional support (Fogel *et al.* 2002; Rimer *et al.* 2005). In general, patients with cancer want information on diagnosis, treatment options and the side-effects of their treatment. They also want to read publications that relate to cancer (Leydon *et al.* 2000). Furthermore, their information needs are complex and vary over time. In the study of Rozmovits and Ziebland (2004) respondents felt that the information that they received from the health-care services was patchy, inconsistent, contradictory and haphazard. The receipt of such incomplete information increases anxiety and affects adjustment to the state of illness. Patients welcome health information on the internet when they do not have access to other sources of information or the information that they have received is unreliable. The attitudes of cancer patients towards seeking or accepting further information are also affected by the approach of individual patients to the management of their cancer (Leydon *et al.* 2000).

A vast amount of medical information is available on the internet, with numerous voices and opinions for the patient to consider. For some patients, this abundance of information may be a stress factor that is difficult to deal with (Josefsson 2005). Another disadvantage of internet-based information is that the quality of the information and support offered can vary and it may be difficult to assess its quality because the reliability of the data cannot be verified (Martin & Youngren 2002). Online self-help groups for cancer report high dropout rates. The reasons for this include a desire to avoid knowledge of painful details about cancer, the patient considering that they are not 'ill enough' to participate, the challenge of establishing a legitimate position in the group, the pressure of everyday life and phases of illness that do not motivate patients to participate in a self-help group (Sandaunet 2008).

The purpose of the study described herein was to identify the initial stimuli and motives of patients with cancer seeking social support on the internet. The research questions were:

- 1 What was the initial stimulus to turn to the internet?
- 2 What are the reasons that make patients with cancer seek support from the internet?

The findings should provide information that can be utilised in cancer nursing and in the development of cancer-related websites.

METHODS

Participants

The participants in the study were adult (over 18 years old) patients with cancer. They were recruited through four discussion forums hosted on the websites of the Cancer Society of Finland. The four forums were: (1) a group for those living on life-support medication and their next of kin that provides the opportunity to reflect, for example, on issues related to palliative treatment and share ideas about the experience of living with a chronic cancer; (2) general cancer forum (free discussion of other cancer-related topics); (3) a forum for female patients with cancer; and (4) a forum for male patients with cancer. The link to the online questionnaire was placed on these four forums and anyone over 18 years old with cancer who was interested in the study was able to participate. The Cancer Society of Finland, which currently has approximately 140 000 members, was selected as the study partner because it is one of the largest non-profit public health organisations in Finland, a country with approximately 5 million inhabitants.

Data collection and analysis

The data were collected in May 2010 using an online questionnaire. The theoretical framework of the questionnaire was the online social support theory developed by LaCoursiere (2001). When developing the questionnaire, the ideas of the developer of the theory were used to guide the setting of the questions. The two sections of the theory, namely, initiating and mediating factors, were used to identify the initial stimulus that led cancer patients to the internet and their motives for using the internet as a source of social support. Online social support begins with initiating events that cause an individual to seek online social support. Those events are an alteration in health status and an alteration in perceived health. Initiating events are influenced by mediating factors, which encompass four categories: health factors, demographic factors, perceived individual factors and internet use factors (LaCoursiere 2001). The questionnaire was developed for the present study and it was piloted with two patients with cancer, with the result that no changes were needed.

The online questionnaire was divided into two sections. The first section gathered information about background factors: demographic factors and health-related factors, using closed-ended questions and one open-ended question. Demographic questions concerned descriptors such as age, gender, educational level and the number of

additional people living in the same household. Health-related factors were the type of cancer, timing of the diagnosis and an open-ended question about current perception of health, and the content of the answers to these questions was content analysed. The second section, which focused on the experience of cancer and use of the internet, consisted of open-ended questions. The answers to two of the questions are reported in the present article, and the other questions will be reported later in upcoming article. In these responses, the participants described their reasons for seeking social support on the internet. After accessing the online questionnaire through the discussion forum, visitors had the opportunity to fill in the questionnaire and forward it by clicking 'save'. The data were collected from the questionnaires within 21 days. The time frame of the data collection was a consequence of the saturation of the data. The majority of questionnaires (64 of 74) were received during the first week.

The data were analysed using inductive content analysis. After the material had been read through several times, it was reduced and categorised (Table 1) (Burns & Grove 2005). During the data reduction, the original expressions of the participants were retained to avoid compacting the data excessively at an early stage and losing data. Original expressions that described the same concept were coded using the same coloured font so that it was easy to track similarities later. Even when grouping the expressions, the original expressions of the participants were used as much as possible (Burns & Grove 2005). Some of the responses comprised only one word, whereas others were longer than one sentence. For this reason, a single word and the entire expression were

selected as units of analysis (e.g. Elo & Kyngas 2008). There were 208 analytical units in total. The demographic and health-related responses were quantified using descriptive statistics, except the open-ended question about perceived health, which was analysed with content analysis.

Ethical considerations

In health research, ethical principles are designed to protect participants from harm and risks (Burns & Grove 2005; Holloway & Wheeler 2010). In the present study, the ethical issues were related to the research topic, permits, participants, data, data analysis and reporting of the results. Consideration of ethical issues concerning the research topic was important because demographic changes in the Finnish population are leading to an increase in the incidence of cancer. This means that, in the future there will be more survivors of cancer. Cancer causes higher levels of threat and fear than many other illnesses. This, together with the spread of the internet, brings challenges to nurses in recognising the importance of the internet for the social support of patients with cancer. The research topic was not considered to be a sensitive one, even though the participants might have been vulnerable because of the nature of their illness. The study was not expected to cause damage or harm to the participants (Holloway & Wheeler 2010). Permission to conduct the research was received from the Cancer Society of Finland. Justice, respect of autonomy and voluntariness were considered with regard to the participants during the data collection process. Given the nature of the online questionnaire, the posting of responses was considered to represent informed consent to participation in the research. The introduction of the online questionnaire was made as informative as possible to enable the respondents to make an informed decision. Security issues are particularly important in relation to online questionnaires. The data were available only to the researchers and were secured by a username and a password. This safeguarded the anonymity of the participants. The fact that it was impossible to track the e-mail or internet protocol (IP) addresses of the participants increased the participants' anonymity.

RESULTS

Participants

Seventy-four patients with cancer participated in the study. The mean age of the participants was 53 years (range 24–72). The majority of participants were women

Table 1. An example of categorisation of the data

Expression groups	Subcategories
Only critical information from nurses and doctors	Lack of information from the public healthcare system
The hospital does not provide enough advice services	
Doctor offers little information	
The information leaflet was old	
No other place to find support	Lack of information and support outside the internet
No other place to find information	
Overall no other place to go	
No previous information on cancer	Limited availability of information
Little information available	
Subcategories	Category
Lack of information from the public healthcare system	The lack of support outside the internet
Lack of information and support outside internet	
Limited availability of information	

(87%, $n = 64$). Most had a polytechnic or college degree (39%). Nearly one in four (24%) had a university degree.

The number of additional people living in the same household varied between zero and seven (mean 1.7). The majority of households (84%, $n = 62$) consisted of one to three persons in addition to the participant.

The most common type of cancer was breast cancer (42%). Among all the cancers reported by participants, the proportion of breast and gynaecological cancers ($n = 76$) was 55%. The frequency of other cancers varied between 1% and 9%. The other cancers reported were cancers of the prostate, colon, stomach, tongue, liver, pancreas, thyroid and lung as well as leukaemia, lymphoma, multiple myeloma, polycythaemia vera, sarcoma and melanoma. More than three quarters of the participants had suffered from cancer for less than 5 years. Only 8% ($n = 7$) of the cancers reported by the participants had been diagnosed in the period 1997–2003. Therefore, the majority of the cancers had been diagnosed between 2004 and 2010.

Seventy-three per cent of the participants felt that their current health was good. Eighteen per cent of the participants reported a moderate level of health, and 9% of the participants felt that their health was poor.

The initial stimuli to search for social support from the internet

The initial stimuli to use the internet as a source of social support could be categorised as ease of communication and access to information, as well as the need for emotional and informational support (Table 2).

Ease of communication and access to information referred to the fact that it was easy to obtain information and support from the internet, as well as to the advantages of information technology. *This ease of access* was so obvious that the word that participants used most often was 'easiness'. The internet was considered to be the easiest way to obtain information and peer support, especially because it could be used either at home or away from home. The support and information received from the internet complemented, for example, the medical and psychological support received. Furthermore, the information technology was technically easy to use. Another *benefits of the information technology* was speed, which, as a benefit, was comparable to the ease of access. The large amount of up-to-date information also attracted patients to the internet. The participants felt that they had access to a huge amount of extensive information, as well as the latest information. In addition to the national cancer websites, the participants used foreign websites, which had a broader readership. One of the benefits of information

technology that was mentioned most often was the absence of time restrictions. The internet was available at any time and could be accessed whenever the participant wanted, even, for example, during convalescence or when the patient was tired. The internet did not require travel, but instead could be used in a cosy environment in peace and quiet. It was possible to discuss matters anonymously on the internet, and also in private when necessary. The anonymity enabled openness and communication with total strangers.

Participants expressed **the need for emotional support** as a result of negative feelings and a lack of peer support. *Peer support* from a person suffering from the same disease was considered to be valuable. In particular, peer support played an important role for young patients and those with rare types of cancer. The internet provided an opportunity to obtain peer support or make new friends if the patient did not know any patients of a similar age or with the same type of cancer or could not make contact with a support person from the cancer society. The expressions that were related to receiving peer support were more diverse than the expressions related to giving it. Giving peer support was felt to be important, and these patients also felt that they received something in return. Patients liked to read about the experiences of their peers and these experiences were seen to be supportive. The reasons given for the need for this type of support were that the participants could not find fellow patients other than on the internet, or it was a long journey to the hospital, or there was no one with the same type of disease in the neighbourhood. The participants considered that only a fellow patient could understand the diversity of their suffering. The illness often increased the sense of isolation by impeding outdoor activities, which led to increased use of their internet. Another reason given for use of the internet was being younger, on average, than the majority of cancer patients. Use of the internet allowed patients with cancer to protect their loved ones. They did not want to overburden their loved ones or relatives with the same stories repeatedly and the loved ones did not always understand the experiences of cancer patients. *Negative feelings* caused by the disease increased the need for emotional support. Disappointment with not receiving support at the appropriate time resulted in some participants no longer searching for support. Insecurity was caused by tremendous anxiety, becoming ill with cancer created high levels of uncertainty and fear.

The need for informational support also provided a stimulus to search for support on the internet. Participants sought information actively, in response to the fact that their needs were not met by the public healthcare

Table 2. The initial stimuli to search for social support from the internet

Categories	Subcategories	Expression groups	Original expressions
The ease of communication and access to information	Information and support on internet available with ease The benefits of information technology	Easiness	'Easiness.'
		Information and peer support obtained with ease	'Internet is the easiest way to get additional information and peer support.'
		Speed	'The fastest and most up-to-date information and also the widest database.'
		Large amount of up-to-date information	
		No time restrictions	'Questions and answers can be reached regardless of the time of the day, public healthcare is available only during office hours.'
		Access to the internet at home	'Getting help at home in peace and quiet.'
		Anonymity	'You can discuss anonymously on the net, and also in private when necessary.'
The need for emotional support	Peer support	Broad readership	'Broad readership.'
		Receiving and giving peer support	'Nowadays I'm giving what I got, in other words support and encouragement, confidence that it's possible to survive from the treatments.'
		Experiences of peers	'Afterwards it's interesting to follow up survival stories.'
		Finding fellow patients	'It gives strength to find fellow patients.'
		Isolation	'The illness has affected the ability to go out.'
		Becoming ill when young	'Being ill on average younger than the majority of ovarian cancer patients.'
		Protection of loved ones	'You can't overburden your loved ones with the same stories.'
The need for informational support	Negative feelings	Disappointment	'I don't seek support anymore, because I didn't get it at the time (2 years ago).'
		Insecurity	'One's tremendous anxiety.'
		Uncertainty	'Terrible uncertainty and fear when getting ill with cancer.'
		Fear	
	Active information seeking	Desire for information	'I want to know about the disease and its prognosis.'
		Rare disease	'A rare disease about which doctors know little but the internet offers a lot of new research.'
		Curiosity	'Curiosity.'
		Interest	'Cancer sites contain.'
		The lack of positive information	'I didn't get positive information about pancreatic cancer, well of course from the doctors and the nurses, but I think that peer support from a person with the same disease is invaluable.'
	Needs are not met by the public healthcare system	Not enough information from the staff, the cancer outpatient clinic or the hospital	'At the outpatient cancer clinic the doctors and the nurses don't offer enough information.'
		Hastiness of the staff	'The information I got from the hospital was inadequate.'
		Inaccessibility of staff	'The staff doesn't have the time to discuss things, especially the doctors.'
	Forgetting questions or information	Did not remember to ask	'Things come to mind at times when public healthcare is not available.'
		Did not remember all the things told	'You don't remember to ask everything during the doctor's round or during telephone appointment.'
			'The doctor really explained things throughout and clearly but my own mind couldn't take it all in.'

system, as well as the tendency to forget information that had been provided. Many factors led to *active information seeking*. Cancer patients wanted information on their illness, prognosis, and illness-related symptoms and ailments. If they had a rare cancer, patients wanted to obtain information from both Finnish cancer sites and those of foreign cancer associations. The information confirmed what was to be expected and increased the patient's ability

to manage the situation. When patients had a rare disease that doctors knew little about, they could access up-to-date research on the internet. Pure curiosity and interest also stimulated use of the internet. If the cancer had a poor prognosis, positive information could not be obtained from the healthcare professionals. In this case, participants searched on the internet for positive information from persons with the same type of cancer, and this

information was valuable for them. It was often the case that *needs were not met by the public healthcare system*. The cancer patients felt that they could not obtain sufficient information from staff, including doctors, oncologists and cancer nurses, about issues related to their illness. Patients were able to find information on the internet that their doctors and nurses did not provide at all, for example, information about alternative therapies and natural remedies. Staff, especially doctors, were often busy, which meant that there was no time to discuss things with them, and staff were often not available at times when issues and questions came to mind. There was also the issue of *forgetting questions or information*. During a consultation or a telephone call with their doctor, patients often did not remember to ask their questions. Furthermore, even if the doctor explained things thoroughly and clearly, the patient was unable to retain all the information.

Motives for using the internet as a source of social support

The motives for using the internet as a source of social support were to obtain information or peer support, the availability of internet technology, the lack of other support outside the internet and negative experiences caused by the illness (Table 3).

The factors underlying the search for **information** could be categorised into the desire for information, limited availability of information, interest and guidance from other people. *The desire for information* appeared as a need for information. The participants expressed an enormous desire for information and a need to know what they might have to face, in both good and bad scenarios. Information was sought on the illness, type of cancer, available treatments and the side-effects of treatments. Information was also sought before the diagnosis, as if in anticipation of future events. Once the diagnosis was obtained, information was sought about possible treatments, for example, surgery. The information enhanced understanding. The need for information was emphasised when there was *a limited availability of information*. Either the participant had very little previous knowledge about cancer or the cancer was so rare that there was little information available. *Interest* was also given as a reason for the search for information. Similar cases of cancer sparked interest, as well as information about the specific type of cancer relevant to the participant. Furthermore, information about chemotherapy and the illness itself, as well as statements written by doctors, aroused the patients' interest. Participants also sought information on the internet in

response to *guidance from other people*. For example, they identified appropriate websites where the information about cancer could be found on the basis of other people's advice. Instructions on how to evaluate information from the internet were also given. For example, one doctor had advised a cancer patient not to read medical articles that were more than 5 years old. Finally, in the modern world, it is the consensus that information is always to be found on the internet.

Peer support was another motive for using the internet. In addition to seeking and giving peer support, the lack of peers was a motive for using the internet. *Seeking peer support* was considered to be very important, especially at the beginning of the illness. Support in real time was highly valued and patients wanted to be involved in discussions. In general, peer support was sought on the internet, because the patient knew no one with cancer within their circle of acquaintances and strongly desired such support. Peer support was also sought for at times of fear or when the patient was unable or unwilling to express their feelings, thoughts or fears to loved ones. The experiences of peers were sought when patient wanted to compare their situation with the experiences of other patients with cancer. Stories of the survival and recovery of other patients with cancer gave hope and were always of interest. *Peer support* was not only sought but it was *also given*. The need to share was the motive for giving support. Sometimes participants did not seek support for themselves at all, but specifically wanted to provide support to others. A further motive for use of the internet was *the lack of peers*. A lack of peers was often associated with the beginning of the illness, when the patient did not know anyone who was suffering from cancer and at that time the internet was a useful peer support channel. In the case of a rare type of cancer, no support persons might have been available through the cancer association, and the only way to find peer support was through the internet. The internet enabled support persons to be found over a much larger area, even abroad.

The availability of **internet technology** also motivated cancer patients to search for support on the internet. One of the perceived advantages of internet technology was *the convenience of the internet*. 'Easiness' was the word that was associated most often with the internet. All information about cancer was of interest and the internet was an easy and practical way to find such information. It was felt that it was easy to get the latest and the most versatile information on the internet. In addition to information on the internet, peer support was sought. The internet was clearly felt to be an easier way to receive peer support than going to meetings organised by the cancer society or

Table 3. Motives for seeking social support from the internet

Categories	Subcategories	Grouped expressions	Original expressions
Information	Desire for information	Need for information	'The need for information was really enormous. I had to get to know what I might face.'
	Limited availability of information	No previous information on cancer	'I had no previous information on cancer because I had never read about the cancer in question.'
	Interest	Little information available Interest Curiosity Statements written by doctors	'A rare cancer, there was little information available.' 'Interest in the chemotherapy given and the disease as a whole.' 'Curiosity.' 'The statements written in the medical report by doctors.'
	Guidance from other people	Other people's advice World today	'My daughter had first sought information on the website of a cancer association and advised me to visit that site.' 'Just the world today: Check the internet.'
Peer support	Seeking peer support	The experiences of peers The seeking of peers	'There are people all over Finland who are in the same situation. You can read experiences about how others are doing. It gives hope to see that others have recovered.' 'Among my friends there's no one who had cancer and I longed for peer support.'
	Giving peer support	Giving support Need for sharing	'I don't seek support; instead I try to support others.' 'Passion for information, need for sharing.'
	The lack of peer support	No peers The lack of support persons	'At the beginning I didn't get any peer support because I didn't know anyone who had the same disease.' 'I didn't find a support person.'
	Convenience of the internet	Overall easiness Easy way to find information Easy way to seek peer support	'Easiness.' 'It's easy to obtain information from the internet.' 'It's easier to find peer support from the net than to go e.g. to the events arranged by a cancer association or to acquire a support person through an association.'
Internet technology	Familiarity with the internet	Practical way Surfing on the net Extensive use of the computer	'It's a practical way for me to find information on all kind of things.' 'In any case I surf a lot on the net.' 'I use the computer a lot and nowadays it is an easy way to find information on different things.'
	The advantages of the internet	Anonymous Rapidness Availability	'Expressing difficult things anonymously.' 'This is a rapid way and it's possible to get help and support on an acute matter fast.' 'From the net you can seek information when you have the time and when needed.'
	Lack of information from the public healthcare system	Only critical information from nurses and doctors Not enough information from the doctors The hospital does not provide enough advice services The information leaflet was old	'From doctors and nurses you can only receive critical information on your situation, drugs and drug side-effects.' 'From the doctors I received information from PV very marginally.' 'I received rather little information from the doctor and so I searched for facts on the net.' 'The information leaflet I received from the outpatient cancer clinic was edited in 1999.'
	Lack of information and support from elsewhere Inaccessibility of professionals	No other place to find information No other place to find support Overall no other place to go The oncologist did not have time Hastiness of the staff Expensive to use a private doctor's services	'There was no other place to make an appointment to obtain information and to ease the initial shock.' 'It seemed like there was no other place to get it [support].' 'To my knowledge there's no other place to go.' 'The public healthcare oncologist didn't have time to help.' 'The urgency of the nursing staff and the doctors.' 'It's expensive to use the services of a private oncologist.'
The lack of support outside the internet	Lack of information and support from elsewhere	No other place to find information No other place to find support Overall no other place to go	'There was no other place to make an appointment to obtain information and to ease the initial shock.' 'It seemed like there was no other place to get it [support].' 'To my knowledge there's no other place to go.'
	Inaccessibility of professionals	The oncologist did not have time Hastiness of the staff Expensive to use a private doctor's services	'The public healthcare oncologist didn't have time to help.' 'The urgency of the nursing staff and the doctors.' 'It's expensive to use the services of a private oncologist.'
	Uncontrolled feelings about the situation	Questions do not come to mind until home Unable to handle the information received Did not know what to ask Did not remember to ask	'The questions come to mind not until you're home when you are in a real situation and you need to get the information from somewhere.' 'During the doctor's round I received only a little information and at that critical moment I was unable to handle the information received.' 'After getting the information from the doctor you couldn't ask anything because your mind was so locked.' 'During the doctor's round and during the treatment you don't know what to ask and you don't remember to ask about things that are on your mind.'
	Threat	Fear Poor prognosis Uncertainty	'A jump to the unknown scared – and also the poor prognosis.' 'The uncertainty about what type of treatment to select, surgery, radiotherapy or something else.'

PV, polycythemia vera.

obtaining a support person from the cancer society. *The familiarity of the internet* was another motive for turning to the internet. The experience of frequent surfing on the internet and the extensive use of computers helped patients to gain information easily. *The advantages of the internet* were undeniable. Anonymity was important: it was significantly easier to express difficult concepts than to express such thoughts face to face. It was also possible to obtain information rapidly and with no time restrictions. Patients could seek information on the internet when they had the time and when it was needed, no appointments were required. In addition, it was possible to return to the matter at a later date, if there was a need.

A lack of support outside the internet often led participants to the internet. One important factor in this respect was that often *the public healthcare system did not meet the patients' needs*. It was felt that doctors and nurses provided only critical information related to the situation, drugs and the side-effects of drugs. The information received during appointments with doctors was scanty, the guidance at the hospital was insufficient and the information leaflets for patients were old. *When information and support were not found elsewhere*, the only option was to turn to the internet. The inaccessibility of professionals was related to the hastiness of staff, which resulted in insufficient time to ask questions of concern. When an oncologist in public healthcare did not have time and it was too expensive to consult a private oncologist, the only alternative was to turn to the internet.

The negative experiences caused by the illness included uncontrolled feelings that were related to the situation and the perceived threats. *Uncontrolled feelings about the situation* arose when patients did not know what to ask, did not remember to ask their questions or questions did not come to mind until they were at home. In such situations, when the patient required information, the internet was felt to be the most appropriate avenue. Doctors offered very little information, and the patients were unable to handle the information received. *Perceived threats* were associated with the feelings caused by the illness and the real threat to life. Becoming ill when young or as a mother of young children, as well as a poor prognosis, caused fear. Suspicion of cancer brought insecurity. Selection of the type of treatment, radiotherapy, surgery or something else, also caused uncertainty.

DISCUSSION

Trustworthiness of the study

In the study, the rigour was reviewed through the assessment of trustworthiness. Trustworthiness represents

methodological soundness and adequacy and it is described using terms such as dependability, credibility, transferability and conformability (Guba & Lincoln 1989). In the present study, dependability meant that all phases of the research process were described as accurately as possible. The analysis aimed at consistency, accuracy and transparency. The categories and subcategories that were developed by the first author, and cross-checked and confirmed by the other authors, were described precisely so that the experienced reader could see what they consisted of. Credibility in qualitative research means that the participants recognise the meaning that they themselves give to a research topic. The research findings must be compatible with the perceptions of the people under study (Holloway & Wheeler 2010; Polit & Beck 2010). In the present study, the research findings could not be returned to the participants for verification because of the nature of the online survey and because the researchers did not have the e-mail addresses of the participants. This may have weakened the credibility of the study. Transferability means that the findings obtained in one context can be transferred to similar situations or participants (Holloway & Wheeler 2010; Polit & Beck 2010). To achieve transferability, the authors sought to describe accurately the participants, their selection criteria and the study context. One limitation of the present study is the transferability of the results. Because the majority of the participants were women and breast cancer patients, the result may not be transferrable to more heterogeneous cancer populations. But on the other hand it is eventually the readers who decide whether the results are transferable or not (Graneheim & Lundman 2004). Conformability means that the results and conclusions, which correspond to the objectives of the study, are not the results of the researcher's own presumptions and preconceptions. The subjectivity of the researchers was not disregarded but they were aware of it at all times (Holloway & Wheeler 2010; Polit & Beck 2010).

Discussion of the results

The purpose of the study was to identify the causes that led the participants to use the internet as a source of social support. The initial stimuli and the motives to use the internet as a source of social support were analysed separately, but in this discussion they are considered jointly because of the similar answers that were obtained. Information was desired and sought on issues related to the illness, and at different phases of the illness. Sometimes the cancer was rare, and it was difficult to obtain information even from doctors or, in other cases, the

participants had no previous information about cancer. A general interest in what had been written about the issue of concern stimulated the search for information. The information received on the internet from official sources was considered to be important and reliable. These results are consistent with those of earlier studies, for example, by Fogel *et al.* (2002), Rozmovits and Ziebland (2004), Ziebland *et al.* (2004), Dickerson *et al.* (2006) and Li *et al.* (2011).

As a reason to turn to the internet, the need for emotional support was associated with negative feelings. Seeking for peer support was often associated with the initial stage of the illness and when the patients had no peers within their circle of acquaintances. It was significant to note that people who had had the same experiences provided the best support. Participants who received support also offered it to the others. Fogel *et al.* (2002) and Rimer *et al.* (2005) stated in their reports that emotional support is sought almost as often as informational support, and this confirms the results of the present study with regard to the need for both peer support and emotional support. The study of Meier *et al.* (2007) emphasised the importance of giving peer support, which was also identified in the present study. Negative feelings, such as disappointment, insecurity and fear, increased the need for emotional support and therefore were initial stimuli to use the internet (see Martin & Youngren 2002; Josefsson 2005; Sandaunet 2008).

A lack of other sources of support outside the internet was a key reason for seeking social support on the internet. For example, this was the case when public healthcare sources did not offer information or support and support could not be found elsewhere. The inaccessibility of professionals was a further reason to turn to the internet (see Rozmovits & Ziebland 2004). Even if information was obtained, for example, from a doctor, the patient was often unable to handle it, or forgot to ask important questions. Rozmovits and Ziebland (2004) also found that hospitals are not considered to be the best source of information and sufficient information is not offered voluntarily, which affects the status of cancer patients, who often do not know what questions to ask. However, patients with cancer appreciate this information more than they appreciate information from other sources (e.g. Norum *et al.* 2003; Clarke *et al.* 2006; Li *et al.* 2011). Healthcare professionals should also remember that matters with which they are familiar are not necessarily clear for patients with cancer. One cancer patient reported that the information obtained from the doctor did not provide any idea of what the disease is by nature, and it was felt that the doctor expected the cancer patient to know what the

terms stage and grade meant. Fear, uncertainty and poor prognosis were seen to be threats caused by the illness (see, e.g. Coleman *et al.* 2005).

The availability of advanced information technology enabled easy communication and access to information. The word that the study participants used most frequently when referring to the internet was 'easiness'. The participants felt that the internet was an easy way to receive information and also a natural way to search for information. However, it was easy only if the patient was already familiar with the internet. The internet was considered to offer many additional advantages, for example, accessibility 24 h a day 7 days a week, anonymity and privacy, and together these factors were the initial stimuli to use the internet as a source of social support (e.g. Martin & Youngren 2002; Im *et al.* 2007). Similar themes have also been found in previous studies; for example, in the study of Rozmovits and Ziebland (2004), access to the empirical knowledge of other cancer patients was appreciated. In addition, in the study by Schultz *et al.* (2003), the internet was seen as a practical tool that could help to distribute information among people with the same experiences.

CONCLUSION

Patients may turn to the internet on multiple grounds. The need for information and emotional support is enormous. The inability of the public healthcare system to meet their needs leads many cancer patients to the internet. In addition, the uncontrolled feelings that are related to the situation and to different threats from the illness are among the negative experiences that lead cancer patients to seek social support on the internet. Advanced information technology makes social support available in an anonymous fashion and regardless of the time of day or the geographical location of the contributors. Cancer treatment is focused in major hospitals, to which cancer patients sometimes have to travel a considerable distance. The question arises as to whether nurses should become more familiar with techniques of virtual communication in order to provide social support for their patients with cancer when needed. For example, nurses can contact their patients after the diagnosis phase or after treatments and respond to their questions. This is very important as patients may not remember everything that they have been told at the hospital. Nurses should also be able to suggest trustworthy websites for their patients where it is possible to find reliable information. It would be interesting to research the effects of virtual communication between nurses and cancer patients on the well-being of

patients, or from the perspectives of both nurses and cancer patients, and to evaluate whether such 'eHealth' activities are valuable. It is important to involve health professionals in online support groups because, according to previous studies, participants read and post significantly more messages in professionally moderated online support groups than in peer-led groups (e.g. Klemm 2012). The importance of research on virtual communication is also increased by the fact that the medical professionals are not always available when cancer patients need to contact them but communication via the internet might overcome this problem. It is also important that the non-profit sector together with the public healthcare sector develop their web pages to better meet the needs of patients with cancer. This study provides some ideas on what kind of problems patients with cancer are dealing with and what are their motives for turning to the internet. For example, young patients with cancer or patients

with a rare cancer may need to turn to the internet because there is no other way to get support or information, as one cancer patient described her situation. It is important to develop the website to meet the needs of these cancer patients as well.

Furthermore, the online social support theory was used as a framework to guide the present study. It can be assumed that the present study has contributed to developing knowledge related to online social support as well as to building an awareness of the potential value of online social support, as LaCoursiere (2001) has stated. The importance of the theoretical framework is seen in the findings of the present study in the way how the findings distinguish the initial stimulus that pushes cancer patients to the internet and the actual reasons that motivate the cancer patients to continue the use of the internet. The initial stimuli and actual motives to use the internet mean different things to different people.

REFERENCES

- Burns N. & Grove S. (2005) *The Practice of Nursing Research. Conduct, Critique and Utilization*, 5th edn. Elsevier Saunders, St Louis, MO, USA.
- Clarke S., Booth L., Velikova G. & Hewison J. (2006) Social support. Gender differences in cancer patients in the United Kingdom. *Cancer Nursing* **29**, 66–72.
- Cohen S. & Syme L. (1985) Issues in the study and application of social support. In: *Social Support and Health* (eds Cohen S. & Syme L.), pp. 3–22. Academic Press, Orlando, FL, USA.
- Coleman J., Olsen S., Sauter P.K., Baker D., Hodgins M.B., Stanfield C., Emerling A., Hruban R.H. & Nolan M.T. (2005) The Effect of a frequently asked questions module on a pancreatic cancer Web site patient/family chat room. *Cancer Nursing* **28**, 460–468.
- Dickerson S., Boehmke M., Ogle C. & Brown J. (2006) Seeking and managing hope: patients' experiences using the Internet for cancer care. *Oncology Nursing Forum* **33**, 8–17.
- Elo S. & Kyngas H. (2008) The qualitative content analysis process. *Journal of Advanced Nursing* **62**, 107–115.
- Fogel J., Albert S., Schnabel F., Ditkoff B. & Neugut A. (2002) Internet use and social support in women with breast cancer. *Health Psychology* **21**, 398–404.
- Graneheim U.H. & Lundman B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* **24**, 105–112.
- Guba E.G. & Lincoln Y.S. (1989) *Fourth Generation Evaluation*. Sage, New York, NY, USA.
- Holloway I. & Wheeler S. (2010) *Qualitative Research in Nursing and Health Care*. Wiley-Blackwell, Oxford, UK.
- Im E., Chee W., Lim H., Liu Y., Guevara E. & Kim K. (2007) Patients' attitudes toward internet cancer support group. *Oncology Nursing Forum* **34**, 705–712.
- Josefsson U. (2005) Coping with illness online: the case of patients' online communities. *The Information Society* **21**, 143–153.
- Kivits J. (2004) Researching the informed patient. The case of online health information seekers. *Information, Communication and Society* **7**, 510–530.
- Kivits J. (2006) Informed patients and the internet. A mediated context for consultations with health professionals. *Journal of Health Psychology* **11**, 269–282.
- Klemm P. (2012) Effects of online support group format (moderated vs. peer-led) on depressive symptoms and extent of participation in women with breast cancer. *CIN: Computers, Informatics, Nursing* **30**, 9–18.
- LaCoursiere S. (2001) A theory of online social support. *Advances in Nursing Science* **24**, 60–77.
- Leydon G., Boulton M., Moynihan C., Jones A., Mossman J., Boudioni M. & McPherson K. (2000) Cancer patients' information needs and information seeking behavior: in depth interview study. *British Medical Journal* **320**, 909–913.
- Li P.W., So W.K., Fong D.Y., Lui L.Y., Lo J.C. & Lau S.F. (2011) The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. *Cancer Nursing* **34**, 49–57.
- Martin S. & Youngren K. (2002) Help on the net: internet support groups for people dealing with cancer. *Home Healthcare* **20**, 771–777.
- Meier A., Lyons E., Frydman G., Forlenza M. & Rimer B. (2007) How cancer survivors provide support on cancer-related internet mailing lists. *Journal of Medical Internet Research* **9**, e12. Available at: <http://www.jmir.org>. doi: 10.2196/jmir.9.2.e12. 22.1.2010
- Norum J., Grev A., Moen M.A., Balteskard L. & Holthe K. (2003) Information and communication technology (ICT) in oncology. Patients' and relatives' experiences and suggestions. *Support Cancer Care* **11**, 286–293.
- Pearlin L.I. (1985) Social structure and processes of social support. In: *Social Support and Health* (eds Cohen S. & Syme L.), pp. 43–60. Academic Press, Orlando, FL, USA.
- Pinar G., Ogdem S., Buyukgonenc L. & Ayhan A. (2012) The relationship between social support and the level of anxiety, depression, and quality of life of Turkish women with gynecologic cancer. *Cancer Nursing* **35**, 229–235.
- Polit D.F. & Beck C.T. (2010) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*, 7th edn. Wolters Kluwer Health, Lippincott Williams & Wilkins, Philadelphia, PA, USA.
- Rimer B., Lyons E., Ribisl K., Bowling J., Golin C., Forlenza M. & Meier A. (2005)

- How new subscribers use cancer-related online mailing lists. *Journal of Medical Internet Research* 7, e32. Available at: <http://www.jmir.org>. doi: 10.2196/jmir.7.3.e32. 28.3.2010
- Rozmovits L. & Ziebland S. (2004) What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Education and Counseling* 53, 57–64.
- Sandaunet A. (2008) The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients. *Sociology of Health and Illness* 30, 131–144.
- Schultz P., Stava C., Beck M. & Vassilopoulou-Sellin R. (2003) Internet message board use by patients with cancer and their families. *Clinical Journal of Oncology Nursing* 7, 663–667.
- Statistics Finland (2010) *Every Second Finn Uses the Internet Several Times a Day*. Available at: http://www.stat.fi/til/sutivi/2010/sutivi_2010_2010-10-26_tie_001_en.html. 18 December 2010.
- Ziebland S., Chapple A., Dumelow C., Evans J., Prinjha S. & Rozmovits L. (2004) How the internet affects patients' experience of cancer: a qualitative study. *British Medical Journal* 328, 564–577.

CONTINUING

EDUCATION

2.8 ANCC
Contact Hours

Online Social Support Received by Patients With Cancer

TIINA YLI-UOTILA, MNSc
ANJA RANTANEN, PhD
TARJA SUOMINEN, PhD

The Internet has made it possible to gain almost unlimited health and illness-related information. Today, 86% of Finns are Internet users.¹ Of Finns, 72% access the Web daily or almost daily.¹ Internet users tend to have higher incomes and education,² and they may write better than do those with less education, and their messages often contain references to employment and occupation in addition to their disease.³ Many patients with cancer use the Internet to seek information and emotional support. Nearly half of patients with cancer (42%) search for medical information and nearly as many search for emotional support.⁴

The Internet offers different kinds of support for patients with cancer. Earlier studies indicate that patients with cancer use the Internet to search for information on the disease. Patients with cancer often look for information about treatments, treatment options, and coping with adverse effects. They may also utilize the Internet to seek a second opinion or validate the physician's instructions.⁴⁻⁹ Disease- and treatment-related information is needed the most after diagnosis and during treatments.¹⁰ In addition to disease-related information, emotional support is very important for patients with cancer. They may search for and provide emotional support to other patients on the Internet.^{11,12} Reading about the experiences of other patients with cancer can help individuals to cope more effectively and help reduce uncertainty and anxiety.^{4,6,11,13,14} Telling their story on the Internet can help break the isolation that patients may experience after a cancer diagnosis. Internet support communities can empower patients with cancer and play a major role in their well-being and rehabilitation.¹⁵ Empowerment may be described as a feeling that one is better informed and as providing greater social wellness.¹⁶

Expertise developed through the Internet in terms of familiarity with a body of medical and experimental knowledge about the illness enables a new kind of social fitness

Patient education in the public healthcare system does not necessarily meet the needs of patients with cancer. Because of this, they may turn to the Internet, or they are guided to electronic sources of social support. The purposes of this study were to describe what kind of social support patients with cancer receive from the Internet and its meaning for them. The data were collected using an online survey that consisted of open-ended questions based on a theory of online social support. The data were analyzed using an inductive content analysis. Online social support consisted of three categories: disease-related information from reliable sources, supportive interaction enhancing positive emotions, and practical tips for daily life with cancer. Three major categories related to the meaning of online social support were identified: peers helping make life easier, empowerment, and inadequate support. The findings can be utilized in tailoring educational interventions for patients with cancer. In the future, the long-lasting effects of online social support need to be examined.

KEY WORDS

Cancer • Internet • Social support

for patients with cancer.^{5,17} Practical advice offered by others may help a patient with cancer to cope with different problems caused by the disease and its treatment. Providing advice on how to communicate with healthcare professionals may be a rewarding role for the support provider.^{4,7}

Currently, there have been only a handful of studies (eg, Klemm,⁸ Ziebland et al⁵) that have examined cancer patients' needs or experiences online using a qualitative approach. These studies have focused either on a limited

Author Affiliations: School of Health Sciences, Nursing Science, University of Tampere (Ms Yli-Uotila and Drs Rantanen and Suominen); and Pirkanmaa Hospital District, Science Center (Dr Rantanen), Finland.

The authors have disclosed that they have no significant relationship with, or financial interest in, any commercial companies pertaining to this article.

Corresponding author: Tiina Yli-Uotila, MNSc, School of Health Sciences, Nursing Science, 33014 University of Tampere, Finland (tiina.yli-uotila@uta.fi).

DOI: 10.1097/CIN.000000000000028

topic or on a limited cancer patient group, usually breast cancer patients. From this point of view, the purposes of the present study were to describe what kind of social support cancer patients receive from the Internet and what the meaning of this social support is to them.

THEORETICAL BASIS

The theoretical framework of the present online survey was the online social support theory developed by LaCoursiere.¹⁸ In this theory, online social support is defined as the cognitive, perceptual, and transactional processes that help to achieve beneficial outcomes in healthcare status, perceived health, or psychosocial processing ability. The theory of online social support consists of four sections, of which two are used as a basis for the present online survey, namely, mediating factors and the outcomes of online social support. Mediating factors are divided into four categories, two of which are relevant to the present study and used as background questions (eg, health factors, demographic factors). An open-ended question was used to garner information about participants' perception of their health. Two kinds of outcomes were identified in LaCoursiere's theory: quantitative and qualitative outcomes. Quantitative outcomes occur on the perceptual level of online social support as a result of support mediation and on the cognitive level as a result of information processing, and both are testable outcomes.¹⁸ In the present study, the qualitative outcomes were of interest. The qualitative outcomes of online social support occur as a result of evaluative functions of online social support. Based on the theory, evaluation questions would focus on contextual processes of communication and experience.¹⁸ Therefore, the outcomes of online social support as presented in this study were examined using two research questions: what kind of social support patients with cancer received from the Internet and what the meaning of social support was to them.

METHODS

Setting and Sampling

The participants of the present study were at least 18 years old, diagnosed with cancer and who visited and/or participated in the Internet discussion forums of the Cancer Society of Finland. This organization was selected as the study partner because it is one of the largest nonprofit public health organizations in Finland and has about 140 000 members. Four discussion forums were selected for inclusion in the study by a representative of the Cancer Society. These included the following: (1) a forum for patients with cancer who live on life-support medication. In this group, patients with cancer and their relatives may

reflect, for example, on issues related to treatments and what it is like to live with a chronic disease; (2) a general cancer forum that provided discussions about cancer-related issues; (3) a forum for women's cancers; and (4) a forum for men's cancers. The women's and men's forums provided a venue for gender-specific issues facing individuals with cancer.

Although the discussion forums of the Cancer Society of Finland were places from which participants were recruited, the focus of the study is on the views of patients with cancer in general who are using the Internet. Therefore, responses of the participants may include the general Internet, discussion forums, Facebook or Twitter, or other cancer-related Web pages (eg, home pages of cancer patients). These responses are not distinguished in this study and the word "Internet" is used as an umbrella concept. The discussion forums of the Cancer Society of Finland are public media, and they are monitored by the administrator of the Cancer Society to avoid inappropriate, obscene, or hurtful messages, but they do not have a professional facilitator. The online survey was placed as a link on these four discussion forums in order to obtain as heterogeneous data as possible. Registered users who visited and/or participated in these four discussion forums were eligible to participate in the study.

Data Collection

Because there were no existing questionnaires for LaCoursiere's theory of online social support, an online survey was developed for this study by the researchers according to the suggestions of the theory developer.¹⁸ The online survey was pilot tested with volunteer patients with cancer to confirm the feasibility of the questions. On the basis of the pilot testing, no changes were made.

The data were collected in May 2010. Patients with cancer who visited the discussion forums and opened the Internet link to the study information had the opportunity to complete the form and submit it by clicking "save." To check the number of the participants and the content of the responses, the data were reviewed daily in order to provide ongoing analyses of the data until saturation was reached.¹⁹ Sixty-four of 74 responses (86%) were received during the first week. No responses were achieved during the last data collection week. After 21 days, the researchers decided to discontinue the data collection because no new information, concepts, or aspects were obtained, and redundancy was achieved.²⁰

Data Analysis

The open-ended questions were analyzed manually using an inductive content analysis.^{20,21} The open-ended questions were as follows: (1) "what kind of support have you received through the Internet?" and (2) "what is the meaning

of online support to you?” Because the data were already in written form, no transcription was needed. In the preparation phase of the inductive content analysis process,²² the unit of analysis was selected. The unit of analysis consisted of either one word or an entire expression (n = 393). In the organizing phase,²² the data were read several times. Guided by the research questions, patterns were identified (open coding). After repeated reading, the patterns found in open coding were grouped into major categories with subcategories according to their similarities or dissimilarities. The contents of the categories and subcategories were compared with each other in order to ensure they belong to a particular group and in order to provide a means of describing the phenomenon under study.²² When organizing the data, the original expressions of the participants were used to keep the analysis as rich and evidentiary as possible.^{20,23} The categories and subcategories were identified with words that characterized the content and were reviewed several times before consensus was achieved among the researchers. The responses regarding mediating factors were quantified using descriptive statistics.

Ethical Considerations

The ethical principles of research were followed to protect the participants’ rights: autonomy, privacy, anonymity, confidentiality, and nonmaleficence.^{21,23} The participants of this study were able to voluntarily choose whether to participate or not. The Internet link in the four online discussion forums providing information about the survey and the form was open to registered visitors with cancer. They could, at any time, discontinue completion of the form without penalty. Everyone who was interested in the study and met the inclusion criteria was eligible to participate. Because of the nature of the online survey, the return of the responses electronically to the researchers was considered an informed consent. During the data collection and analysis, privacy and anonymity were ensured by storing the data electronically behind a username and a password. The data were collected so that it was impossible to track the e-mail addresses or other identifying information of the participants. The research permit was obtained from the Cancer Society of Finland, and the research proposal was approved by the Scientific Further Education Board at the University of Tampere, Finland.

RESULTS

Participants

Sixty-four women (87%) and 10 men (13%) participated in the study. Thirty participants (41%) were 51 to 60 years of age. Nearly one-fourth (24%) had a university degree.

The majority of the households (84%, n = 62) consisted of one to three persons in addition to the participant. In the responses to the open-ended question on perceived health, the participants responded that their current health was either good (n = 54, 73%), moderate (n = 13, 18%), or poor (n = 7, 9%) (Table 1).

The most common cancer was breast cancer (42%). The majority of the cancers (n = 67, 91%) had been diagnosed between 2004 and 2010.

The Social Support Received From the Internet

The first open-ended question that participants were asked to answer focused on the kind of social support they received from the Internet. Three major categories were identified from the responses: disease-related information from reliable sources, supportive interaction enhancing positive emotions, and practical tips for daily life with cancer. In addition, 14 subcategories of social support were gleaned from the data (Table 2).

The category of disease-related information from reliable sources included information about experiencing the disease, treatments, and treatment options, as well as information from reliable sources and communication with professionals. The participants wanted “information on experiences of the disease” itself that was specific to the type of cancer they had. Information related to the disease


Table 1			
Participant Characteristics (n = 74)			
		n (%)	
Gender	Female	64 (87)	
	Male	10 (13)	
Age	≤40	6 (8)	
	41–50	21 (28)	
	51–60	30 (41)	
	61–70	16 (22)	
	≥71	1 (1)	
Education	University	18 (24)	
	Polytechnic or college	29 (39)	
	Vocational	25 (34)	
	No education	2 (3)	
No. additional people living in the same household	0	7 (10)	
	1	31 (42)	
	2	17 (23)	
	3	14 (19)	
	4	3 (4)	
	5	1 (1)	
	6	0 (0)	
	7	1 (1)	
Perceived health	Good	54 (73)	
	Moderate	13 (18)	
	Poor	7 (9)	

Table 2**The Social Support Received From the Internet**

Subcategory	Category	
Information on experiences of the disease	Disease related information from reliable sources	Social support received from the Internet
Information about treatments and treatment options		
Information from reliable sources		
Communication with a professional	Supportive interaction enhancing positive emotions	
Peerness		
Interaction with peers		
Inner strengthening		
Channel for releasing pressure and stress	Practical tips for daily life with cancer	
A place for entertainment		
Spiritual experiences		
Advice and instructions on searching for information		
Advice on problems caused by the disease		
Advice on coping with the disease treatment		
Instructions on personal rights		

included the diagnosis and medical tests. The participants also searched for information related to the progression of the disease, adverse effects, and life expectancy. Some participants reported that they looked for information without defining what specific information they needed. Information on being ill was considered important. Some participants stated, for example, “basic information on the disease, the diagnosis, lab tests.”

“Information on treatments and treatment options” was focused on treatment methods, treatment options, and adverse effects of treatments. Many participants reported that information on adverse effects was useful. When patients know that a specific symptom occurs in others, they may realize that it is part of the disease in a way. “Information from reliable sources” included research findings and facts provided by other cancer patients and cancer-related information from the Web sites of the Cancer Society and hospitals, as well as from international sources, for example, “the latest articles and research results easily from the Internet” and “expert information.”

“Communication with professionals” consisted of communication with the oncology nurse at the hospital. The participants had communicated with an oncology nurse, but they considered the threshold to initiate contact to be high. Supportive interaction enhancing positive emotions consisted of “peerness” and interaction with peers. Patients reported that supportive interaction helped them find their inner strength. The Internet also functioned as a channel for releasing pressure and as a place for entertainment, both of which were reported as part of the supportive interaction, as well as spiritual experiences. “Peerness” consisted of peer support and peer friends. Participants sought peer support from patients who had gone through the same experiences. The participants looked for peer support to help with issues associated with their disease. They mentioned face-to-face meetings, finding someone to talk to,

exchange of opinions, and reading about peer experiences as forms of “interaction with peers.” Participants sometimes arranged face-to-face meetings, and some had found understanding and long-term friends with whom to talk. The participants referred to reading the online messages of others and commenting on them as an exchange of opinions. Participants also reported that reading about the experiences of their peers was helpful. For example, one participant wrote that “Of course, it was also helpful to read about the experiences of companions in misfortune.”

“Inner strengthening” was described as the feeling of not being alone with the disease. The encouragement, support, and consolation received from the Internet and hope and faith in recovery and becoming cured and caring were factors that increased inner strengthening. For example, “I have realized that you can actually survive this disease like any other.”

As part of supportive interaction, the participants noted that the Internet functioned as “a channel for releasing pressure.” They reported that they could even argue with peers on the Internet without worrying about it. One participant wrote that “Possibility to argue without worrying about it too much, about XXXX’s health care reform/European healthcare.”

This activity helped release their emotional pain, and in this way they were able to avoid burdening their families too much. When the participants did not want to think about the disease and wanted to be cheered up, the Internet functioned as “a place for entertainment.” Spiritual experiences on the Internet in the form of spiritual help, such as prayers, were also mentioned as helpful.

Practical tips for daily life with cancer consisted of many kinds of instructions and advice. This included searching for information, problems caused by the disease, treatment of the disease, and personal rights. The participants received “advice on searching for information” from their

peers. Information provided by peers helped many patients with cancer enhance their knowledge related to their disease. The participants also received guidance from their family and professionals when searching for information about their cancer. For instance, a doctor explained that it is useless to read research studies more than 5 years old. The participants discovered “advice on problems caused by their disease” from the Internet. The participants found advice from the Internet that they had not received from the hospital’s cancer clinic. In addition, participants found advice for difficult situations and answers to questions that they had not even come to think about. “Advice on coping with the disease treatment” was related to coping with the adverse effects of the treatments and cytotoxic treatments. For instance, one patient with cancer had received good advice from another patient with cancer on wearing frozen gloves during a docetaxel infusion in order to avoid nail damage, and this way the patient was able to receive the treatment. A patient with cancer reported that:

I have gotten tips on, for example, coping with the adverse effects of treatments; using frozen gloves during Taxotere infusions has made these treatments possible, as the treatment had to be stopped the last time because of severe nail damage.

“Advice on personal rights” was also accessed from the Internet. Some participants received advice to ask for their personal patient documentation in writing from their health-care professional. Advice and instructions were also related to social security and the compensability of drugs.

The Meaning of Online Social Support

The second open-ended question that participants were asked to answer was “What is the meaning of online support to you?” Three major categories were identified from the data: peers helping make life easier, empowerment, and inadequate support. In addition, 10 subcategories were derived from the data (Table 3).

The category of peers making life easier consisted of the peer community, peers helping to carry the load, becoming

understood, and the possibility of interaction. The “peer community” was strengthened by the fact that others were in the same situation. Patients with cancer were not alone, but there were others who had gone through the same initial shock and the same experiences in general. The peer community was also strengthened by identification with others. The virtual peers were seen as an important support network in addition to the participants’ own family. The participants wrote that the Internet increased the amount of support they received in general, and some participants were even dependent on it. Support was reported to be invaluable especially in the early phase of the disease and during the treatments. Some participants wrote that:

I’m definitely not alone, but others who have gone through the same initial shock have the same kind of experiences.

I always have a friend there.

The peers also affected the lives of the respondents by helping to “share the load.” Peer messages were often read on a daily basis, and the participants stated that the fellow patients were on their side. One participant wrote that

The importance has been big because I haven’t had to burden my close relatives all the time. I recommend the Internet for sharing your journey with the disease, although it should not be your only companion.

The Internet also functioned as a channel for releasing anxiety. The subcategory of “becoming understood” was described as the way that the experiences of others helped to understand one’s own situation, and the participants wrote that only people who have gone through the same can best understand what it is like to have cancer. Through the Internet, there was “a possibility for interaction.” For many, the people on the Internet were discussion partners in solitude. The participants often wrote that the Internet was their connection to the rest of the world. For example, “Great importance. I would be isolated without the Internet.”

Empowerment was seen in strengthening and knowledge, as well as in independence. “Strengthening” was described as the way that support from the Internet gave strength. Hope of survival was seen as a paramount issue,

Table 3		
The Meaning of Online Social Support		
Subcategory	Category	
Peer community	Peers helping make life easier	The meaning of online social support
Peers sharing the load		
Becoming understood		
Possibility of interaction		
Strengthening	Empowerment	
Knowledge		
Independence		
Support was not received	Inadequate support	
Limited support		
The support has negative effects		

and the participants looked for this kind of hope from persons who had experienced the same and who seemed to understand them the best. Hope was particularly important when the participant received the information that he/she might only survive a few months with cancer. The social support received from the Internet was also seen in how faith in recovery was strengthened. Coping in everyday life was influenced by the support received from the Internet so that it improved the participant's mood and cheered him/her up. Some participants mentioned that they started to feel better when they discovered that things could be even worse. One participant wrote that:

Also the point that you have to be realistic about your situation. I have lost some of my companions in misfortune, but you shouldn't fall into despair.

Empowerment was also seen in the "knowledge" of the participants. The Internet provided information to the participants that they did not receive from the hospital staff. Information about the disease was seen as important by the participants and helped them to tolerate the adverse effects of the treatments better. The participants were able to compare their own knowledge with information from the Internet and increase their own understanding. For example:

Before visits to the doctor, I have often prepared by looking for basic information on issues that are currently relevant. Or I will increase my understanding after a visit to the doctor, and so on.

The support received from the Internet increased empowerment through "independency" and increased the choices available to the participants. The fact that information from the Internet was easy to get increased the independency of the participants because there were no time restrictions, and making appointments was not needed. The participants were able to access the Internet when needed. Anonymity enabled the free expression of emotions regarding how it felt to be a cancer patient, and the contact threshold to reach for support from the Internet was low.

Sometimes, online support was inadequate. In these cases, the participant received no support at all, or the support was considered limited or thought to be negative in nature. Some participants had not received support from the Internet, reporting that they had written comments to the forums, but nobody had answered them. They thought that this was due to them having an easier experience with cancer. Some participants reported that they had tried to find online support, but had not been able to find peers or could find only a few of them. Some participants reported that they had not received support because they had not looked for it. Other participants noted that "support from the Internet was limited." Some participants also mentioned that the support received from the Internet had a "negative effect." When the support was

negative in nature, it led to anxiety and caused the participant to think about the disease all the time and left the participant alone with the disease causing distress. For example, one participant stated that

Especially in the beginning, for example, discussion forums were even distressing, and I often felt that they were more trouble than they were worth.

DISCUSSION

The current study aimed to address questions about what kind of social support patients with cancer received from the Internet and the meaning of this support to them. In studies related to patients with cancer and the Internet, the participants are usually well educated, predominantly female patients with cancer, and middle-aged,^{4,5,24,25} as was the case in this study.

The Social Support Received From the Internet

The social support received from the Internet consisted of disease-related information from reliable sources, supportive interaction enhancing positive emotions, and practical tips for daily life with cancer.

Patients with cancer search for reliable information related to their illness and experiences of it. In Rimer et al,⁴ the participants (N = 293) used mailing lists to obtain information on how to deal with cancer, to gain support, to learn about other patients' experiences, and to help others. In this regard, the results of this study are similar. In a qualitative study by Ziebland et al⁵ (N = 175) on how men and women talk using the Internet, the results are also similar to our results. In that study, participants used the Internet to seek support and experiential information. The category of information from "reliable sources" identified in the current study was reported by others. For example, in a qualitative study by Clarke et al,²⁶ both male and female cancer patients considered staff to be a preferable information source, which was also mentioned in our study as a reliable source of information.

The present study differs from the study mentioned previously and from the study of James et al²⁷ in one aspect. They examined cancer patients' (N = 800) and carers' (N = 200) use of, and attitudes to, the Internet as an information source compared with other media. Hospitals, doctors, and leaflets, which may be considered reliable sources of information, as well as family, were mentioned as primary information sources. In the current study, the participants also considered official or scientific sources of information to be reliable. However, family members were not mentioned in our study as a reliable source of information at all. Healthcare professionals and especially

physicians as a source of information were valued by participants in our study.

Patients with cancer find a wide range of support from the Internet. For patients with cancer, sharing experiences with peers and access to experimental information were highly valued. Participants in the qualitative study by Rozmovits and Ziebland,¹⁰ which included prostate and breast cancer patients (N = 28), stated that experiences of people in a similar situation were both informative and reassuring. Communicating with others with a similar condition was a reason for every fifth cancer patient (N = 293) to use the Internet in a study by Rimer et al.⁴ These findings are in line with the present study. In contrast to previous studies, we did not find any expressions that would be described in terms of cancer awareness. For example, Ginossar²⁸ found the category of politics and advocacy in her study that examined 1432 e-mail messages posted in two online cancer communities (lung cancer and chronic lymphocytic leukemia).

In addition to the information and support, cancer patients value practical tips for daily life with cancer. In their quantitative substudy with 41 respondents, LaCoursiere et al¹¹ reported the phenomenon of patients receiving instructions from peers on finding information. In their qualitative online forum study (N = 16, 81% women) exploring patients' attitudes toward Internet cancer support groups using a feminist perspective, Im et al.¹² have noted that patients look for advice on the Internet on different problems caused by their disease. Instructions related to the treatment of the disease, such as coping with adverse effects of treatments, were reported as an important issue in Rimer et al.⁴ Advice on personal rights, such as social security and the compensability of drugs, was part of practical support. These studies reflect the findings in the present study. Other researchers have stressed the importance of financial advice.^{28,29} In this study, financial issues were mentioned in terms of compensations of drugs, but they were not related to income issues. This may be due to the fact that all people living in Finland are included within the scope of health insurance. This is paid as sickness benefit, reimbursements for medicines, travel expenses when receiving treatment, private healthcare costs, private dental care costs, reimbursements for examinations, and treatment prescribed by physicians.³⁰

Meaning of Online Social Support

Social support received from the Internet manifested itself in the way that peers helped to make life easier, in empowerment, and as inadequate support.

People who had gone through the same experiences, who were the same age, and who had had the same treatments were highly valued in the present study and in the study by Rozmovits and Ziebland.¹⁰ Im et al¹² reported that cancer patients valued being members in a group and

appreciated meaningful interaction with others, especially if they had difficulties interacting with their families or friends because of the illness. A qualitative study by Broom³¹ explored how Australian patients with prostate cancer perceive and experience online support groups. Online groups were seen as useful because one could share feelings of weakness and vulnerability on the Internet and avoid straining the next of kin, as was found in the present study. In her article based on data from three related studies using a qualitative approach, Josefson³² concluded that patients' online communities provide not only medical facts but human understanding as well. The expressions of understanding one's own situation and being understood were also found in the current study.

One aspect of social support received from Internet was empowerment. Radin³ found themes related to strengthening through which cancer patients became empowered. These are in line with the findings in this study. For example, supportive messages in time of stress, good wishes, and prayers were exchanged. A phenomenological study by Dickerson et al,⁶ which aimed to describe experiences of cancer patients (N = 20, all women) using the Internet for information and support to manage the self-care aspects of illness and treatment, including symptom management, also showed that the empowering of patients as partners in decision making was shown to enhance their coping with the disease. The issue of being informed was mentioned in the current study as well. Independency as a part of empowerment has not been noted in earlier studies. In the current study, it was reported in terms of freedom to choose between an online support person or to have a support person from the cancer society, having no time restrictions (to get the information when needed), and freedom to express feelings.

Sometimes, online social support was inadequate. Fogel et al³³ also reported that those using the Internet for breast health issues did not benefit from tangible social support. In our study, inadequate support was also related to the negative side of social support in addition to tangible support.

Limitations of the Study

In the current study, "Internet" was used as an umbrella concept. Therefore, it was not possible to confirm where exactly the patients with cancer received online social support (eg, support groups, educational sites, and cancer-related sites). This study utilized the theory of online social support espoused by LaCoursiere¹⁸ to guide the data collection. To our knowledge, this theory has not been used in other research as a framework for evaluating online support for cancer patients. However, the developer of the theory provided some suggestions about how the theory can be implemented in future research.¹⁸ This may have been a limitation of the present study, but the researchers hope to contribute to building an awareness of the

potential value of online social support, an aim supported by LaCoursiere.¹⁸

The sample selection was a convenience in nature and chosen by a representative of the Cancer Society of Finland. Only those visitors who had access to the four selected discussion forums were included. Another limitation of the present study was a lack of diversity among the participants, particularly regarding gender. The participants were predominantly women. Although the Internet link to the study was placed on four different discussion forums, male patients with cancer were less likely to participate. Also the fact that the majority of cancer types were women's cancers may limit the transferability of the findings. Further investigations in a more heterogeneous sample of patients with cancer will provide a better understanding of online social support. In this study, a member check was not used because of the nature of the online survey. The researchers did not have the e-mail addresses of the participants. This may have weakened the credibility of the study.

CONCLUSION

The findings in this study suggest that patients with cancer, especially female patients with cancer, are turning to the Internet to receive information from reliable sources and support as well as practical tips for daily life with cancer. In nursing, it is essential to be aware of those information sources patients with cancer use in order to guide them to reliable Web sites.

It is very important that healthcare personnel treating patients with cancer identify different needs for support. It is also important to identify patients who do not look for support on the Internet and who might need another kind of support mechanism (eg, face-to-face support, individual counseling). The key question to consider, however, will be how persons not using the Internet will receive social support in the future because the delivery of support is shifting toward the Internet.

Implications for Practice and Research

The major categories identified in this study can be utilized as a structure or framework when tailoring educational and supportive interventions for patients with cancer either face-to-face or electronically.

Because earlier studies examining the experiences of online support of patients with cancer are mainly cross-sectional, the long-lasting effects of online support need to be examined in the future, for example, by using the identified categories.

In the present study, the theory of online social support was used; however, only two sections of the theory were utilized, namely, mediating factors and qualitative out-

comes. Therefore, in the future research, it is important to use also other sections of the theory (eg, the process of online social support) in order to understand through which mechanisms individuals with cancer achieve beneficial outcomes and not only the outcomes of online social support.

REFERENCES

1. Statistics Finland. Statistics Finland Web site. <http://www.stat.fi>. Accessed June 21, 2011.
2. Carlsson ME. Cancer patients seeking information from sources outside the health care system: change over a decade. *Eur J Oncol Nurs*. 2009;13(4):304–305.
3. Radin P. “To me, it’s my life”: medical communication, trust and activism in cyberspace. *Soc Sci Med*. 2006;62(3):591–601.
4. Rimer BK, Lyons EJ, Ribisl KM, et al. How new subscribers use cancer-related online mailing lists. *J Med Internet Res*. 2005;7(3):e32. www.jmir.org. Accessed March 28, 2010.
5. Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the Internet affects patients’ experience of cancer: a qualitative study. *BMJ*. 2004;328(7439):564–577.
6. Dickerson SS, Boehmke M, Ogle C, Brown JK. Seeking and managing hope: patients’ experiences using the Internet for cancer care. *Oncol Nurs Forum*. 2006;33(1):8–17.
7. Meier A, Lyons EJ, Frydman G, Forlenza M, Rimer BK. How cancer survivors provide support on cancer-related Internet mailing lists. *J Med Internet Res*. 2007;9(2):e12. www.jmir.org. Accessed January 22, 2010.
8. Klemm P. Late effects of treatment for long-term cancer survivors: qualitative analysis of an online support group. *Comput Inform Nurs*. 2008;26(1):49–58.
9. Rogers SN, Rozek A, Aleyaasin N, Promod P, Lowe D. Internet use among head and neck cancer survivors in the North West of England. *Br J Oral Maxillofac Surg*. 2012;50(3):208–214.
10. Rozmovits L, Ziebland S. What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Educ Couns*. 2004;53(1):57–64.
11. LaCoursiere SP, Knopf MT, McCorkle R. Cancer patients’ self-reported attitudes about the Internet. *J Med Internet Res*. 2005;7(3):e22. www.jmir.org. Accessed February 22, 2010.
12. Im EO, Chee W, Lim HJ, Liu Y, Guevara E, Kim KS. Patients’ attitudes toward Internet cancer support group. *Oncol Nurs Forum*. 2007;34(3):705–712.
13. Beaudoin C, Tao C. Benefiting from social capital in online support groups: an empirical study of cancer patients. *Cyberpsychol Behav*. 2007;10(4):587–590.
14. Lieberman M. The role of insightful disclosure in outcomes for women in peer-directed breast cancer groups: a replication study. *Psychooncology*. 2007;16(10):961–964.
15. Høybye MT, Johansen C, Tjørnhøj-Thomsen T. Online interaction. Effects of storytelling in an Internet breast cancer support group. *Psychooncology*. 2005;14(3):211–220.
16. van Uden-Kraan CE, Drossaert CHC, Taal E, Shaw BR, Seydel ER, Mart AFJ. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qual Health Res*. 2008;18(3):405–417.
17. Ziebland S. The importance of being expert: the quest for cancer information on the Internet. *Soc Sci Med*. 2004;59(9):1783–1793.
18. LaCoursiere SP. A theory of online social support. *Adv Nurs Sci*. 2001;24(1):60–67.
19. Green J, Thorogood N. *Qualitative Methods for Health Research*. 2nd ed. London: Sage; 2009.
20. Polit DF, Beck CT. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. 7th ed. Philadelphia, PA: Wolters Kluwer Health, Lippincott Williams & Wilkins; 2010.
21. Burns N, Grove SK. *The Practice of Nursing Research. Conduct, Critique and Utilization*. 5th ed. St Louis, MO: Elsevier Saunders; 2005.

22. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107–115.
23. Holloway I, Wheeler S. *Qualitative Research in Nursing and Healthcare*. 3rd ed. Oxford: Wiley-Blackwell; 2010.
24. Klemm P, Bunnell D, Cullen M, Soneji R, Gibbons P, Holecsek A. Online cancer support groups. A review of the research literature. *Comput Inform Nurs*. 2003;21(3):136–142.
25. Im EO, Chee W, Liu Y, et al. Characteristics of cancer patients in Internet cancer support groups. *Comput Inform Nurs*. 2007;25(6):334–343.
26. Clarke SA, Booth L, Velikova G, Hewison J. Social support. Gender differences in cancer patients in the United Kingdom. *Cancer Nurs*. 2006;29(1):66–72.
27. James N, Daniels H, Rahman R, McConkey C, Derry J, Young A. A study of information seeking by cancer patients and their carers. *Clin Oncol*. 2007;19(5):356–362.
28. Ginossar T. Online participation: a content analysis of differences in utilization of two online cancer communities by men and women, patients and family members. *Health Commun*. 2008;23(1):1–12.
29. Im EO, Chee W, Lim HJ, Liu WM. An online forum exploring needs for help of patients with cancer: gender and ethnic differences. *Oncol Nurs Forum*. 2008;35(4):653–660.
30. Ministry of Social Affairs and Health. Support and benefits. 2011. http://www.stm.fi/en/income_security/benefits. Accessed December 13, 2012.
31. Broom A. The eMale. Prostate cancer, masculinity and online support as a challenge to medical expertise. *J Sociol*. 2005;41(1):87–104.
32. Josefson U. Coping with illness online: the case of patients' online communities. *Inf Soc*. 2005;21:143–153.
33. Fogel J, Albert SM, Schnabel F, Ditkoff BA, Neugut AI. Internet use and social support in women with breast cancer. *Health Psychol*. 2002;21(4):398–404.

For more than 32 additional continuing education articles related to computers in nursing, go to
NursingCenter.com\CE.



The need for social support provided by the non-profit cancer societies throughout different phases in the cancer trajectory and its integration into public healthcare



Tiina Yli-Uotila ^{a,*}, Marja Kaunonen ^{a,b}, Liisa Pylkkänen ^c, Tarja Suominen ^a

^a School of Health Sciences, Nursing Science, University of Tampere, FI-33014, Finland

^b Pirkanmaa Hospital District, Science Center, Finland

^c Cancer Society of Finland, Unioninkatu 22, 00130 Helsinki, Finland

ARTICLE INFO

Article history:

Received 21 January 2015

Received in revised form

27 April 2015

Accepted 3 February 2016

Keywords:

Patient with cancer

Cancer trajectory

Electronic social support

Non-profit cancer societies

ABSTRACT

Purpose: To describe the phases of the cancer trajectory when social support, in the form of electronic counselling services, as provided by the non-profit cancer societies, is needed, as well as how these services are integrated into the cancer care in public healthcare.

Methods: In this descriptive qualitative study a purposive sample of patients with cancer ($n = 12$) were interviewed. The data were content analysed inductively.

Results: Social support was needed when emotional well-being was weakened, when the body broke, when the care pathway induced unawareness, and when empowerment needed strengthening. There was no need for social support when well-being was considered in balance. The electronic counselling services were integrated into cancer care by supporting the patient with cancer emotionally, developing the informational expertise of the patient with cancer, expanding the opportunities for support, and supporting public healthcare. Integration required improvements to the actions of the patients and various actors involved in the healthcare system. There was no integration due to the health status of the patient and the sufficiency of the primary support sources. The received social support was not integrated into the actual cancer treatment process of the patient with cancer in the public healthcare system.

Conclusions: The phases of support needed in the cancer trajectory as defined by the patient differ from the traditional biomedical phases of treatment.

© 2016 Elsevier Ltd. All rights reserved.

1. Introduction

Cancer and its treatments may cause a wide range of physical, informational, emotional and social unmet needs in the cancer trajectory of patients (So et al., 2013). These needs may not be met by public healthcare and therefore, patients with cancer may need to turn to other sources of social support (Yli-Uotila et al., 2013). Social support needs are predominantly studied by the phases of disease treatment, leaving relatively little attention paid to how the patients define these phases (Fowler et al., 2013). When searching for social support the non-profit cancer societies play an important

role for patients, but the research on how the electronic counselling services (ECS) of the cancer societies, including telephone, email, and online chat counselling, are integrated into the cancer care in public healthcare are currently neglected.

During the cancer trajectory, cancer itself and its treatments raise many issues and may have profound implications on patients' lives. Patients with cancer may experience physical disabilities, severe fatigue, depression, changes in body image and sexual function, difficulties in adjusting to daily living and fear of recurrence (Mohamed et al., 2014; Peters et al., 2014; Simard et al., 2013). It is evident that in addition to medical care, patients need supportive care services in the cancer trajectory. While the medical care in Finland is performed mainly in the public healthcare system, supportive services are mostly offered by non-profit cancer societies. Social support, as resources given or received by other people, has proven to have either positive or negative effects on health

* Corresponding author.

E-mail addresses: yli-uotila.tiina.m@student.uta.fi (T. Yli-Uotila), marja.kaunonen@staff.uta.fi (M. Kaunonen), liisa.pylkkanen@cancer.fi (L. Pylkkänen), tarja.suominen@uta.fi (T. Suominen).

(Cohen and Syme, 1985). According to a study that evaluated the hospital-based cancer information and support centre, participants desired these kinds of services because they provided additional support to enhancing self-care capacity (Kinnane, 2012). It has also been shown that social support increases quality of life and decreases anxiety and depression (Pinar et al., 2012). Alternatively, social support can also be inadequate in nature, leading to anxiety and distress (Yli-Uotila et al., 2014). Social support can also vary during the trajectory, depending on what kinds of problems patients are confronting, as well as on the sources of support that are available to them and the nature and form of the support they are receiving (Pearlin, 1985). For example, in the study of Thompson et al. (2013), it was found that breast cancer patients experienced a high level of perceived social support at the time of diagnosis. However, two years after diagnosis, some patients showed declines related to the social supports that were associated with higher level of depressive symptoms, suggesting the patients continued to benefit from high levels of social support (Thompson et al., 2013).

The studies of social support needs usually focus on a certain phase of disease treatment. For example, a study among breast cancer patients revealed five themes of social support needs between diagnosis and surgery: available support, information and advice, care, having confidants and balancing distance and closeness (Drageset et al., 2012). In another study, the aim was to identify the trajectories of illness intrusiveness over the first two years after a breast cancer diagnosis, resulting in a high percentage of participants experiencing low intrusiveness. However, the results also suggested the effects of breast cancer on some participants' lives might have been specific to certain areas (Sohl et al., 2014). In a systematic review, the fear of cancer recurrence was reported to remain stable over the survivorship trajectory (Simard et al., 2013).

Most often, patients with cancer desire cancer-related information (Li et al., 2011), which can enhance involvement in treatment decision-making (Davison and Breckon, 2012). Emotional support, in terms of availability and regardless of whether used or not, is needed, as well as practical tips on how to manage cancer in daily life (Drageset et al., 2012; Yli-Uotila et al., 2014).

It was concluded in previous studies that the health benefits depend on, for example, the source of social support. There may be cultural differences, as in a Chinese study, the preferred sources of support were family and society (You and Lu, 2014), whereas the preferred sources in the western world were hospital staff (Koutsopoulou et al., 2010; Park et al., 2014). Cancer societies, in general, are not utilised for support very often and they do not place the same importance on patients with cancer as they do the family (You and Lu, 2014). However, there is little research in this area globally.

In summary, patients with cancer experience a wide range of needs during the cancer trajectory, and social support is essential during the whole cancer trajectory. The phases of the cancer trajectory when social support is needed are usually determined by the phases of disease treatment. Therefore, the purpose of the present study is to investigate those phases as defined by the patients themselves. To our knowledge, there is no existing research on the integration of the ECS into the cancer care of patients in public healthcare, which is why our second purpose is to describe that area as well. Hence, the purposes of the present paper are, first, to describe from the patients' points of view the phases of the cancer trajectory when patients need to contact the ECS and, second, to describe how the ECS are integrated into the cancer care of patients in the public healthcare system.

2. Methods

This paper is part of a larger study that aims to describe the

experiences of the ECS of non-profit cancer societies, as reported by adult cancer patients and counselling nurses. In this cross-sectional descriptive qualitative study, we were especially interested in the perspectives of adult patients with cancer. In other papers we discuss the ECS as a source of social support for patients with cancer and how the counselling nurses in the ECS view the facilitators and barriers for social support of these patients.

2.1. Participants and data collection

A purposive sampling (Holloway and Wheeler, 2010) of adult patients with cancer ($n = 12$) was recruited from The Cancer Society of Finland and from two regional cancer societies from the western part of Finland. The Cancer Society of Finland comprises 12 regional cancer societies, five nationwide patient organisations, The Finnish Cancer Registry, Cancer Foundation and the Foundation for the Finnish Cancer Institute. Over 120,000 people are members of patient and regional organisations of The Cancer Society of Finland and it is one of the largest non-profit public health organisations in Finland (Cancer Society of Finland (2014)).

The participants were recruited by the counselling nurses (registered nurses and public health nurses) working in the ECS. They received written and oral instructions for the recruitment and written materials to be handed out to the participants from the researcher. The inclusion criteria were 1) a cancer diagnosis, 2) age ≥ 18 years, 3) pre-treatment, in-treatment or post-treatment phase of the disease, 4) contact in telephone, email or online chat counselling services, 5) able to be interviewed face-to-face within a two-hour drive from the researchers' university or by telephone nationwide and 6) willingness to participate in the study. Recruitment was carried out either face-to-face or in electronic counselling meetings with counselling nurses between May 2013 and May 2014. The aim was to recruit as heterogeneous a sample of patients with cancer as possible.

The interview guide (Table 1) was based on the literature and on the discussions with the representatives of the cancer societies when designing the study. The interview questions were pilot tested with two patients with cancer to ensure their feasibility. Based on the pilot interviews, the questions, as well as the way the researcher was performing the interviews were discussed and refined together with two advanced nurse researchers (Doody and Noonan, 2013). Pilot interviews were included in the data. The sociodemographic data were collected using a structured interview form (Holloway and Wheeler, 2010). Of the 12 interviews conducted by the first author, seven were conducted by telephone. Face-to-face interviews ($n = 5$) were conducted at the participant's home ($n = 2$), at the cancer society ($n = 2$) or at the participant's work place ($n = 1$). The interview time per participant was an average of 31 min, varying from 20 min to 55 min. The field notes of the interviews were utilised in the data analysis.

2.2. Data analysis

The data was analysed using an inductive content analysis (Elo and Kyngas, 2008). A content analysis in which data is categorised inductively is suitable for complex and sensitive nursing phenomena or if little is known about the phenomenon under study (Vaismoradi et al., 2013). The recorded interviews were transcribed verbatim by the researcher and downloaded to the qualitative data analysis software Atlas.ti (ATLAS.ti Scientific Software Development GmbH, Berlin) for organising the data. In the analysis process, the focus was on the manifest content of the data and the analysis was guided by the research questions (Vaismoradi et al., 2013). The interviews were read repeatedly in detail and the unit of analysis was identified. The unit of analysis

Table 1
The interview guide.

Semi-structured interview questions and subquestions
1. Experiences in the use of electronic counselling services ^a
a. In which phase of the cancer trajectory the ECS were needed most?
2. The integration of the ECS to the cancer care
a. The meaning of support from the ECS to the patient with cancer
b. The meaning of support from the ECS to the relationship between healthcare personnel and the patient with cancer
c. The meaning of support from the ECS to the treatment of cancer

^a Other subquestions are reported elsewhere.

consisted of expressions in which patients with cancer described the content related to the research questions. The units of analysis were then transferred to the word processing programme for reductions of the data. There were 784 reductions in total. Based on the similarities and differences among the reductions, sub-categories, categories and main categories were developed and named after their content (Elo and Kyngas, 2008). To keep the analysis as rich and evidentiary as possible, the original expressions of the participants were used while organising the data (Polit and Beck, 2010). During the whole analysis process, there were reflective discussions with other researchers until a consensus was achieved. The background data were quantified using descriptive statistics.

2.3. Ethics

The permission to conduct this study was obtained from the Regional Ethics Committee of Pirkanmaa Hospital District (R12271H) and from the cancer societies involved in this study. All participants signed the informed consent form. All identifying information was removed to ensure the anonymity of the participants (Holloway and Wheeler, 2010).

2.4. Rigour

Rigour was achieved by purposive sampling that ensured the data was as heterogeneous as possible, accurate descriptions of the participants and their selection criteria and the context of the research and the analytic discussions of the data between researchers (Polit and Beck, 2010).

3. Results

3.1. Participants

In total, 12 patients with cancer participated in this study. Nearly half were male patients with cancer ($n = 5$, 42%) and the age of the participants ranged from 40 to 66 years, while the mean age was 54 years. One participant had an education at the university level, whereas 92% ($n = 11$) had an education at a polytechnic or college level school ($n = 3$) or lower ($n = 8$). Every third participant had breast cancer ($n = 4$) and every fourth had prostate cancer ($n = 3$), which is in accordance with the cancer incidence rates of Finland. Other tumour sites were the bladder, testicles, polycythemia vera, ovaries and tongue, with one instance of each. The mean time since diagnosis was five years (range < 1–17), although the time since last use of the ECS was short. Over half the participants were in the post-treatment phase of their disease ($n = 8$, 67%). One participant was in the pre-treatment phase and every fourth participant ($n = 3$) was interviewed at the time of their cancer treatment. The most oft-used form of the ECS was telephone counselling ($n = 10$, 63%), whereas five participants (31%) used email counselling and one participant (6%) used online chat counselling. Four participants

used more than one form of ECS. The majority of participants ($n = 9$, 75%) contacted the ECS a few times (2–6 times), two participants (17%) contacted randomly and one participant contacted the ECS regularly (once a month).

3.2. The phase of the cancer trajectory when social support was needed from the ECS

The phases of the cancer trajectory when social support was needed were 1) when emotional well-being was weakened, 2) when the body broke, 3) when the care pathway induced unawareness and 4) when empowerment needed strengthening, but 5) there was no need for social support when well-being was considered in balance (Table 2).

3.2.1. When emotional well-being is weakened

Emotional well-being was weakened when participants felt distressed, when they needed emotional supporting or when the interaction with healthcare providers was difficult. Participants felt distressed when dejection dominated their mood. For example, they were desperate during treatment, they just could not cope with the disease anymore or they felt the world was crashing onto them. They also began to conceive things. Anxiety took over, especially in the evenings, at nights or when something was confusing them.

The participants needed emotional support and someone to support them in moving on. They also needed someone to confirm that they would survive. Poor interaction with the hospital doctor or with another counselling nurse were factors that weakened the participants' emotional well-being. In addition, the dialogue was inadequate when participants did not understand anything that was told either at the hospital or in written statements sent to their homes.

3.2.2. When the body broke

Participants needed social support when their bodies broke. Participants lost the physical integrity of their bodies, for example, when they lost their hair, breasts or even their health. The continuation of life became endangered when they were not given the promise of recovery or when they did not know whether the cancer had spread. They also needed to contact the ECS when they suffered from symptoms of the medication, as well as the treatment caused physical problems or severe fatigue.

3.2.3. When the care pathway induced unawareness

The treatment of the disease defined the phases in which the participants contacted the ECS. The phases described by the participants were the time when they were informed they had cancer, before and after the specified cancer diagnosis, when waiting to access medical procedures, before and after treatments, in-treatment phases, in the survivorship phase and before having a doctor appointment. The participants contacted the ECS when they were looking for significance in the phases of disease treatment. For

Table 2

The phases in the cancer trajectory when social support is needed from the ECS.

Category	Main category	Examples of patient quotes
When distressed	When the emotional well-being was weakened	"I called, sometimes twice a day. I called immediately when I got the feeling that the world was crashing down on me."
When needing emotional supporting		"When, once again, I was floating in the quagmire of uncertainty and when I looked at the nurses' faces, well, this is it, they gave me the MRI-documents and said thank you and good bye."
When the interaction was difficult with healthcare providers	When the body broke	"When I lost my breast, when I lost my hair ..."
When losing physical integrity		"I asked the counselling nurse, when I had pain in my remaining breast, if this was because of the ovariectomy and the lack of hormones ..."
When the continuation of life was endangered	When the care pathway induced unawareness	"It was when I asked the doctor if she/he knew any patients like me that had been cured and the doctor didn't give any promises about getting well."
When the body responded to the treatments		"When I knew nothing except that I had breast cancer."
When the treatment of the disease defined the phase		"During the treatment, I wanted a second opinion on the phlebotomy."
When looking for significance in the phases of disease treatment	When empowerment needed strengthening	"When I asked for information and methods to aid in recovery after surgery and some contact information, I could ask for experienced advice ..."
When complementing the resources		"When it was quite a new situation, and I was looking for peer support groups, I could get information and support and ask questions ..."
When achieving peace of mind		"It means, that you have sort of accepted it, and you think that you'll recover and you're hopeful ... then you accept it, and okay, this can be treated and it's not spread and that's when you need as much information as possible."
No need when the support network was sufficient	No need for support when well-being was considered in balance	"In the occupational health care services, I have two very supportive doctors and my wife works there as a nurse, so I get all the information I need from there and my two brothers are doctors, so they have helped me a lot."
No need when the disease was disappearing		"Well, not so much anymore, there's nothing disastrous happening at the moment because my cancer is in a good phase."

example, after diagnosis, they wanted information about the nature of the disease, information about treatment options, a recovery schedule and information about aid devices, including breast prosthesis, wigs, scarves and wound dressings.

3.2.4. When the empowerment needed strengthening

Participants contacted the ECS when they needed to strengthen their empowerment including the phases when they needed to complement their resources, as well as after they had first achieved peace of mind. The resources were complemented when the participants accessed the services from the cancer societies or from the National Social Insurance Institution. The participants also contacted the ECS as a part of complementing their resources when they required information about peer support, as well as information on how to support their self-care and how to manage the information found on the Internet. Participants contacted the ECS after they first achieved peace of mind. In other words, they needed first to deal with the disease by themselves, accept the diagnosis and wait until the overwrought reactions of the shock caused by the cancer diagnosis were over.

3.2.5. No need to contact the ECS when well-being is in balance

There were phases when the participants did not need to contact the ECS. This was when the participants considered their well-being as in balance. In this circumstance, the participants considered their support network sufficient. In such a situation, the participants reported they received enough support from the hospital, their family or their peers. Furthermore, the participants reported no need for support when the disease was disappearing. For example, when the disease had no room in their thoughts or when there were no signs of recurrence. There was also a need for less contact when more time since diagnosis has elapsed.

3.3. The integration of the support from the ECS to the care of a patient with cancer in public healthcare

The support from the ECS was integrated into the cancer care by 1) supporting a patient with cancer emotionally, 2) developing the informational expertise of a patient with cancer, 3) expanding the

opportunities for support and 4) assisting public healthcare. However, integration requires the improvements of the actions of a patient with cancer and of the various actors involved in cancer care. Integration was lacking due to the health status of a patient with cancer and because of the sufficiency of the primary support sources. Furthermore, there was no integration into the actual cancer treatment process of a patient with cancer in public healthcare (Table 3.).

3.3.1. Supporting the patient with cancer emotionally

When the ECS was integrated into cancer care by supporting the patients with cancer emotionally, participants reported that the sufficiency of their emotional resources was taken care of and their self-efficacy was increased. The participants reported they received compassion, as well as the feelings of successful support and being heard. They also reported they had a chance to discuss without hurry and how they were not alone with the disease.

They were given hope for recovery and they were helped to understand that getting cancer is not the end of life. The support from the ECS also raised the mood, and participants were calmer when they went to their treatments. Participants also reported that their burden to face relatives was lightened. The self-efficacy of a patient was increased because of the support from the ECS. Participants coped with the problematic situations better and their decisions were confirmed by the counselling nurses.

3.3.2. Developing the informational expertise of a patient with cancer

The support from the ECS was integrated into the cancer care by developing the informational expertise of the participant. This was seen as increased access to information and helping to understand the care process as a whole. Very important was the translation of the hospital jargon to the common language.

3.3.3. Expanding the opportunities for support

Expanding the opportunities for support was realised when the support from the ECS was considered an actor that would provide support in the future. In addition, providing technological pre-requisites to enable support, such as by providing different

Table 3

The integration of the ECS into the cancer care in public healthcare.

Category	Main category	Examples of patient quotes
By taking care of the sufficiency of the resources of a patient By increasing the self-efficacy of a patient By lightening the burden of a patient to face relatives By increasing access to information By helping to understand the care process as a whole By translating the hospital jargon to the common language	By supporting a patient with cancer emotionally By developing the informational expertise of a patient with cancer	<i>"I think this is the place which has given me the most ... I've been given the best support. Without this support, I couldn't have survived."</i> <i>"During the phone counselling, they confirm that I have done the right things and they encourage me."</i> <i>"From the phone counselling, I received information to help me answer my folks' questions ... and I can tell them to call counselling services."</i> <i>"I've had answers and tips and, well, I've been guided to other sources of information when needed."</i> <i>"It was easier to go to the treatments because they (the CNs) supplied information about what kinds of treatments you are given and what the treatments consist of and that's how my understanding expanded."</i> <i>"I was informed in plain Finnish because many times these things you find in the doctor's statements and everywhere are in Latin, so I was informed in plain language."</i>
By providing support in the future By providing technological prerequisites to enable support By making the ECS a visible part of care on the hospital side	By expanding the opportunities for support	<i>"For me, it's clear when I know where I can get help and advice and where I can call."</i> <i>"Well, of course when it comes to the big city, this is not a problem (to visit the cancer society personally) and services are easier to access, but if you live somewhere in the countryside, you can't go anywhere just like that. So it is probably important (to use the ECS) in cases like that."</i> <i>"So, uh, there should be more discussions like: 'By the way, are you aware of these services.' Because then, when the darkest moment arrives, you need to get help somewhere."</i>
By reducing the hospital workload in a care of a patient By promoting the care process	By assisting public healthcare	<i>"She (the social worker) realised that I was already aware of all the information she was about to tell me, so she couldn't tell me anything new because I had been in contact with the cancer society."</i> <i>"Many times I've had to contact the cancer society and they have given me advice and suggested contact the doctor."</i>
Integration requires taking into account the individuality of a patient with cancer Integration requires the service expertise from the ESC Integration requires an active role from the patient Integration requires a partnership between different healthcare actors	Integration requires improvements in the actions of a patient with cancer and various actors involved in cancer care	<i>"It (the message) could be, well, more personal and less about statistics. It should take the patient into account individually and maybe suggest these support groups or something like that instead of sending statistics. I felt that the answer I was given was a copy of a standard answer to certain kinds of questions"</i> <i>"You need to be a person who actively seeks support channels because nobody told me about this."</i> <i>"Well, somehow there should be more co-operation with hospitals, well, I don't know how much they have, but really, people should be able to seek help this way, specifically from reliable sources."</i>
No integration when the hospital information was considered professional No integration due to the sufficiency of the support network No integration due to the health status of a patient with cancer	Lack of integration because of the health status of a patient with cancer and the sufficiency of the primary support sources	<i>"I'd rather receive the information from the hospital doctor because I consider the information more reliable and the doctors know better."</i> <i>"The support from the ECS has not been integrated into my cancer care because I get enough support from my relatives, occupational health care services and private doctors."</i> <i>"The treatments went well. I was in a good shape. It must have affected me because I didn't need to contact the ECS as much as others in a similar situation. I have also been able to maintain a balance in my life so I didn't have the need."</i>
No integration in the treatment options No integration in the relationship between a patient with cancer and healthcare providers No knowledge of the integration due to the invisible impact of the integration	No integration into the actual cancer treatment process of a patient with cancer in public healthcare	<i>"It is simply the fact that you are in a hospital and there are healthcare providers who tell you how things will proceed. I don't think anyone is asking advice outside the hospital. Yes, probably you proceed the way they say."</i> <i>"No, I can't see any effect on the relationship with healthcare providers."</i> <i>"I can't tell since the care has always been very good in the hospital. I haven't found anything to support the conclusion that the ECS affects the care."</i>

channels for communication, no geographical restrictions and quick access to support, is considered an important avenue for integration into cancer care in public healthcare. Integration became possible on the hospital side. The hospital personnel made the ECS visible, encouraged patients to contact the ECS and showed the patients that they trusted the expertise of the counselling nurses.

3.3.4. Assisting public healthcare

The support from the ECS was integrated to the cancer care by assisting public healthcare. This was the case when contacting the ECS resulted in reduction in the workload of the hospital and in promoting the care process. The participants stated that sometimes they did not care to bother the hospital staff instead, they contacted

the ECS, or thanks to discussions with a counselling nurse, there was no need for the help of a psychiatric nurse at the hospital. Nurses at the hospital even discontinued offering consultations when they were told about contacts to the ECS.

Participants reported that the support from the ECS was compensating for the lack of resources in and substituting for public healthcare. They also reported that the support from the ECS was integrated into cancer care because care in public healthcare is performed at a minimum level determined by the law, simply, to avoid malpractice.

The support from the ECS was integrated into the cancer care by promoting the care process in public healthcare. Participants were guided by the ECS to contact the hospital if symptoms required hospital care. Participants also reported that they received good

nursing care in the hospital after sharing they were in contact with the ECS.

3.3.5. *The integration requires improvements to the actions of a patient with cancer and the various actors involved in healthcare*

There were prerequisites for the support from the ECS to be integrated into the cancer care in public healthcare. To be integrated in cancer care, support from the ECS must consider the individuality of a patient with cancer. The integration also requires service expertise from the ECS personnel, including generally answering questions, offering peer support and lessening cancer statistics and tabulations. Patients with cancer also need to take an active role in the integration process by being able to find support services, taking initiative in information seeking, being inquisitive and being able to make conclusions based on the cancer statistics received from the ECS. First, the integrations requires contacting the ECS. The amount of integration depends on the phase of the illness and to what extent the patients with cancer are able to benefit from the received support during the integration process.

Furthermore, participants reported that the integration of the support received from the ECS in cancer treatment requires a partnership between various healthcare actors, such as, between occupational healthcare services and public and private healthcare and the non-profit sector.

3.3.6. *No integration because of the health status of a patient with cancer and the sufficiency of the primary support sources*

There was no integration of the ECS to the cancer care in public healthcare when the information received from the hospital was considered more professional than what was received from the ECS. If the participants had a functional network, they did not see room for integration. As well, if the participants were feeling well or if they could not handle the received information, they did not see any integration possibilities.

3.3.7. *No integration into the actual cancer treatment process of a patient with cancer in public healthcare*

The support from the ECS had an impact neither on the treatment options nor on the relationships between patients with cancer and healthcare providers. The participants also mentioned they could not tell how the support from the ECS was integrated into their cancer care because the impact was invisible. For example, the patient with cancer after discussing contacting the ECS could not distinguish the impact of the support from the ECS from the care from the public healthcare system. This is because the care has always been good and the participant did not know to what extent the nurses in the hospital exchange information with each other about the discussions they have had with patients.

4. Discussion

In this qualitative study, the purpose was to describe the phases in the cancer trajectory when the patients with cancer needed social support from the ECS. Furthermore, the purpose was to describe how the support from the ECS was integrated to the cancer care in public healthcare. In Finland, the non-profit cancer societies that provide psychosocial support may play an important role because it is rare that hospitals in Finland have psychosocial units in oncology departments. If they have units, they accept patients based on an oncologist's referral only (HUS, 2014).

In previous studies, the treatment phases have dominated the interpretation of the needs of patients with cancer (Peters et al., 2014). However, it is essential to give voice to patients when they define the times they are in need of support. The cancer trajectory can no longer be determined solely by the treatment phases,

because the patients with cancer identify the need for support in the cancer trajectory differently than what is usually understood in healthcare.

During the treatment phases of the illness, the patients with cancer needed support from the ECS when they were not feeling well emotionally. Previous studies have shown there are many trajectories of psychological distress in the cancer care continuum and, for example, one in three breast cancer patients experience distress in the in-treatment or post-treatment phases of their cancer care (Henselmans et al., 2010).

Cancer treatments many times result in broken bodies. There is a range of studies supporting this for example, changes in body image, life-style and sexual function have been reported, especially in the survivorship phase (Mohamed et al., 2014). In addition, the recurrence of cancer and death are issues raised by patients with cancer (Simard et al., 2013). These results are in line with the findings of our study, showing what kinds of problems patients with cancer are facing in the cancer trajectory, and patients therefore need support when these issues occur.

Despite the fact that patients with cancer parse the phases of the cancer trajectory when support is needed differently than care providers, they typically need disease- and treatment-related information. Information is vital to patients with cancer in all phases of the cancer trajectory and an essential part of good quality nursing. It has been reported that patients with cancer do not receive enough information, and healthcare professionals may underestimate the capabilities of patients to cope with the disease-related information (Charalambous et al., 2008). In line with the present study, participants most often desire cancer-related information (Grimsbo et al., 2012) and they need to receive it during their time of need.

It was surprising to learn that patients with cancer contacted the ECS only when they had first achieved peace of mind. They also contacted the ECS when they needed resources. Therefore, it is important to focus on patient support needs at the right time to avoid leaving the patients with cancer to their own devices without a hand to hold (Larsson et al., 2007). Before achieving peace of mind, the participants went through a stressful period, which was also identified in a Danish qualitative metasynthesis of lung cancer patients (Refsgaard and Frederiksen, 2013).

What was not surprising was the result that the use of the ECS was not needed when participants had a sufficient support network, when some time had passed since the diagnosis and active treatments and when they did not think of the recurrence of cancer as much as has been reported previously (Sohl et al., 2014; You and Lu, 2014). The phases of the support needs of patients with cancer may be difficult to identify due to the different interpretations, nevertheless, it is very important not to endanger the patients' well-being.

The integration of the support from the ECS to public healthcare is a strongly understudied area. It is a matter of concern that patients with cancer must seek support outside their cancer care when they need to be supported emotionally, although the psychosocial support should be a natural part of current cancer care. It has been reported in a Danish study, for example, that 53% of breast cancer patients have unmet needs in the area of counselling at some point between diagnosis and the end of primary treatment (von Heymann-Horan et al., 2013).

It was unexpected how important the role of the support from the ECS still played in developing the informational expertise of a patient with cancer, even though the patients' right to be informed is written in the law in Finland (Finlex 785/1992, 1992) and is an essential part of involvement in treatment decision-making (Davison and Breckon, 2012). However, in line with this study, it has been reported that the cancer network partnership groups have

an influence at the grassroots level by contributing information to patients as well as access to services (Attree et al., 2011), such as by expanding the opportunities for support, which was the case in this study.

The support from the ECS was integrated into the public healthcare by assisting in its basic tasks. This may be beneficial for both the patients and public healthcare. It is also worth discussing whether it is in accordance with the current recommended cancer care to leave the patients solely in the hands of the counselling services in times of support need. The support from the ECS corrects the deficiencies in the care of a patient and may reduce the use of healthcare services (Ezendam et al., 2013). The key question is how to make this kind of cooperation visible and recognisable.

This study revealed it is not obvious that the support from the ECS was integrated into the cancer care in public healthcare. There are prerequisites for the ECS to be integrated into the cancer care. Patients with cancer must take an active role, for example, in seeking information to take part in decision-making (Lambert et al., 2009). The ECS must develop their services to meet better the needs of patients. In a previous study, it was reported that healthcare professionals as a source of information achieved a relatively high level of satisfaction, but the satisfaction level with the information they provided ranged from approximately 53%–73% (Li et al., 2011). This may have an impact on the integration of the support from the ECS into the cancer care in public healthcare.

Based on the results of this study, the support from the ECS does not need to play a role in the cancer trajectory when the primary sources of support (e.g. hospital doctor, family, peers) are sufficient. This is in line with previous studies indicating the physician is the preferred source of support (Li et al., 2011), as well as the family (You and Lu, 2014).

5. Conclusions

This study provides an understanding and awareness of the phases in the cancer trajectory when patients with cancer are in need of support from the ECS. The phases of support needs are now parsed from the perspective of the patients and they differ from the traditional biomedical phases of treatment.

The ECS compensate for the deficiencies in the public healthcare but integrating the support from the ECS into the public healthcare is not self-evident. There are several prerequisites for both the patients and counselling nurses to integrate the support from the ECS into the cancer care, and there are occasions when integration is not even necessary.

In the nursing practice, when we determine the cancer trajectory, it is necessary to remember that phases of support needs are not necessarily structured in the same way in the patient's world. Therefore, it is essential to pay attention to the phases of support needs as defined by the patients with cancer. Because there will always be limited resources in public healthcare the partnership with the ECS should be made visible and recognisable to provide comprehensive and recommended current cancer care to our patients.

Conflict of interest statement

This work has not been published and is not being considered for publication elsewhere.

There are none conflict of interest.

References

ATLAS, 25.8.2014. Ti Scientific Software Development GmbH. Berlin. Atlas.ti. <http://atlasti.com/>.

- Attree, P., Morris, S., Payne, S., Vaughan, S., Hinder, S., 2011. Exploring the influence of service user involvement on health and social care services for cancer. *Health Expect.* 14 (1), 48–58.
- Cancer Society of Finland, 2014. Organisation. Retrieved from: <http://www.cancer.fi/en/organisation/>, 28.9.2014.
- Charalambous, A., Papadopoulos, I.R., Beadsmoore, A., 2008. Listening to the voices of patients with cancer, their advocates and their nurses: a hermeneutic-phenomenological study of quality nursing care. *Eur. J. Oncol. Nurs.* 12 (5), 436–442.
- Cohen, S., Syme, L., 1985. Issues in the study and application of social support. In: Cohen, S., Syme, L. (Eds.), *Social Support and Health*. Academic Press, INC., Orlando, pp. 3–22.
- Davison, B.J., Breckon, E.N., 2012. Impact of health information-seeking behavior and personal factors on preferred role in treatment decision making in men with newly diagnosed prostate cancer. *Cancer Nurs.* 35 (6), 411–418.
- Doody, O., Noonan, M., 2013. Preparing and conducting interviews to collect data. *Nurse Res.* 20 (5), 28–32.
- Drageset, S., Lindstrom, T.C., Giske, T., Underlid, K., 2012. “The support I need”: women's experiences of social support after having received breast cancer diagnosis and awaiting surgery. *Cancer Nurs.* 35 (6), E39–E47.
- Elo, S., Kyngas, H., 2008. The qualitative content analysis process. *J. Adv. Nurs.* 62 (1), 107–115.
- Ezendam, N.P., Nicolaije, K.A., Boll, D., Lybeert, M.L., Mols, F., Pijnenborg, J.M., van de Poll-Franse, L.V., 2013. Health care use among endometrial cancer survivors: a study from PROFILES, a population-based survivorship registry. *Int. J. Gynecol. Cancer* 23 (7), 1258–1265.
- Finlex 785/1992, 1992. Act on the Status and Rights of Patients. Retrieved from: http://www.finlex.fi/en/laki/kaannokset/1992/19920785_28.9.2014.
- Fowler Jr., F.J., Gerstein, B.S., Barry, M.J., 2013. How patient centered are medical decisions?: results of a national survey. *JAMA Intern. Med.* 173 (13), 1215–1221.
- Grimso, G.H., Ruland, C.M., Finset, A., 2012. Cancer patients' expressions of emotional cues and concerns and oncology nurses' responses, in an online patient-nurse communication service. *Patient Educ. Couns.* 88 (1), 36–43.
- Henselmans, I., Helgeson, V.S., Seltman, H., de Vries, J., Sanderman, R., Ranchor, A.V., 2010. Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. *Health Psychol.* 29 (2), 160–168.
- Holloway, L., Wheeler, S., 2010. *Qualitative Research in Nursing and Healthcare*, third ed. Wiley-Blackwell, Oxford.
- HUS, 2014. Psychosocial Support. Retrieved from: http://www.hus.fi/en/medical-care/medical-services/Oncology/Support_for_the_patient/Pages/Psychosocial-support.aspx, 27.11.2014.
- Kinnane, N.A., 2012. Evaluation of a hospital-based cancer information and support centre. *Support. Care Cancer* 20 (2), 287–300.
- Koutsopoulou, S., Papatheanassoglou, E.D.E., Katapodi, M.C., Patiraki, E.I., 2010. A critical review of the evidence for nurses as information providers to cancer patients. *J. Clin. Nurs.* 19 (5–6), 749–765.
- Lambert, S.D., Loisel, C.G., Macdonald, M.E., 2009. An in-depth exploration of information-seeking behavior among individuals with cancer: part 1: understanding differential patterns of active information seeking. *Cancer Nurs.* 32 (1), 11–23.
- Larsson, M., Hedelin, B., Athlin, E., 2007. Needing a hand to hold: Lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nurs.* 30 (4), 324–334.
- Li, P.W., So, W.K., Fong, D.Y., Lui, L.Y., Lo, J.C., Lau, S.F., 2011. The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. *Cancer Nurs.* 34 (1), 49–57.
- Mohamed, N.E., Chaoprang, Herrera, P., Hudson, S., Revenson, T.A., Lee, C.T., Quale, D.Z., Zarcadoolas, D.Z., Hall, S.J., Diefenbach, M.A., 2014. Muscle invasive bladder cancer: Examining survivor burden and unmet needs. *J. Urol.* 191 (1), 48–53.
- Park, J., Neuman, H.B., Bennett, A.V., Polskin, L., Phang, P.T., Wong, W.D., Temple, L.K., 2014. Patient expectations of functional outcomes after rectal cancer surgery: a qualitative study. *Dis. Colon Rectum* 57 (2), 151–157.
- Pearlin, L., 1985. Social structure and processes of social support. In: Cohen, S., Syme, L. (Eds.), *Social Support and Health*. Academic Press, INC., Orlando, London, pp. 43–60.
- Peters, M.E., Goedendorp, M.M., Verhagen, C.A., van der Graaf, W.T., Bleijenberg, G., 2014. Severe fatigue during the palliative treatment phase of cancer: an exploratory study. *Cancer Nurs.* 37 (2), 139–145.
- Pinar, G., Okdem, S., Buyukgonenc, L., Ayhan, A., 2012. The relationship between social support and the level of anxiety, depression, and quality of life of Turkish women with gynecologic cancer. *Cancer Nurs.* 35 (3), 229–235.
- Polit, D., Beck, C., 2010. *Essentials of Nursing Research. Appraising Evidence for Nursing Practice*, seventh ed. Wolters Kluwer, Lippincott Williams & Wilkins, Philadelphia.
- Refsgaard, B., Frederiksen, K., 2013. Illness-related emotional experiences of patients living with incurable lung cancer: a qualitative metasynthesis. *Cancer Nurs.* 36 (3), 221–228.
- Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., Ozakinci, G., 2013. Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *J. Cancer Surviv* 7 (3), 300–322.
- So, W.K., Chan, C.W., Choi, K.C., Wan, R.W., Mak, S.S., Chair, S.Y., 2013. Perceived unmet needs and health-related quality of life of Chinese cancer survivors at 1 year after treatment. *Cancer Nurs.* 36 (3), E23–E32.
- Sohl, S.J., Levine, B., Case, L.D., Danhauer, S.C., Avis, N.E., 2014. Trajectories of illness

- intrusiveness domains following a diagnosis of breast cancer. *Health Psychol.* 33 (3), 232–241.
- Thompson, T., Rodebaugh, T.L., Perez, M., Schootman, M., Jeffe, D.B., 2013. Perceived social support change in patients with early stage breast cancer and controls. *Health Psychol.* 32 (8), 886–895.
- Vaismoradi, M., Turunen, H., Bondas, T., 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs. Health Sci.* 15 (3), 398–405.
- von Heymann-Horan, A.B., Dalton, S.O., Dziekanska, A., Christensen, J., Andersen, L., Mertz, B.G., Olsen, M.H., Johansen, C., Bidstrup, P.E., 2013. Unmet needs of women with breast cancer during and after primary treatment: a prospective study in Denmark. *Acta Oncol.* 52 (2), 382–390.
- Yli-Uotila, T., Rantanen, A., Suominen, T., 2013. Motives of cancer patients for using the internet to seek social support. *Eur. J. Cancer Care* 22 (2), 261–271.
- Yli-Uotila, T., Rantanen, A., Suominen, T., 2014. Online social support received by patients with cancer. *CIN-Comput. Inf. N. U.* 32 (3), 118–126.
- You, J., Lu, Q., 2014. Sources of social support and adjustment among chinese cancer survivors: Gender and age differences. *Support. Care Cancer* 22 (3), 697–704.

Facilitators and barriers for electronic social support

Tiina Yli-Uotila RN, MHSc (PhD(c))¹, **Marja Kaunonen** RN, PhD (Professor)^{1,2}, **Liisa Pylkkänen** MD, PhD (Chief Medical Officer, Adjunct Professor)³ and **Tarja Suominen** RN, PhD (Professor)¹

¹School of Health Sciences, Nursing Science, University of Tampere, Tampere, Finland, ²Pirkanmaa Hospital District, General Administration, Tampere, Finland and ³Cancer Society of Finland, Helsinki, Finland

Scand J Caring Sci; 2016; 30; 547–556

Facilitators and barriers for electronic social support

Background: Nonprofit cancer societies play an important role in providing social support for patients with cancer through nonprofit electronic counselling services (ECS) provided by counselling nurses (CNs) with experience in oncology nursing. To date, there exist only few studies addressing the facilitators and barriers for social support of patients with cancer as reported by CNs.

Objective: To describe the facilitators and barriers for electronic social support of patients with cancer received from the ECS in the nonprofit cancer societies as reported by CNs.

Methods: Qualitative design with three group interviews was conducted with 10 CNs in three nonprofit cancer societies in southern and western parts of Finland. Interviews were recorded, transcribed verbatim and content analysed inductively.

Findings: The facilitators were promotion of the access to ECS, functioning structures of ECS, utilisation of the strengths of an individual CN in ECS, promotion of the life management of patients, patient-centeredness as a

basis of ECS and reliability of ECS. The barriers for electronic social support were the unmet paths between ECS and patients, nonfunctioning structures of ECS, inadequacy of mutual communication and lack of shared viewpoints between CNs and patients.

Conclusions: Facilitators and barriers for electronic social support of patients with cancer were related to organisation, individuals and counselling process. The counselling work in ECS as its best promotes the life management of patients with cancer but, alternatively, can lead to conflicts in communication and therefore be a barrier for electronic social support.

Implications for practice: To make the nonprofit ECS better known, the cooperation with hospitals is needed to enable social support for patients. To improve communication between CNs and patients, continuous communications skills training and functional working environments are needed.

Keywords: electronic social support, counselling nurses, nonprofit cancer societies, patients with cancer.

Submitted 19 April 2015, Accepted 8 July 2015

Introduction

Cancer is a common multifaceted disease. In 2012, there were 32.6 million cancer survivors worldwide (within 5 years of diagnosis) (1). Of the survivors, 254 000 live in Finland, a country with 5.4 million inhabitants (2, 3). Patients with cancer may experience a wide array of biopsychosocial problems during their cancer trajectory such as nausea, vomiting, fatigue, hair and weight loss, neuropathy (4), depression, changes in body image and sexual function, difficulties in adjusting to daily living (5) and fear of cancer recurrence (6). Biomedical cancer care in Finland is mainly a function of public health care, but

to date, only one hospital has a psychosocial unit in the Oncology Department (7). Therefore, nonprofit cancer societies play an important role in providing additional social support for patients with cancer. In this study, we focused on the electronic social support.

To define electronic social support, we used the theory of online social support developed by LaCoursiere (8) as a framework. According to this theory, online social support is defined as a cognitive, perceptual and transactional process. This process initiates, participates in and develops electronic interactions or means of electronic interactions that seek beneficial outcomes in perceived health, health-care statuses or psychosocial processing abilities (8). We used the term electronic social support in our study to represent social support that is delivered through both mobile-based and Web-based technologies (i.e. through electronic devices). Electronic social support is delivered to patients through electronic counselling services (ECS),

Correspondence to:

Tiina Yli-Uotila, School of Health Sciences, Nursing Science, University of Tampere, FI-33014 Tampere, Finland.
E-mail: yli-uotila.tiina.m@student.uta.fi

including phone counselling, email counselling and online chat counselling. It can be considered a structural aspect of electronic social support, as previously defined in the earlier literature (9). In turn, the content of electronic social support is a functional aspect of support (9). Social support, whether delivered face-to-face, via the phone, or online, has shown to reduce anxiety (10) and symptom distress (11), increases quality of life (10) and enables transfer of information (12), but it may also decrease quality of life (13).

There are over 130 000 members in patient and regional cancer societies countrywide, which makes them one of the largest nonprofit public health organisations in Finland (14). These cancer societies provide social support to patients with cancer and their relatives via counselling nurses (CNs), who are Registered Nurses and public health nurses with experience in oncology nursing. In addition to the possibility of peer-support and face-to-face counselling, cancer societies provide phone, email and online chat counselling, which is the focus of this study (15). According to previous studies, phone interventions have proven to be well accepted among patients with cancer (16) and perceived as more normal than attending hospital sessions (17). There are less email and online chat intervention studies, but email prompts seem to be a good way to increase self-monitoring of healthy behaviour (18). Furthermore, online patient–nurse communication can provide patients with a forum to raise questions and concerns related to symptom experiences, fear of relapses and uncertainty in everyday life when given the opportunity (19).

CNs, defined as Registered Nurses or public health nurses with experience in oncology nursing working in nonprofit cancer societies, face patients with cancer who are in different phases of their cancer trajectory. To date, very few studies address both facilitators and barriers for the electronic social support of patients with cancer as perceived by CNs. However, there is evidence that communication processes and skills are essential when providing support (20, 21) along with the ability to facilitate the task and relational aspects of social support (22).

The purpose of this study was to identify facilitators and barriers to electronic social support processes that might impact patients' perceived health, health-care statuses or psychosocial processing abilities as reported by CNs working in the ECS in nonprofit cancer societies. The research questions were as follows:

- (1) What are the facilitators for electronic social support for patients with cancer provided by the ECS as reported by CNs?
- (2) What are the barriers to electronic social support for these patients as reported by CNs?

Methods

Design

This paper is a part of a larger study that explores the experiences of the ECS in nonprofit cancer societies as reported by adult patients with cancer and CNs. This cross-sectional descriptive qualitative study with group interviews focused on the perspectives of CNs (23).

Setting and sample

The regional cancer societies from which the CNs were recruited for this study are located in the southern and western parts of Finland. The CNs were recruited for the study by purposive sampling (24). The inclusion criteria were present employment in the ECS and voluntary participation in the study.

Data collection

The data collection method consisted of group interviews (formal natural groups) with semi-structured interview questions, meaning that it was possible to gather data from more than one participant simultaneously (24). This method also made the interactions between participants accessible, thereby providing a more naturalistic setting (24). In addition, group interviews can generate authentic and even forgotten information (25). The CNs were first asked to fill in a structured background questionnaire (age, gender, profession, working years in nursing, working years in oncology nursing, working years in ECS and additional training for counselling work). After filling in the background questionnaire, the CNs were encouraged to discuss the facilitators and barriers for support of patients with cancer.

The recruitment of the CNs was carried out by a contact CN in each cancer society. After the interview date was decided, all the available CNs on duty that day participated in the interviews. All three group interviews were performed in May 2014 by the first author in three cancer societies in three different cities. There were three groups in total. Two groups included three participants, while one group included four participants. In each interview, the participants sat in a semicircle so that they could have eye contact with each other (25). The interviews were conducted in a quiet room at each cancer society. With the permission of the participants, a tape recorder was placed as close to the participants as possible to ensure the quality of recording (24). All the participants could speak freely, and participants were encouraged to speak freely even when faced with different points of views. One group interview was interrupted for a few minutes for a consultation by a co-working CN who was not a participant in the

interview. The researcher's role in the group interviews was to stimulate the discussion with clarifying questions and with prolonged engagement to deepen the topic and ensure that all data regarding to research questions could be gathered (24). The interviews lasted an average of 47 minutes.

Data analysis

The recorded interviews were transcribed verbatim, and similarity of the contents was verified by the first author (25). Inductive content analysis with focus on the manifest content was utilised to reduce the data to more general rules (26). The written data were read through several times and guided by the research questions, and the units of analysis (expressions regarding to research questions) of each individual interview were identified (26). We identified 522 reductions from the units of analysis. The reductions were placed onto a matrix, and according to their similarities and differences, subcategories ($n = 110$), categories ($n = 30$) and main categories ($n = 10$) were developed and labelled after their contents (26). During the data analysis process, the first author had reflective discussions with senior researchers to ensure the credibility of the analysis (24). Table 1 shows an example of the analysis process.

Trustworthiness

All phases of the study were described as precisely as possible, aiming at consistency, accuracy and transparency. Peer debriefing and a detailed analysis process grounded in the data aimed to ensure the credibility and conformability of the findings. To achieve transferability of the

findings, we sought to describe accurately the participants and their selection as well as the study context (24).

Ethics

Ethical approval was obtained from the Regional Ethics Committee of Pirkanmaa Hospital District (R12271H) as well as from each nonprofit cancer society. All the CNs signed informed consent forms in which they were informed that they could withdraw from the study participation at any time and that all the data obtained would be treated confidentially (24). To ensure the participants' anonymity, all identifying information was removed from the data (24).

Findings

Participants

The CNs were all female and middle aged. Most of them were Registered Nurses. Of nine Registered Nurses, two had a public health nurse education. One CN was solely a public health nurse. Some CNs also had additional education and were dental assistants, supervisors or psychotherapists. Their average work experience as nurses was a bit over 26 years, while in oncology nursing, it was slightly over 17 years. The work history in the ECS ranged from <1 year to 18 years. All the CNs had additional training for the ECS work, formal or informal. Formal additional training that entitled them to credit points consisted of, for example, oncology nurse training. Informal training, in turn, consisted of training such as National Oncology Nurses' Educational Days held each year, pain management and palliative care, for which

Table 1 An example of the data analysis process

<i>Reduction of the original expression</i>	<i>Subcategory</i>	<i>Category</i>	<i>Main category</i>
Being on the same plane as patients Making patients feel that they are understood	Showing understanding to patients	Promoting the mental survival of patients	Promoting the life management of patients
Being someone who listens CNs ability to listen to patients	Listening to patients		
Patients can ask embarrassing questions Patients can ask about issues that frighten them	Opportunity to discuss sensitive issues with CNs	Sharing untold issues of patients	
Patients can vent their negative feelings Patients can vent problems occurred in public healthcare	The ECS as a medium for venting the negative feelings of the patients		
Strengthening the patients' belief of the importance of things Giving positive feedback to patients	Valuing the actions of a patient with cancer	Strengthening the self-efficacy of patients	
Encouraging patients to act independently Encouraging patients to figure out issues by calling	Strengthening the self-help of a patient with cancer		

they were not entitled to credit points (Table 2). Table 3 shows the results of the analysis of the interview data.

Facilitators for social support

The facilitators for the social support of patients with cancer were promotion of access to ECS, functioning structures of ECS, utilisation of the strengths of an individual CN in the ECS, promotion of the life management of patients, patient centredness as a basis for ECS and the reliability of ECS.

Promotion of access to ECS. Promotion of access to ECS was related to the comprehensiveness of the ECS activities, continuity of the communication ensured by CNs as well as CNs' cooperation with nurses in public health care. In order for the ECS to be comprehensive, they need to be diverse but uniform across the country, and publicly available and accessible in terms of extended office hours and possibility of contact even during the holiday seasons. The CNs ensured continuity of contact with the patients by ensuring that the handling of the patient's case progressed: for example, in cases where the CN could not solve the problem in one session, she promised to contact the patient later. The continuity of contact was also ensured by making appointments, especially in the online chat service. This was important when the patient contacted the CN from abroad. In addition, cooperation with oncology nurses in public health care was considered an important facilitator for the social support of patients from the ECS. The CNs contacted the hospital oncology nurses when they needed informational support or when the oncology nurses were needed to guide the patients about the ECS.

Functioning structures of the ECS. The functioning structures of the ECS refer to the organisation of CNs' work to enable counselling, working environments, CNs' work

load as well as competent personnel. When the work in the ECS is organised well, the workload of the CNs at the cancer society is shared, especially during the rush hours, and the CN can focus on patient counselling work. Functional working environments require a quiet working station and functional devices such as phone headsets. Furthermore, the diverse competencies of CNs are required to deliver social support to the cancer patients, such as knowledge of cancer, family issues and the health-care service system; diverse working experience; and the use of different discussion frameworks in counselling.

Utilisation of the strengths of an individual CN in the ECS. The utilisation of the strengths of an individual CN in the ECS was considered as a facilitator when a CN could utilise her personal experiences at work, for instance, experiences from different roles (e.g. mother, nurse and next of kin) and crises in her own life, to increase her understanding of the patient's situation. High self-awareness, in terms of identifying one's own strengths and weaknesses, was recognised as a facilitator for social support for patients with cancer. Furthermore, emotional skills were essential. CNs stated that they must be able to control their own feelings, for example in provocative situations, and have the ability to work in emotionally charged situations. Most of all, CNs reported that they need to be sensitive to the patients' nonverbal messages.

Promotion of the life management of patients. Promoting the life management of patients is a paramount area of counselling work, even though it is carried out via the telephone, over email or online. It includes promoting the mental survival of patients, CNs' mindfulness, an understanding of the patients, the ability to be on the same plane with patients and the ability to listen to the patients. It also includes sharing untold issues of patients that might be too embarrassing or frightening (e.g. sexual and death-related issues) to share with anyone else. In addition, the ECS act as a medium for patients to vent out their negative feelings and problems they face in public health care; this was also considered as a facilitator of social support. As reported by the CNs, involving the family in the counselling process was essential. The CNs reported that it is important to discuss how the illness affects the family as well as keep the family updated and help them cope with the illness. Sometimes, the support needed to be delivered to a patient through a family member. Strengthening the self-efficacy of patients as a part of life management included CNs valuing the actions of a patient with cancer and strengthening their self-help. This involves giving positive feedback and strengthening the patients' belief of the importance of certain issues, as well as encouraging patients to act and figure out issues independently. The CNs needed to screen the life management of patients systematically by asking relevant questions concerning the

Table 2 Sociodemographic characteristics of the CNs

Characteristics (N = 10)	n	Mean	Range
Age		52.4	43–61
Nursing education ^a			
Registered nurse	9		
Registered public health nurse	3		
Additional education	4		
Working years in nursing		26.2	8–39
Working years in oncology nursing		17.2	2.5–36
Working years in ECS		9.2	0.3–18
Additional training for counselling work ^b			
Formal training (entitled to credit points)	6		
Informal training (not entitled to credit points)	10		

CNs, counselling nurses; ECS, electronic counselling services.

^aSome CNs were both Registered Nurses and public health nurses.

^bSome CNs had both formal and informal training in counselling.

Table 3 Facilitators and barriers for electronic social support of patients with cancer in the ECS

Facilitators	Barriers
Promotion of access to ECS 'First we intend to call back if we don't have [to talk] the time at the moment and we see that the need for support is great (...) It is important that the person gets the information that his/her case is progressing (...) So, it helps the patient'	Unmet paths between ECS and patients 'The phone line is busy. We don't have the kind of service that would put the client in a queue if the line was busy. They have to dial the number over and over again'
Functioning structures of ECS 'Well, in a way, we have strong expertise and experience: work experience and other experiences'	Non-functioning structures of ECS 'And then we have this workload, which is quite heavy at the moment. During the one hour time for phone counselling you can't always sit behind your desk and be on the computer that you need for the counselling work; you have to do other tasks as well, for example you may end up doing equipment maintenance with a mobile phone in your other hand. The one hour time for counselling is not just for counselling'
Utilisation of the strengths of an individual CN in ECS 'The fact is that we're all mothers and wives and we've kids and we're nurses. And many of us have been in the role of a next-of-kin. All these factors together (...) All these factors and the life crises that you've gone through and survived are useful'	Inadequacy of mutual communication 'It's difficult if you can't hear well. For example, if the person has hearing disabilities. It can also be very rough if the person can't use email or chat'
Promotion of the life management of patients 'Yes, I think that it's quite a big issue concerning how people perceive receiving support. It is just the thing that they need, for someone to listen to them. It doesn't have to be anything special, only that someone listens. Someone who has the time to listen. When someone listens, they can somehow reflect on their experiences while telling someone else about them. So, they kind of analyse their experiences in a better way'	Lack of shared viewpoints between CNs and patients 'Yes, the thing is that if the client wants to hear specific things about what the nurse is not saying, meaning that the nurse is sticking to the truth, there may be a decline in the interaction. If the nurse doesn't conform to the patient's thoughts just like that, but instead, brings up another perspective to consider that would be more beneficial and appropriate, it can irritate some patient'
Patient-centredness as a basis of ECS 'He/she gets the feeling that he/she is understood and that we are with him/her on the phone in that moment'	
Reliability of ECS 'We are clearly an expert organisation. Of course it matters that people receive personal support and expert information and guidance'	

ECS, electronic counselling services; CN, counselling nurse.

patients' life (family situation, occupational status and cancer treatment situation) as well as screening the resources or lack of them (strengths/strains) and the need for support in daily life. To manage their life when ill, patients needed disease-related information, and the CNs also complemented, corrected and verified the information patients had. One of the tasks, as reported by the CNs, was to offer information about useful services, such as the activities of cancer societies (e.g. toll-free national helpline, face-to-face counselling, rehabilitation services and volunteers), and public mental health and social security services. In addition, the CNs reported that patient-related facilitators such as increased competency in the form of increased capacity benefit the ECS and increase activity with regard to staying in contact with the ECS.

Patient centredness as a basis of ECS. Patient centredness was considered as a facilitator for the social support of patients. This meant that the type of contact chosen, the situation and the individuality of a patient were considered

as the basis of all counselling work. Patient-centred counselling respects the background of patients (age, gender, education, etc.). A shared language (dialect/common language) and the possibility of clarifying the patients' messages instantly were considered as facilitators for the social support of patients with cancer.

Reliability of the ECS. The ECS was considered reliable when the counselling was safe in terms of anonymity, confidentiality, toll-free contact with the national helpline of the Cancer Society of Finland, and the provision of a serene atmosphere. In addition, professional expertise was considered to indicate the reliability of the ECS. The ECS was trusted, and the CNs had the opportunity to consult their chief medical officer when needed.

Barriers for social support

The barriers for social support were as follows: unmet paths between the ECS and patients, nonfunctioning

structures of the ECS, inadequacy of mutual communication and lack of shared viewpoints between the CNs and patients.

Unmet paths between the ECS and patients. Lack of mutual contact was one of the causes of the unmet paths between the ECS and patients. In such cases, the patients did not contact the ECS because of various reasons, for example, lack of email addresses, lack of online chat skills and unawareness of the existence of the ECS. Another reason for the unmet paths was the absence of a CN specifically for the patient. The CNs also reported that one reason for the unmet paths was the lack of guidance on the part of the ECS at the hospital. The CNs stated that the guidance of the ECS was not a primary task at the hospital that the guidance was often nurse dependent, or that the nurses did not have knowledge of the ECS. In addition, another cause of the unmet paths was inaccessibility to the ECS. The ECS was not accessible due to changes in the reported office hours, congestion of the telephone line during peak hours and difficulties in coordinating the schedules between patients and the ECS. One reason for the inaccessibility of the ECS was the costs of the calls in regional cancer societies.

Nonfunctioning structures of ECS. The structures of ECS can also act as a barrier for the social support of patients when they do not function properly. An improper working environment consists of a tumultuous working station, nonfunctioning devices (mobile phones, phone headsets, etc.) and shortage of personnel in the ECS. The workload of CNs was considered as a barrier for social support. Concurrent tasks, too many tasks, as well as lack of time for the counselling work were reported by the CNs. Replying to email messages was time-consuming. Furthermore, unexpected contact (e.g. improper time and place for answering the calls) increased the workload. The lack of professional competence of a CN was considered as a nonfunctioning structure of the ECS. Inexperience, lack of empathy, inability to identify patients' needs, problems in developing trust, negative feelings in patients caused by the method of communication of a CN and inadequacy of the answers given to patients were listed by the CN as barriers to social support.

Inadequacy of mutual communication. As a barrier to social support, mutual communication was considered inadequate when the information received from a patient was not sufficient. The reasons for this were too concise messages from patients and patients' inability to disclose their needs. Furthermore, functional impairments, such as hearing and sight difficulties, as well as diminished resources (e.g. depression, and fatigue) and circumstances at the patients' home (e.g. a patient could not talk due to

the presence of a family member), were other inadequacies. Mutual communication was inadequate due to the difficulties caused by the form of counselling as well. It was difficult to support patients by writing, and in some cases, the patients were not comfortable talking on the phone, especially younger patients, and there was a lack of visual communication and lack of clarity in the online chat appointment system.

Lack of shared viewpoints between CNs and patients. The data revealed that the lack of shared viewpoints between the CNs and patients was due to the fact that the content of the counselling did not meet patients' needs or there was lack of mutual understanding between patients and CNs. The CNs stated that patients sometimes considered the counselling too general or that the CNs did not say things that the patients expected to hear, such as promising the patients that they would get better. In addition, the CNs explained that the inability of CNs to influence the cancer treatment process at the hospital was considered as a barrier for social support by patients with cancer. Furthermore, confidentiality was sometimes a barrier as well. This occurred when the CNs did not have permission to share information with the family, although it would have benefitted the patient. Language problems, such as the use of different dialects, especially when the same word had different connotations for patients or CNs, caused confusion or misunderstanding; moreover, if there was a need for services in a foreign language, it was also a barrier to social support.

Discussion

This study highlights the need for the ECS to strengthen their presence in general public and hospital settings, as it is a facilitator for the social support of patients with cancer. In line with Högberg et al. (27), who described the prerequisites for the provision and use of Web-based communication for psychosocial support, an effective organisation around psychosocial support is one of the prerequisites for the use of Web-based communication. In relation to this, the central issues are how the contact information of the ECS could be more effectively communicated to patients with cancer, online or offline, and how patients with cancer could be more systematically informed of the ECS in hospitals. It would be a matter of concern and a barrier for social support if guidance on the ECS in hospitals is nurse dependent. In addition, it is suggested that the ECS is accessible, for example, in terms of the office hours matching patients' timetables and times of need. The possibility of a 24/7 service was addressed, but it is currently not provided to patients at cancer societies. A noteworthy finding, according to an earlier study, is that every fourth call to cancer help lines is made outside office hours (28).

The structures of the ECS were both facilitators and barriers to the social support of patients with cancer. The way the work is organised in the ECS may either facilitate or act as a barrier for social support. When the work was organised well, there were enough personnel to share the workload, especially during peak hours; conversely, the workload was considered too high when there was not enough time or resources for the job, which was a barrier for social support. As identified in earlier studies, high workload is considered as one of the most stressful factors in oncology nursing (29) and a risk factor for intention to leave the position (30). Surprisingly, the CNs in this study did not address leadership as a facilitator or barrier for the social support of patients although the leadership, along with proper staffing and working environments, is one of the factors that influence retention.

The data showed clearly the importance of the use of CNs' own personality as a working tool. The CNs' own life events as well as certain personal characteristics were considered as facilitators and even necessary factors for delivering social support to the patients. When one's own personality is used as a working tool, especially in emotionally charged situations, it may have an impact on how CNs cope with work. Therefore, it is important to develop effective organisational interventions to detect CNs' occupational stress and coping resources in order to support their mental well-being (31). In this study, the communication skills of CNs were highlighted. Along with competence, self-awareness, sensitivity to patients' nonverbal messages and display of genuine interest, CNs' mindfulness was also listed as an important facilitator for social support. This complies with the findings of earlier studies (32, 33). Communication skills may be improved, for example, in workshops (34), although there is no sound evidence that these types of interventions are effective (35).

Promotion of the life management of patients often included the family, who needs support as well, and was underlined in this study. According to an earlier study, nurses sometimes regard the needs of the family to be more important than the family itself (36), which is effective in situations where counselling situations could be over-interpreted. Although the promotion of self-efficacy as a part of promoting the life management of patients was reported as a facilitator for social support, self-efficacy as a patient outcome may not be self-evident. CNs listed indicators, such as depression and physical function, that affect the level of self-efficacy, which has also been identified previously (37); therefore, it is beneficial to take them into account when assessing the self-efficacy of patients. In addition to the promotion of self-efficacy, cancer-related information and information on available services for patients with cancer as a part of promoting life management were reported. Attree et al. (38) also found that the primary aim of cancer partnership groups is to

improve cancer services through knowledge of those affected by cancer. The importance of the actions of patients was highlighted as well. The patients themselves need to be motivated and competent enough to stay in contact with CNs to benefit from the ECS. This requires the patients to be able to identify and judge their motivating reasons (27), which according to this study, are usually cancer-related health problems.

As expected, patient centredness was mentioned as a basis of counselling work and a facilitator for support. This is not surprising because patient centredness has been a prevalent issue in nursing for decades. Therefore, the question to be raised is why there is still a need to mention this issue and why it is not already a part of quality nursing in different contexts. It was recommended that information, support, and most importantly, language be adjusted for individual patients with cancer as a part of patient-centred cancer care. This is in line with the study of Uphoff et al. (39), who have listed communication as one of the generic evidence-based quality indicators for patient-centred cancer care, for example, in terms of adjusting information to individual patients and language skills.

Minimal disclosure of information by patients was considered a barrier for mutual communication and therefore for social support. Whatever the reasons for this (e.g. mood and health condition), the willingness and readiness of patients to talk need to be assessed. The results are in agreement with systematic review that reported the factors affecting effective communication between Registered Nurses and cancer patients in an inpatient setting. In the aforementioned review, the evidence suggested that patients are reluctant to discuss, for instance, difficult emotions (32). In the present study, telling the truth or not telling patients what they want to hear, especially information related to prognostic, was often the cause of conflict between the shared point of view of patients and CNs and was a barrier for social support. Prognostic issues have been identified as an ethical dilemma in oncology nursing and should be addressed by physicians in order to prevent CNs from giving false hope to patients (40). Conflict in communication between the CNs and patients was sometimes observed as a barrier in this study as well. According to the literature, it would be beneficial to distinguish the types of conflicts (e.g. relationships vs. task conflicts), as if properly understood and managed, it can lead to positive outcomes such as stronger relationships (41).

Using the perspective of the theory of online social support, we explored the facilitator and barriers that potentially affected the electronic social support of patients with cancer as perceived by CNs. In the interactional process of online social support between a nurse and a patient, it is essential to pay attention to the factors that may impact the process. In using the theory of

online social support in this study, it was necessary to include the thoughts and beliefs of nurses who were engaged in online activities (8) because it was important to disclose their perspectives as well. Therefore, we believe that the results of the present study developed existing knowledge about this theory.

Methodological considerations

The present study provides information on facilitators and barriers for the electronic social support of patients with cancer as perceived by CNs. The group interviews were considered appropriate for generating different views and experiences (23). Consequently, the data were rich, versatile and covered various dimensions of information. The inductive content analysis, with its focus on the manifest content, was justified because the purpose was to gain insight into the phenomena that have been rarely studied (26). The findings were identified through consensus between the authors, which strengthens the dependability and credibility of the findings. One limitation of the study was related to the cancer societies chosen for the study, as they represented only the southern and western parts of Finland. In addition, the use of member checks might have increased the credibility of the findings.

Implications for practice and future research

To make nonprofit ECS better known to patients with cancer, the cooperation of hospitals starting from the beginning of the cancer trajectory is essential to enable social support for patients. Furthermore, to promote communication between the CNs and patients, continuous communication skills training is recommended, but the impact of such interventions requires further investigations. The patients need to be encouraged to stay in contacts with the ECS, and proper electronic communication devices and quiet working stations would facilitate the work of CNs. High standards set for work by CNs themselves and daily involvement in emotionally charged situations may require regular evaluations of the occupational well-being of CNs.

Conclusions

The facilitators and barriers for the social support of patients in the ECS were related to organisations,

individuals (CNs and patients) and the counselling process. At an organisational level, the facilitators for the social support of patients with cancer are the online and offline publicity of ECS as well as the accessibility of ECS. In addition, a functional working environment with proper equipment and workload supports the work of the ECS. At an individual level, the personal characteristics required for emotionally charged work and the comprehensive professional skills of CNs are the basis for delivering social support to patients with cancer. Furthermore, there are also patient-related characteristics, such as capability and motivation to look for support, that are needed to benefit from social support from the ECS. At a counselling process level, the counselling at its best promotes the life management of patients with cancer but, alternatively, can lead to conflicts in communication in some cases and therefore may be a barrier for social support.

Acknowledgements

We want to express our gratitude to the counselling nurses who volunteered to share their valuable experiences with us, as well as to The Finnish Cancer Foundation for supporting this study financially.

Author contributions

TY, MK and TS made substantial contributions to concept and design, TY contributed to the acquisition of data, and TY, MK and TS contributed to the analysis and interpretation of data. MK, LP and TS participated in drafting the article or revising it critically for important intellectual content; and TY, MK, LP and TS gave final approval for the submitted version and any revised version of the manuscript.

Ethical approval

The ethical approval was obtained from the Regional Ethics Committee of Pirkanmaa Hospital District, Finland (R12271H).

Funding

The Finnish Cancer Foundation.

References

- 1 World Health Organization. GLOBOCAN 2012: Estimated cancer incidence, mortality and prevalence worldwide in 2012. 2015; Available at: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx (last accessed 31 January 2015).
- 2 Finnish Cancer Registry. Cancer statistics. 2013; Available at: <http://www.cancer.fi/syoparekisteri/en/statistics/cancer-statistics/koko-maa/> (last accessed 5 January 2015).
- 3 Statistics Finland. Population. 2014; Available at: http://www.stat.fi/til/vrm_en.html (last accessed 30 August 2014).

- 4 Pedersen B, Koltved DP, Nielsen LL. Living with side effects from cancer treatment—a challenge to target information. *Scand J Caring Sci* 2013; 27: 715–23.
- 5 Mohamed NE, Chaoprang Herrera P, Hudson S, Revenson TA, Lee CT, Quale DZ, Zarcadoolas C, Hall SJ, Diefenbach MA. Muscle invasive bladder cancer: examining survivor burden and unmet needs. *J Urol* 2014; 191: 48–53.
- 6 Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, Ozakinci G. Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *J Cancer Surviv* 2013; 7: 300–22.
- 7 HUS. Psychosocial support. 2014; Available at: http://www.hus.fi/en/medical-care/medical-services/Oncology/Support_for_the_patient/Pages/Psychosocial-support.aspx (last accessed 27 November 2014).
- 8 LaCoursiere SP. A theory of online social support. *Adv Nurs Sci* 2001; 24: 60–77.
- 9 House JS, Kahn RL. Measures and concepts of social support. In *Social Support and Health Orlando* (Cohen S, Syme LS eds), 1985, Academic Press, Inc., Florida, 83–108.
- 10 Pinar G, Okdem S, Buyukgonenc L, Ayhan A. The relationship between social support and the level of anxiety, depression, and quality of life of Turkish women with gynecologic cancer. *Cancer Nurs* 2012; 35: 229–35.
- 11 Gustafson DH, Dubenske LL, Namkoong K, Hawkins R, Chih MY, Atwood AK, Johnson R, Bhattacharya A, Carmack CL, Traynor AM, Campbell TC, Buss MK, Govindan R, Schiller JH, Cleary JF. An eHealth system supporting palliative care for patients with non-small cell lung cancer: a randomized trial. *Cancer* 2013; 119: 1744–51.
- 12 Li PW, So WK, Fong DY, Lui LY, Lo JC, Lau SF. The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. *Cancer Nurs* 2011; 34: 49–57.
- 13 Salonen P, Tarkka MT, Kellokumpu-Lehtinen PL, Koivisto AM, Aalto P, Kaunonen M. Effect of social support on changes in quality of life in early breast cancer patients: a longitudinal study. *Scand J Caring Sci* 2013; 27: 396–405.
- 14 Cancer Society of Finland. Organisation. 2014; Available at: <http://www.cancer.fi/en/organisation/> (last accessed 30 August 2014).
- 15 The Cancer Society of Finland. Patients and relatives. 2014; Available at: <http://www.cancer.fi/potilaatjalaheiset/neuvontakuntoutus/neuvontapuhelin/> (last accessed 1 January 2015).
- 16 Garrett K, Okuyama S, Jones W, Barnes D, Tran Z, Spencer L, Lewis K, Maroni P, Chesney M, Marcus A. Bridging the transition from cancer patient to survivor: pilot study results of the Cancer Survivor Telephone Education and Personal Support (C-STEPS) program. *Patient Educ Couns* 2013; 92: 266–72.
- 17 Beaver K, Williamson S, Chalmers K. Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses. *J Clin Nurs* 2010; 19: 2916–24.
- 18 Greaney ML, Sprunck-Harrild K, Bennett GG, Puleo E, Haines J, Viswanath KV, Emmons KM. Use of email and telephone prompts to increase self-monitoring in a Web-based intervention: randomized controlled trial. *J Med Internet Res* 2012; 14: e96.
- 19 Grimsbo GH, Finset A, Ruland CM. Left hanging in the air: experiences of living with cancer as expressed through E-mail communications with oncology nurses. *Cancer Nurs* 2011; 34: 107–16.
- 20 Watts R, Botti M, Hunter M. Nurses' perspectives on the care provided to cancer patients. *Cancer Nurs* 2010; 33: E1–8.
- 21 Botti M, Endacott R, Watts R, Cairns J, Lewis K, Kenny A. Barriers in providing psychosocial support for patients with cancer. *Cancer Nurs* 2006; 29: 309–16.
- 22 Beck SJ, Keyton J. Facilitating social support: member-leader communication in a breast cancer support group. *Cancer Nurs* 2014; 37: E36–43.
- 23 Polit D, Beck C. *Essentials of Nursing Research. Appraising Evidence for Nursing Practice*, 7th edn. 2010, Wolters Kluwer, Lippincott Williams & Wilkins, Philadelphia.
- 24 Green J, Thorogood N. *Qualitative Methods for Health Research*, 2nd edn. 2009, SAGE, London.
- 25 Burns N, Grove S. *The Practice of Nursing Research. Conduct, Critique and Utilization*, 5th edn. 2005, Elsevier Saunders, Philadelphia, PA.
- 26 Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013; 15: 398–405.
- 27 Hogberg K, Sandman L, Nystrom M, Stockelberg D, Brostrom A. Prerequisites required for the provision and use of web-based communication for psychosocial support in haematologic care. *Eur J Oncol Nurs* 2013; 17: 596–602.
- 28 Reid J, Porter S. Utility, caller, and patient profile of a novel chemotherapy telephone helpline service within a regional cancer centre in Northern Ireland. *Cancer Nurs* 2011; 34: E27–32.
- 29 Barnard D, Street A, Love AW. Relationships between stressors, work supports, and burnout among cancer nurses. *Cancer Nurs* 2006; 29: 338–45.
- 30 Shang J, Friese CR, Wu E, Aiken LH. Nursing practice environment and outcomes for oncology nursing. *Cancer Nurs* 2013; 36: 206–12.
- 31 Ruotsalainen JH, Verbeek JH, Marine A, Serra C. Preventing occupational stress in healthcare workers. *Cochrane Database Syst Rev* 2014; 12: 002892.
- 32 Tay LH, Hegney D, Ang E. Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: a systematic review. *Int J Evid Based Healthc* 2011; 9: 151–64.
- 33 Heyn L, Finset A, Ruland CM. Talking about feelings and worries in cancer consultations: the effects of an interactive tailored symptom assessment on source, explicitness, and timing of emotional cues and concerns. *Cancer Nurs* 2013; 36: E20–30.
- 34 Kennedy Sheldon L. Communication in oncology care: the effectiveness of skills training workshops for healthcare providers. *Clin J Oncol Nurs* 2005; 9: 305–12.
- 35 Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA.

- Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev* 2013; 3: 003751.
- 36 Pinkert C, Holtgrawe M, Remmers H. Needs of relatives of breast cancer patients: the perspectives of families and nurses. *Eur J Oncol Nurs* 2013; 17: 81–87.
 - 37 Qian H, Yuan C. Factors associated with self-care self-efficacy among gastric and colorectal cancer patients. *Cancer Nurs* 2012; 35: E22–31.
 - 38 Attree P, Morris S, Payne S, Vaughan S, Hinder S. Exploring the influence of service user involvement on health and social care services for cancer. *Health Expect* 2011; 14: 48–58.
 - 39 Uphoff EP, Wennekes L, Punt CJ, Grol RP, Wollersheim HC, Hermens RP, Ottevanger PB. Development of generic quality indicators for patient-centered cancer care by using a RAND modified Delphi method. *Cancer Nurs* 2012; 35: 29–37.
 - 40 McLennon SM, Uhrich M, Lasiter S, Chamness AR, Helft PR. Oncology nurses' narratives about ethical dilemmas and prognosis-related communication in advanced cancer patients. *Cancer Nurs* 2013; 36: 114–21.
 - 41 Almost J. Conflict within nursing work environments: concept analysis. *J Adv Nurs* 2006; 53: 444–53.