Development and effectiveness testing of a strengths-oriented therapeutic conversation on sexual adjustment and intimacy among females with cancer and their partners

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Thesis for the degree of Philosophiae Doctor

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June 2021

UNIVERSITY OF ICELAND
SCHOOL OF HEALTH SCIENCES

FACULTY OF NURSING

Þróun styrkleikamiðaðra meðferðarsamræðna við konur með krabbamein og maka þeirra og prófun á ávinningi af að styrkja aðlögun tengda kynlífi og nánd

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Júní 2021

UNIVERSITY OF ICELAND
SCHOOL OF HEALTH SCIENCES
FACULTY OF NURSING

ISBN 978-9935-9589-0-7

Orchid ID 0000-0002-3457-0293

Printing by Háskólaprent.

Reykjavik, Iceland 2021

Ágrip

Markmið: Markmið doktorsrannsóknarinnar var að lýsa stöðu þekkingar á meðferðarrannsóknum eftir greiningu og meðferð krabbameins sem ætlað er að draga úr kynlífsvanda og efla nánd hjá pörum. Ennfremur var markmiðið að þróa og meta árangur nýrrar styrkleikamiðaðrar stuðningsmeðferðar og fræðslu fyrir pör þar sem konan hefur greinst með krabbamein, í því skyni að efla aðlögun hvað varðar kynlíf og nánd.

Bakgrunnur: Vandamál sem tengjast kynlífi og nánd eru algeng hjá konum með krabbamein og geta haft neikvæð áhrif á kynferðislega vellíðan og náið samband. Gott parsamband og stuðningur maka getur hins vegar dregið úr streitu sem tengist breytingum á kynlífi og nánd eftir greiningu og meðferð krabbameins. Hjúkrunarfræðingar með framhaldsmenntun á þessu sviði geta þróað og veitt pörum stuðningsmeðferð og fræðslu hvað varðar kynlíf og nánd eftir krabbameinsgreiningu og meðan á krabbameinsmeðferð stendur.

Aðferðir: Doktorsverkefnið hefur að geyma þrjár rannsóknir. Fyrsta rannsóknin var kerfisbundin, fræðileg samantekt. Stuðst var við handbók Joanna Briggs og Preferred Reporting Items for Systematic Reviews and Meta-Analyses til að greina stöðu þekkingar á meðferðarrannsóknum við kynlífsvanda hjá fullorðnum einstaklingum og mökum eftir greiningu og meðferð krabbameina, og setja fram niðurstöður. JBI-Meta Analysis of Statistics Assessment and Review Instrument var notað til að meta aðferðafræðileg gæði rannsókna. Rannsóknarsnið í meðferðarrannsókn var fyrir og eftir hálf-tilraunasnið. Meðferð í rannsóknum tvö og þrjú fólst í þremur 50 mínútna löngum styrkleikamiðuðum meðferðarsamræðum þar sem hjúkrunarfræðingur með sérfræðiþekkingu í kynlífsheilbrigði hitti parið augliti til auglitis. Á milli fyrstu og annarrar samræðu liðu 1–2 vikur og sú síðasta fór fram sem eftirfylgdartími þremur mánuðum eftir fyrstu samræður. Eftir fyrstu samræður fengu pörin aðgang að læstri vefsíðu með upplýsingum um kynferðislegar aukaverkanir krabbameinsmeðferðar ásamt úrræðum. Tilgangur meðferðar var að efla styrkjandi viðhorf í aðlögun varðandi kynlíf og nánd og greina hindrandi viðhorf. Í fyrsta tíma var lagður grunnur að góðum meðferðartengslum og parinu boðið að segja frá sinni reynslu, skoða áhyggjuefni sín og ígrunda eigin aðstæður. Í öðrum tíma var lögð áhersla á að skoða þær breytingar sem parið vill sjá og vinna með styrkleika beggja. Í þriðja og síðasta eftirfylgdartíma var skerpt á þeim jákvæðu breytingum sem urðu hjá parinu og þær festar í sessi. Kenningafræðilegur grundvöllur meðferðarrannsóknanna voru styrkleikamiðaðar fjölskyldusamræður, Illness Beliefs-líkanið, Neotheoretical-kenning kynverundar og New View-stefnuyfirlýsingin. Rannsókn tvö byggðist á konum í virkri krabbameinsmeðferð (N=60) og mati á áhrifum fræðslu og stuðningsmeðferðar á kynferðisleg áhyggjuefni hjá konunum og áhrif krabbameinsveikinda á daglegt líf fyrir meðferð (T1), með samanburði við tvær meðferðarsamræður (T2), og að lokinni meðferð eftir þriðja og síðasta fræðslu- og stuðningsmeðferðartímann (eftirfylgdartímann) (T3). Þriðja rannsóknin byggðist á konum í virkri krabbameinsmeðferð (N=60) og mökum þeirra (N=60) og mati á árangri fræðslu- og stuðningsmeðferðarinnar varðandi það hve mikla fullvissu konan og maki hennar telja sig hafa um áhrif styðjandi og hindrandi viðhorfa á kynlíf og nánd og gæði parasambands á tímapunktum T1, samanborið við eftirmeðferðina á tímapunkti T2, og að lokinni meðferð, eftir þriðja fræðslu- og stuðningsmeðferðartímann á tímapunkti T3. Í meðferðarrannsóknunum var notuð dreifigreining fyrir endurteknar mælingar (rannsókn II og III), pöruð t-próf milli T1-T2 og T2-T3 (rannsókn II) og milli T1-T2, T2-T3, og T1-T3 (rannsókn III) til að kanna ávinninginn af fræðslu- og stuðningsmeðferðinni.

Niðurstöður: Niðurstöður úr fyrstu rannsókn sýndu að ekki ríkir einhugur um hvernig best sé að hanna meðferðarrannsóknir fyrir pör, þegar ætlað er að efla kynlíf og nánd, hvað varðar innihald meðferðar eða hvernig hún skuli fara fram. Þetta undirstrikar skort á gagnreyndri þekkingu sem hindrar framþróun á þessu sviði í klínísku starfi hjúkrunarfræðinga. Mikilvægustu niðurstöður úr rannsókn tvö voru þær að konur með krabbamein greindu síður frá kynferðislegum áhyggjuefnum eftir styrkleikamiðuðu fræðslu- og stuðningsmeðferðina samanborið við það sem áður var og lýstu engum marktækum áhrifum krabbameinsveikinda yfir tíma á nánd. Helstu niðurstöður úr þriðju rannsókn voru þær að konur með krabbamein og makar þeirra greindu frá marktækt meiri gæðum parsambandsins og aukinni fullvissu um áhrif viðhorfa á kynlíf og nánd eftir styrkleikamiðuðu fræðslu- og stuðningsmeðferðina samanborið við það sem áður var.

Ályktun: Rannsókn eitt leiddi í ljós hvernig megi auka megi gæði meðferðarrannsókna fyrir pör í framtíðinni til að efla klíníska hjúkrun. Niðurstöður úr rannsókn tvö styðja gagnsemi styrkleikamiðaðra meðferðarsamræðna til að draga úr áhyggjum sem tengjast kynlífi og nánd hjá konum í virkri krabbameinsmeðferð. Loks sýndu niðurstöður úr rannsókn þrjú fram á árangur af styrkleikamiðuðum meðferðarsamræðum fyrir pör til að efla aðlögun kvenna með krabbamein og maka hvað varðar kynlíf og nánd.

Þessi gagnsemi og ávinningur styrkleikamiðaðra meðferðarsamræðna ætti að virka hvetjandi fyrir hjúkrunarfræðinga sem vilja stuðla að bættu kynlífsheilbrigði. Í heild varpa niðurstöður doktorsrannsóknarinnar ljósi á það hvernig hjúkrunarfræðingar geta þróað og samþætt nýja meðferð sem byggð er á gagnreyndri þekkingu innan fjölskylduhjúkrunar og kenningum um kynverund í því skyni að bæta kynlífsheilbrigði hjá pörum.

Lykilorð: Krabbamein, konur, makar, kynlífsheilbrigði, kynverund, kynlíf, nánd, styrkleikamiðaðar meðferðarsamræður, stuðnings-og fræðslumeðferð, klínísk hjúkrunarrannsókn

Abstract

Aims: The present thesis aimed to describe the characteristics of couple-based intervention studies that address sexuality after cancer and develop and test the effectiveness of a novel nurse-managed couple-based strengths oriented (CO-SOTC) intervention for women with diverse types of cancer and their intimate partners.

Background: Problems related to changes in sexuality and intimacy are common among women with cancer, which threatens their sexual well-being and intimate relationships. Good relationship quality and perceived partner support can reduce stress associated with sexual changes in women with cancer. Nurses with the appropriate knowledge, skills, and training in sexual health can develop and offer couple-based interventions addressing sexuality and intimacy after cancer.

Method: This doctoral research project comprises three studies. Study I was a systematic literature review that assessed the characteristics of couple-based intervention studies addressing sexuality following cancer. The reporting of Study I was guided by checklists for quantitative research evidence in the Joanna Briggs Institute Reviewer's Manual and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. Studies II and III were quasi-experimental single-group pre-post-follow-up design studies. The theoretical frameworks guiding the intervention are the Family-strengths oriented therapeutic conversation intervention, the Illness Beliefs Model, the Neo-theoretical framework of sexuality, and the New View Manifesto. The nurse met the participating couples face to face and engaged in three strengths-oriented therapeutic conversations (CO-SOTC) focusing on addressing changes in sexuality and intimacy after cancer. After the first session, the couples were also provided access to evidence-based educational information on a secure website about the most common sexual side effects of cancer treatment and possible solution. The second study, conducted in women in active cancer treatment (N = 60), assessed a nurse-managed CO-SOTC intervention on the women's sexual concerns and illness interference in daily life measured preintervention at baseline (T1), postintervention after receiving two sessions of the intervention (T2), and after a follow-up booster session after 3 months (T3). The third study, conducted in women in active cancer treatment (N = 60) and their intimate partners (N = 60), evaluated the effects of the CO-SOTC intervention on the relationship quality and confidence of the participating women and their intimate partners about how their illness beliefs affect sexuality and intimacy with regard to cause, control, effect, suffering, and support, measured at T1, T2, and T3. In Studies II and III, repeated measures ANOVA was used for assessing outcome differences over time. The Kolmogorov-Smirnov test was used to assess normality before the intervention at baseline. In study II, the treatment effect over the three time points was assessed using an F test and a paired t test was used to further compare the outcomes of the CO-SOTC intervention between measurements at T1–T2 and T2–T3. In study III, the treatment effect over the three time points was assessed using an F test, and a paired t test was used to further compare the outcomes of the CO-SOTC intervention between measurements at T1–T2, T2–T3, and T1–T3. Dyadic difference scores between the participating women and their intimate partners were computed using an F test.

Results: Findings from Study I suggested a current lack of consensus about how couple-based interventions addressing sexuality after cancer are best structured in terms of content and delivery, thus highlighting the limited empirical data available to guide clinical nursing practice. The main findings of studies II and III were that women with cancer reported benefits of the intervention with respect to sexual concerns, no significant changes over time were observed related to illness interference on intimacy, and the women with cancer and their intimate partners showed significant improvements in relationship quality and confidence about how their illness beliefs affect sexuality and intimacy which may help the couple to deal with changes in sexuality and intimacy following cancer diagnosis and treatment.

Conclusion: Study I offered speculative evidence on how the quality of future couple-based intervention research can be improved to benefit clinical practice. Study II findings suggested that the novel nurse-managed couple-based intervention is beneficial in lessening concerns related to sexuality and intimacy in women in active cancer treatment. The findings of Study II also supported the feasibility of integrating empirical knowledge of family nursing with theories about sexuality to improve sexual health outcomes for couples. Findings of Study III indicated that the dyadic CO-SOTC intervention was effective in supporting sexual adjustment in women in active cancer treatment and their partners. The components of the CO-SOTC intervention – active listening, validation of the unique individual couple narrative, and facilitation of constructive beliefs – are a powerful tool to help couples manage changes related to sexuality and intimacy after cancer. The overall positive findings should encourage nurses with appropriate qualifications to further advance psychosexual support in cancer care. In addition, findings of this doctoral research project add new empirical evidence to the very limited pool of couple-based nurse-managed interventions designed to address changes in sexuality and intimacy for women after cancer.

Keywords: Cancer, women, intimate partner, sexual health, sexuality, intimacy, strengths oriented therapeutic conversations, couple-based intervention, clinical nursing research

Acknowledgements

For six years I have been strongly committed to my doctoral research project and to be honest, it has been a challenging journey at times. However, the realization of the research is truly a collaborative effort of many individuals, all of whom I owe my gratitude. First of all, I wish to express genuine gratitude to my supervisor, Erla Kolbrún Svavarsdóttir, for her unwavering support in my endeavors as a doctoral student; I could always rely on her support and guidance. Erla's boundless, sometimes out of this world, energy and enthusiasm toward this research project was immensely helpful in carrying the project forward, be it rain or shine. I also greatly appreciate the contributions by the members of my doctoral committee who kindly shared their knowledge and expertise along the way: Helga Jónsdóttir, Kristine L. Kwekkeboom, and Rúnar Vilhjálmsson.

I would like to thank Marianne E. Klinke for sharing her expertise as a co-author on Paper I. I owe gratitude to Guðný Bergþóra Tryggvadóttir for assisting with data analysis and statistical computations.

In particular, I want to thank all the women and their intimate partners who participated in my doctoral research project; without them, the study would not have been possible. It was truly remarkable meeting all the couples and learning from their cancer experience; some couples explicitly stated that they wanted to participate in the study so they could give something back to the health care system.

I also want to thank the dedicated clinical nurses and radiologists working at Landspitali University Hospital who assisted in recruiting the participants.

I wish to express my heartfelt thanks to Nanna Kolbrún Sigurðardóttir, who I have considered my mentor in the field of sexology in Iceland. Throughout the years, she has provided me invaluable advice, and our enjoyable discussion sessions have always been an important source of inspiration and strength. I also owe my deepest gratitude to Nanna Friðriksdóttir and Hildur Einarsdóttir for our rewarding collaboration in educational projects aimed at advancing sexual health care at Landspitali University Hospital. My participation in these projects and consequent job offer as a sexual counselor at the hospital weighed substantially into my decision to embark on a doctoral research project.

My fellow doctoral students were an inspiration and support along the way; thank you all and good luck on your individual journeys. I want to especially thank Margrét Gísladóttir and Ásta Bjarney Pétursdóttir for their collegial support and for kindly sharing their knowledge. I also want to thank Áslaug Kristjánsdóttir for enjoyable regular meetings and discussions that are a vital lifeline in our area of specialization.

The research was generously supported by grants from the following institutions: Research Fund of Ingibjorg R. Magnusdottir, the Icelandic Nurses´Association Scientific Fund, the Landspitali University Hospital Scientific Fund, and the Scientific Fund of the Icelandic Cancer Society.

Big thanks go to my sister Eydís Þuríður for lending a helping hand in times of need and to Þorvaldur Kristinsson for assistance at a crucial moment. I express gratitude to my friend Hildur Vera Sæmundsdóttir for our cherished experiences together and for her thoughtful insight and abundant kindheartedness. I want to thank my son Kári Svan, my daughter Sólrún Klara and her fiancée Margrét Ósk for showing active interest in my journey as a doctoral student. Finally, I express infinite gratefulness to my spouse Þórir, the love of my life and my best friend, for his earnest support in everything I do and dream of doing.

„One doesn’t discover new lands without consenting to lose sight of the shore for a very long time.”

André Gide (1869-1951)

Contents

List of abbreviations

ANOVA, Analysis of Variance

CO-SOTC, Couple-Strengths Oriented Therapeutic Conversation

FAM-SOTC, Family-Strengths Oriented Therapeutic Conversation

HCP, Health Care Provider

IBM, Illness Beliefs Model

ICE-Couple, Ice-Beliefs Questionnaire for Couples

IIRS, Illness Intrusiveness Rating Scale

PFB, Partnership Questionnaire (Partnerschaftsfragebogen [PFB])

SCQ, Sexual Concern Questionnaire

SHC, Sexual Health Care

SHCC, Sexual Health Cancer Care

SPSS, Statistical Package for the Social Sciences

List of figures

List of tables

List of original papers

This thesis is based on the following original publications:

I. Jonsdottir, J. I., Jonsdottir, H., & Klinke, M. E. (2018). A systematic review of characteristics of couple-based intervention studies addressing sexuality following cancer. Journal of Advanced Nursing, 74(4), 760-773.

II. Jonsdottir, J.I., Vilhjalmsson, R., & Svavarsdottir, E.K. (2021). The Benefit of a Couple-Based Intervention Among Women in Active Cancer Treatment on Sexual Concerns. Accepted for publication in Cancer Nursing.

III. Jonsdottir, J.I., Vilhjalmsson, R., & Svavarsdottir, E.K. (2021). Effectiveness of a couple-based intervention on sexuality and Intimacy among women in active cancer treatment: a quasi-experimental study. Accepted for publication in European Journal of Oncology Nursing.

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Declaration of contribution

Study I: Jóna Ingibjörg Jónsdóttir (JIJ), Helga Jónsdóttir (HJ) and Marianne E. Klinke (MEK) were responsible for the study conception and design. JIJ performed the initial literature searches. JIJ and HJ performed the initial assessment of risk of bias. MEK was involved in consensus discussion. Data was extracted by JIJ and MEK. JIJ was responsible for drafting the manuscript, and MEK and HJ made critical revisons to the article for important intellectual content.

Study II: JIJ, and Erla Kolbrún Svavarsdóttir (EKS) were responsible for the development of the intervention and the structure of the data collection as well as the study conceptional design. JIJ conducted the study. JIJ, EKS and Rúnar Vilhjálmsson (RV) were responsible for analysis and interpretation of data. JIJ was responsible for drafting the manuscript with supervision from EKS. EKS and RV made critical revisions to the paper for important scientific and intellectual content. Guðný Bergþóra Tryggvadóttir (GBT) assisted with statistical analysis computation.

Study III: JIJ, and Erla Kolbrún Svavarsdóttir (EKS) were responsible for the development of the intervention and the structure of the data collection as well as the study conceptional design. JIJ conducted the study. JIJ, EKS and Rúnar Vilhjálmsson (RV) were responsible for analysis and interpretation of data. JIJ was responsible for drafting the manuscript with supervision from EKS. EKS and RV made critical revisions to the paper for important scientific and intellectual content. Kristine L. Kwekkeboom (KLK) provided constructive criticism in the preparation of the manuscript. GBT assisted with statistical analysis computation.

1 Introduction

1.1 Global Trends in Sexuality, Intimacy and Cancer, and Nurses' Role

The increasing number of cancer survivors worldwide in past decades has introduced a shift in focus from survival to improvement in quality of life (QOL); sexuality is a dynamic component of QOL, and thus this shift also highlights the centrality of intimate relationships in people's lives (Enzlin & De Clippeleir, 2011). Research from Western countries, mostly those in North America, Europe, and Australia, has described how cancer diagnosis and cancer treatment negatively affect sexual well-being and intimacy among adult cancer survivors and their partners, regardless of the type of cancer (Ussher et al., 2012a; Perz et al., 2014; Parton, 2019). Three crucial facts emerge from this literature. First, interventions for sexual and intimacy concerns of women with cancer have not been adequately implemented in cancer care (Lindau et al., 2015). Second, research findings demonstrate the usefulness of implementing a dyadic approach to interventions addressing sexual concerns in cancer care (Perz et al., 2013). Finally, it appears that nurses have neither conducted nor published research studies on the development and testing of couple-based interventions addressing sexuality after cancer (Charalambous et al., 2018; Papadopoulou et al., 2019).

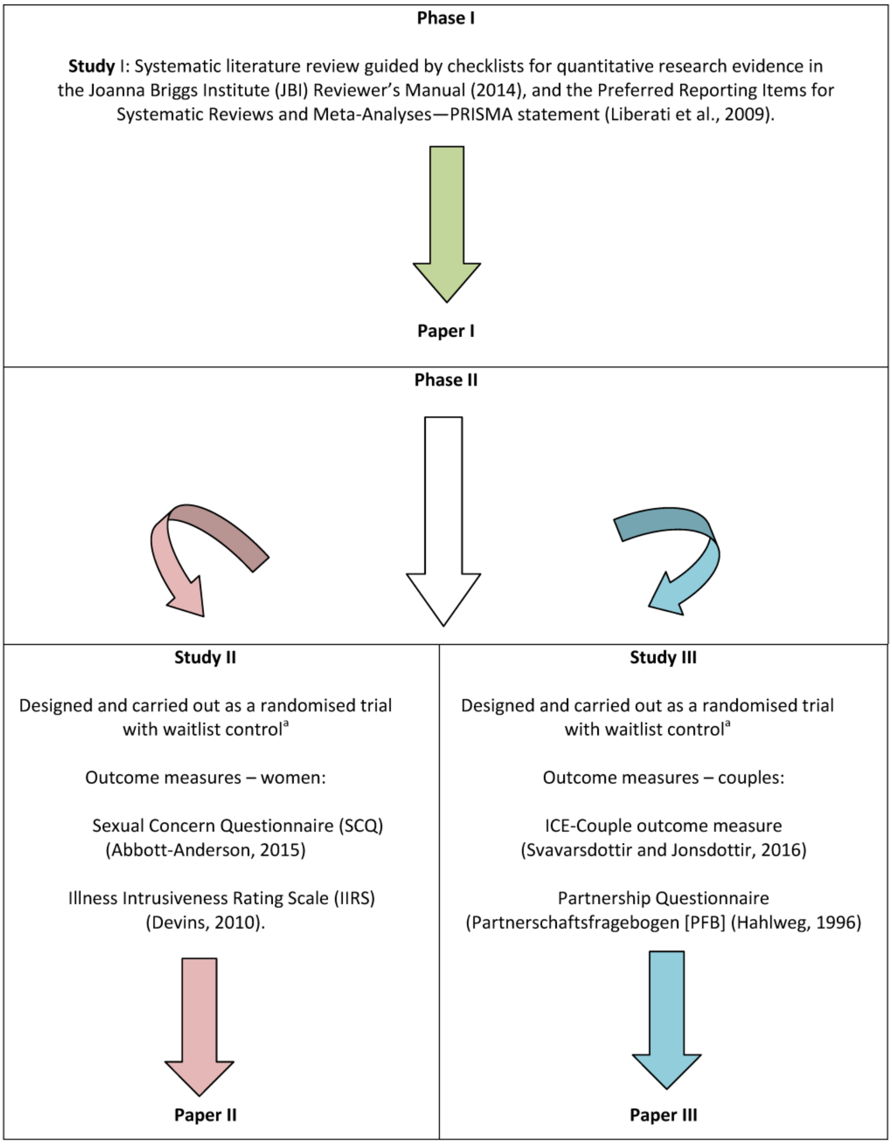
The above-mentioned global developments and research findings underline the role and responsibility of health care providers (HCPs), including nurses, in cancer care in providing interventions and information to cancer survivors for sexuality-related concerns. This accountability of HCPs has been described in various recent and most recent clinical practice guidelines in the field of health care intended to address adverse sexual side effects of cancer treatment to improve sexuality in cancer survivors (Barbera et al., 2017; Denlinger et al., 2017; Carter et al., 2108). Overall, on the basis of available evidence-based data, these guidelines recommend various interventions such as psychosocial counselling, educational interventions, and pharmacological approaches and devices. In addition, these guidelines collectively indicate the weak evidence base for interventions addressing sexual problems in women with cancer and underscore that high-quality research is needed in this population (Barbera et al., 2017; Denlinger et al., 2017; Carter et al., 2108). Furthermore, the most recent guidelines recommend offering couple-based interventions to partnered women to improve intimacy and relationship issues because previous research indicates that couple-based interventions are more effective than usual care (Barbera et al., 2017; Carter et al., 2018).

Cancer nurses have traditionally provided education, guidance, and counselling. They most often provide education and psychosocial and psychosexual support on an individual basis or assist cancer survivors with symptom management (Charalambous et al., 2018). This demonstrates a basic competence among nurses to provide sexual health care (SHC) (Charalambous et al., 2018). Specialist cancer care nurses or nurses with appropriate competency levels in providing SHC are in an ideal position to provide appropriate sexual interventions to couples coping with chronic illnesses such as cancer (International Family Nursing Association, 2017; Papadopoulou et al., 2019). Nurses can provide complex interventions such as those in a collaborative non-hierarchical therapeutic relationship with couples where the focus is on illness narratives, strengths, therapeutic questions, and resiliency instead of pathology (International Family Nursing Association, 2017; Gottlieb & Gottlieb, 2017, Svavarsdottir & Gisladottir, 2019).

A recent scoping review confirms that in the past two decades, cancer care nurses have progressed beyond symptom management to provide an increasing number of complex interventions (Charalambous et al., 2018). Despite this progress in nursing practice and although illness management can be viewed as a dyadic phenomenon, the majority of illness management research has focused on individual patients or their intimate partners (Lyons & Lee, 2018). Furthermore, although specialist cancer care nurses may be providing sexuality-related interventions for couples, this specific supportive care in cancer has not been documented in the literature. Supportive care in cancer has been defined as “the prevention and management of the adverse effects of cancer and its treatment” (Surbone et al., 2010, p. 255). Likewise, another review has underlined that little action has been taken toward the development of nursing theory for sexual health, which has resulted in limited contribution of the nursing profession to sexual health concerns (Rew et al., 2017).

Although nurses in cancer care are aware of the importance of providing education and support for sexual concerns to individuals, interventions that address couples’ sexual concerns are lagging behind. Although cancer nurses play a key role, reviews have identified a persistent lack of cancer nurse-managed interventions for couples’ sexual concerns (Charalambous et al., 2018; Jonsdottir et al., 2018; Papadopoulou et al., 2019). Consequently, this lack of evidence-based interventions is a major obstacle for nurses who want to address sexual concerns in women with cancer and their partners and advance the provision of SHC in clinical practice.

This doctoral thesis addresses the development and effectiveness testing of a theoretically based, nurse-managed, couple-based intervention for adult women with cancer and their partners, which was intended to facilitate adjustment to changes in sexuality and intimacy after cancer. Findings from a systematic literature review of the characteristics of couple-based interventions addressing sexuality following cancer are also presented, exposing substantial gaps in nurse-managed interventions for sexual concerns among women with cancer and their partners. The findings of the systematic literature review and the novel couple-based intervention are discussed in the context of improving nursing practice and SHC. Overall, this doctoral thesis makes an important contribution toward addressing the gap in providing psychosexual interventions for women with cancer and their partners.



Study I: Systematic literature review guided by checklists for quantitative research evidence in the Joanna Briggs Institute (JBI) Reviewer's Manual (2014), and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—PRISMA statement (Liberati et al., 2009).

Designed and carried out as a randomised trial with waitlist control[a]

Outcome measures – women:

Sexual Concern Questionnaire (SCQ) (Abbott-Anderson, 2015)

Illness Intrusiveness Rating Scale (IIRS) (Devins, 2010).

Designed and carried out as a randomised trial with waitlist control[a]

Outcome measures – couples:

ICE-Couple outcome measure (Svavarsdottir and Jonsdottir, 2016)

Partnership Questionnaire (Partnerschaftsfragebogen [PFB] (Hahlweg, 1996)

[a] Analyzed as a single group pre-post-follow-up design due to baseline differences after randomization

Figure 1: Phases of the study

1.2 Prevalence and Incidence Rate of Cancer

The global cancer incidence is growing rapidly; in 2020, over 19.3 million new cancer cases were estimated to occur in both women and men combined (Sung et al., 2021). Globally, 1 in 10 women are estimated to develop cancer in their lifetime; breast cancer is the most frequently diagnosed cancer in women, followed by colorectal cancer and lung cancer (Bray et al., 2018).

In Iceland (population 364,134 on January 1, 2020), between 2014 and 2018, on average 815 women and 832 men were annually diagnosed with cancer (Statistics Iceland, 2021; the Icelandic Cancer Registry [ICR] 2021). Breast, lung, colon, and rectum are the most common cancer sites among Icelandic women, followed by skin, uterus, brain and central nervous system, non-Hodgkin’s lymphoma, and other unspecified sites (ICR, 2021). Since the registration by the Cancer Registry started in Iceland in 1934, the five-year survival rate of cancer patients has more than doubled.

1.3 Definitions of Sexuality-related Concepts

In this thesis, the following definitions related to sexuality, sexual health, intimacy, and relationship quality are used. In addition, the Neo-theoretical framework of sexuality (Cleary & Hegarty, 2011) and the New View Manifesto of women’s sexual problems were utilized (Tiefer & Kaschak, 2001).

According to the World Association for Sexual Health, sexuality is defined as “a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles, and relationships. While sexuality includes all these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, and religious and spiritual factors” (World Association for Sexual Health, 2008). Similarly, sexual health is conceptualized as a “state of physical, emotional, mental, and social well-being related to sexuality; it is not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled” (World Association for Sexual Health, 2008).

A basic definition of intimacy is that it is “the ability to display one’s inner life in the relationship with one’s partner” (Schnarch, 1991, p. 122). Intimacy has different meanings for individuals and couples, and this applies to different contexts such as the cancer experience. Regardless of the meaning it has for an individual couple, when one partner has cancer, intimacy is likely to be affected in a positive or negative way—often both. In clinical practice, couples from all walks of life (and not necessarily coping with cancer) often describe intimacy as both a feeling and a behavior that increases the closeness and bonding between them and makes them feel better in the relationship. Thus, intimacy can be viewed as emotional sharing, communication, and physical intimacy that increases the sense of closeness (Hordern, 2008).

Relationship quality is an important component of relational health and is one of the outcomes assessed in this study. There is no consensus either on the definition of relationship quality or on the theory underpinning such a definition (Reynolds et al., 2014). Generally, however, relationship quality refers to how happy or satisfied an individual is in their relationship. Remarkably, a meta-analysis of empirical articles published over the past 50 years showed that greater marital relationship quality was related to better physical health (Robles et al., 2014). According to Reynold and colleagues (2014) there are two main approaches to understanding relationship quality; the interpersonal or relationship approach and the intrapersonal approach. The relationship or interpersonal approach focuses on the interaction between couples such as communication, conflict behaviors, and how time is spent with each other. The intrapersonal approach focuses not on behaviors and interactions in the relationship but rather on the subjective evaluation of how individual partners rate their satisfaction in the relationship. A combination of both approaches was used in this study.

1.4 Prevalence of Sexuality-related Problems in Women experiencing Cancer and their Intimate Partners

1.4.1 Holistic Understanding of a Sexual Problem

A holistic understanding of sexuality-related problems is crucial when nurses plan to offer appropriate interventions for women with cancer and their partners (Jonsdottir, 2009). It is not only cancer diagnosis and cancer treatment that affects women’s sexual lives and influences what a woman considers to be a sexual problem. Therefore, in this thesis, a woman-centered definition of sexual problems, according to the New View Manifesto on women’s sexual problems, was used (Tiefer & Kaschak, 2001; Section 1.10.2). Dissatisfaction with sexual experience may arise in one or more interconnected aspects of a woman’s sexual life such as sociocultural, psychological, and medical factors and factors related to partner or relationship (Tiefer & Kaschak, 2001).

The tendency to emphasize the physical aspects of sexuality has prevented a comprehensive understanding of sexuality-related problems and sexual concerns of women. This emphasis is problematic because not only are women’s sexual problems after cancer marginalized in research in comparison with men’s sexual problems after cancer but research on women’s sexual concerns is often limited to fertility issues, contraception, menopausal status, and ability to have vaginal intercourse (White et al., 2011, 2013; Hordern, 2008). Such emphasis on the physical aspects of women’s sexuality is restricted and may not adequately reflect women’s psychological and partner-related sexual concerns (Rasmusson & Thome, 2008; Abbott-Anderson & Kwekkeboom, 2012; Varela & Bober, 2013; Halley et al., 2014). For instance, focusing attention on restoring the physical aspects of sexual function after cancer may divert the attention from unmet needs regarding sexual adjustment in women and their partners (Donovan et al., 2007; Gilbert et al., 2009, 2010; Sadovsky et al., 2010). This is an unfortunate consequence as women with intimate partners are at risk of experiencing sexual side effects of cancer treatment with subsequent changes in their sense of femininity, loss of sexual intimacy, and relationship strain (Ussher et al., 2015).

Various integrative approaches that reflect a holistic understanding of women’s sexual concerns after cancer have been described in the literature (Bober & Varela, 2012; Cleary & Hegarty, 2011). These approaches are of value for nurses who intend to gain a holistic understanding of sexuality-related problems after cancer. For instance, Bober and Varela (2012) emphasize the importance of embracing an integrative biopsychosocial approach in both assessment and intervention of cancer-related sexual problems. Their approach embraces biological, psychological, interpersonal, and sociocultural dimensions. Another example is the neo-theoretical framework of sexuality devised by Cleary and Hegarty (2011), who describe three core aspects or domains of sexuality: sexual function, sexual relationship, and sexual identity. Alterations in these three major components of sexuality influence each other—for example, lower perceived sexual attractiveness can interfere with sexual functioning, which can affect the sexual relationship.

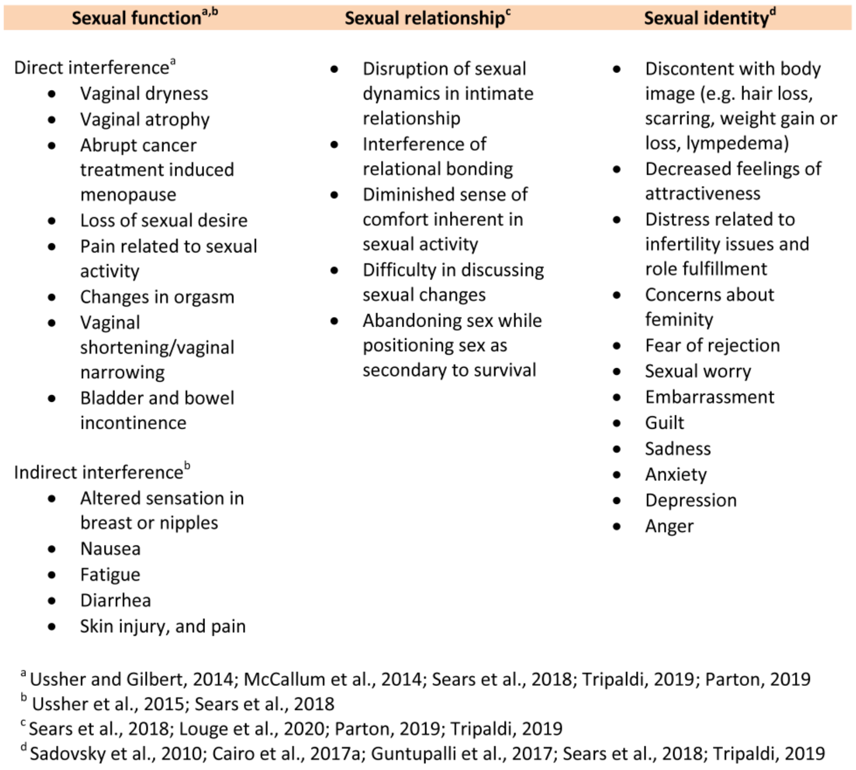
To summarize, a holistic understanding of women’s sexuality and sexual concerns is of paramount importance and may increase the likelihood of successful sexual adjustment following the cancer experience.

1.4.2 Adverse effects of Cancer treatments on Women's Sexuality

Cancer itself rarely leads to sexual problems; however, disease progression may affect sexuality depending on the cancer site—for example, in gynecological, colorectal, and breast cancer—and cancer stage (Mercadante et al., 2010; Charif et al., 2016, Røhrl et al., 2016). It is mostly the cancer treatments—such as surgery, radiation therapy, chemotherapy, and endocrine therapy—that may interfere with women's sexuality (Krychman & Millheiser, 2013; Goldfarb et al., 2015; Table 1).

The precise prevalence of sexual problems associated with cancer is difficult to determine as it can vary depending on, for example, the type of cancer treatment, definition of sexual problems and sexual concerns, and methods used to assess a sexual problem (Mercadante et al., 2010). However, previous data suggest that prevalence of sexual problems among women with a cancer diagnosis ranges between 30% and 100% (Dizon et al., 2014; Reese et al., 2019; Valpey et al., 2019; Masjoudi et al., 2019). Among women who have been diagnosed with gynecological cancer and undergone surgery, the prevalence may be at the higher end (Guntupalli et al., 2017). It is also important to note that cancer treatment for any type of cancer may negatively affect all the major, interrelated aspects of women's sexuality: sexual function (desire, arousal, and orgasm), sexual relationship (communication and intimacy), and sexual identity (body image, sexual esteem, and sexual self-schema; Cleary & Hegarty, 2011; Tan et al., 2002; Mulhall et al., 2011; Sadovsky et al., 2010; De Vocht, 2011).

Table 1: Possible sexual side effects of cancer treatment on the main domains of sexuality



Sexual function[a,b]	Sexual relationship[c]	Sexual identity[d]
Direct interference[a] • Vaginal dryness • Vaginal atrophy • Abrupt cancer treatment induced menopause • Loss of sexual desire • Pain related to sexual activity • Changes in orgasm • Vaginal shortening/vaginal narrowing • Bladder and bowel incontinence Indirect interference[b] • Altered sensation in breast or nipples • Nausea • Fatigue • Diarrhea • Skin injury, and pain	• Disruption of sexual dynamics in intimate relationship • Interference of relational bonding • Diminished sense of comfort inherent in sexual activity • Difficulty in discussing sexual changes • Abandoning sex while positioning sex as secondary to survival	• Discontent with body image (e.g. hair loss, scarring, weight gain or loss, lympedema) • Decreased feelings of attractiveness • Distress related to infertility issues and role fulfillment • Concerns about feminity • Fear of rejection • Sexual worry • Embarrassment • Guilt • Sadness • Anxiety • Depression • Anger

[a] Ussher and Gilbert, 2014; McCallum et al., 2014; Sears et al., 2018; Tripaldi, 2019; Parton, 2019
[b] Ussher et al., 2015; Sears et al., 2018
[c] Sears et al., 2018; Louge et al., 2020; Parton, 2019; Tripaldi, 2019
[d] Sadovsky et al., 2010; Cairo et al., 2017a; Guntupalli et al., 2017; Sears et al., 2018; Tripaldi, 2019

Sexual problems in women may persist for many years, sometimes long after cancer treatment has ended (Charif et al., 2016; Parton, 2019). Women who undergo pelvic brachytherapy/radiotherapy, chemotherapy for anal cancer, endocrine therapy, and allogenic hematopoietic stem cell transplantation are considered at high risk of having sexual late-effects (Rowlands et al., 2014; Sears et al., 2018). In addition, undergoing an adjuvant treatment may have long-term adverse consequences for women’s sexual well-being (Rowlands et al., 2014; White & Grayer, 2018).

The most commonly reported changes in women’s sexuality after cancer treatment are vaginal dryness, loss of desire, arousal difficulties, pain related to sexual activity, scarring from surgery, and positioning sex as secondary to survival resulting in sexuality being suspended for a time. (McCallum et al., 2014; Cella & Fallowfield, 2008; Carter et al., 2011; Ussher et al., 2014).

In addition to cancer treatment, multiple other factors may influence the manifestation and severity of sexuality-related problems in women:

- Many women undergo a combination of cancer treatment modalities, which may intensify the negative effects of treatment on sexuality.
- Some women may also experience sexual problems or concerns before they are diagnosed with cancer, for example, owing to (another) chronic illness, medication, personality, and psychological factors or because of physical post-menopausal factors (Den Oudsten et al., 2010; DeSimone, et al., 2014). For instance, natural menopause leads to certain sexual changes, such as increased pain during intercourse and diminished sexual desire, which are also common in cancer-treatment-induced menopause (Avis et al., 2009).
- However, cancer-treatment-induced menopause, such as that after endocrine therapy in breast cancer, is different from natural menopause; premature or abrupt hormonal deprivation can be greater in intensity and duration and be especially distressing to younger pre-menopausal women (Rosenberg & Partridge, 2013, Deniz et al., 2007; Parton, 2019).
- Research has suggested that women who are younger at the time of cancer diagnosis are particularly at risk of developing sexuality-related problems and may find it more difficult to renegotiate their sexual sense of self, in the context of concerns about femininity and desire for children in the future (Rowlands et al., 2014; Guntupalli et al., 2017; Ljungman et al., 2018).
- Among partnered women who are sexually active and having lower perceived attractiveness are associated with more sexual problems (Avis et al., 2018).
- Higher age, lower relationship satisfaction, and depressive symptoms are predictive of worse sexual health among breast cancer survivors than among women from the general population (Oberguggenberger et al., 2017).

1.4.2.1 Sexual function

Healthy sexual function or sexual response is highly dependent on intact neural, vascular, and hormonal physiology. Physical changes resulting from various cancer treatments directly interfere with the sexual function (sexual response) leading to symptoms such as vaginal dryness, vaginal atrophy, dyspareunia, less frequent and impaired orgasm, and vaginal shortening and narrowing (Fobair & Spiegel, 2009; Ussher and Gilbert, 2014; McCallum et al., 2014; Sears et al., 2018; Tripaldi, 2019). Other factors may intensify the changes in sexual function; for example, after colorectal surgery, women may experience bowel and bladder incontinence and have an ostomy bag, which may affect sexual activity (Tripaldi, 2019; Almont et al., 2019). Many other side effects of cancer treatment may also affect physical well-being and thus indirectly affect sexual function, for example, altered or lost sensation in breasts or nipples after mastectomy, nausea, fatigue, diarrhea, skin injury, and pain (Sears et al., 2018). Moreover, because biopsychosocial factors are interconnected, they can interact and influence sexual function (Den Oudsten et al., 2010). For example, emotional issues related to the cancer diagnosis and disruptions of daily life caused by cancer treatments—such as sadness, anxiety, depression, frustration, anger, embarrassment, guilt, and feeling unattractive—directly or indirectly interfere with sexual function (Sadovsky et al., 2010; Ussher et al., 2015; Sears et al., 2018).

1.4.2.2 Sexual relationship

Sexual side effects of cancer treatment disrupt the sexual dynamics within an intimate relationship, interfere with the closeness, and threaten relational bonding and sense of comfort inherent in sexual activity (Parton, 2019; Rottmann et al., 2017). In addition, the couple may refrain from discussing changes in sexual function or reduce non-coital sexual activities such as kissing or caressing or the woman may fear rejection related to partner’s potential response to physical and sexual changes (Reese et al., 2014; Sears et al., 2018; Parton, 2019; Louge et al., 2020; Tripaldi, 2019). Furthermore, Sadovsky and colleagues (2010) state that the sexual response of women with cancer are affected more by their well-being and relationship factors than as a direct consequence of an operation. Similarly, Bennet and colleagues (2016) mention that cancer survivors’ levels of relationship distress are among the factors that are more influential than hormonal levels in affecting sexual response.

1.4.2.3 Sexual identity

Changes in sexual identity or sexual sense of self may manifest as discontent with body image (e.g., owing to disfigurement and scarring, hair loss, lymphedema, and weight gain or loss), decreased feelings of sexual attractiveness, distress associated with infertility issues and role fulfillment, sexual worry, guilt, sadness, anger, embarrassment, and anxiety, (Cairo Notari et al., 2017a; Sears et al., 2018; Tripaldi, 2019; Park et al., 2007). Furthermore, partnered female cancer survivors who are not sexually active are more likely to be less satisfied with their sex lives, feel less attractive, and more self-conscious about their appearance than those who are sexually active (Marino et al., 2017).

1.4.3 Unmet Needs in Cancer care Related to Sexual Problems

Previous studies have consistently reported widespread unmet needs for support and information related to sexuality after cancer (Duimering et al., 2020). For instance, one large population-based cohort study in Denmark showed that the most common unmet needs in cancer rehabilitation were associated with sexual problems (50%) whereas the least common ones were associated with physical problems (17%; Holm et al., 2012). In particular, significant unmet needs have been identified among women with cancer, more commonly, unmet needs regarding SHC in partnered women (Hill et al., 2011; Holm et al., 2012; Stabile et al., 2017). For example, one study reported that approximately 40% of gynecological and breast cancer survivors expressed interest in receiving SHC, whereas few had ever sought such care, indicating significant unmet needs (Hill et al., 2011). Furthermore, research findings from a study among women with gynecological cancer suggest that importance of sexuality is not associated with cancer type but with age, relationship status, and sexual activity (Hay et al., 2018).

Unmet needs in cancer care related to sexuality may affect health and QOL. For instance, in the first longitudinal population-based study in Iceland on QOL among cancer patients receiving chemotherapy, the sexual QOL was most affected and >50% of patients had problems in relation to body image and sexual interest and performance (Saevarsdottir, Fridriksdottir and Gunnarsdottir, 2010). The authors concluded that sexual functioning and sexuality issues need to be addressed as an essential part of patient’s QOL. Other studies have supported this finding; for example, a study in women with breast cancer showed that sexual activity was significantly associated with better health status and better QOL (Mayer et al., 2019).

High sexual health needs and wish for support for those needs have been identified among subgroups of women with cancer. For example, findings from studies in women treated for gynecological cancer show that higher sexual health needs were associated with younger age, menopausal status before diagnosis, more vaginal changes post cancer treatment, and cancer diagnosis less than 2 years ago (McCallum et al., 2014; Albers et al., 2020a). In addition, women with breast cancer with metastatic cancer and those who experience the less common side effects such as lymphedema may be especially at risk of having their sexual health needs overlooked by HCPs (Male et al., 2016).

Contrary to what many health professionals believe, majority of the patients after cancer treatment appreciate the opportunity to reassess what is important in their lives, including the more intimate and sexual aspects of their lives (Hordern & Street, 2007a; Flynn et al., 2011; 2012; Almont et al., 2018). For instance, in a study in cancer survivors, 78% of survey respondents believed that it was important to have discussions with health professionals about sexual problems (Flynn et al., 2012). Not providing individuals with cancer an opportunity to discuss sexual concerns may have negative consequences. For example, studies show that women with cancer are disappointed about the perceived lack of interest in their emotional and sexual well-being after cancer treatment (White et al., 2013; Sekse, 2013). In another study, women with gynecological cancer described the lack of conversation with HCPs about altered sex life after cancer and bodily changes as a lonely process (Sekse, 2013).

As sexuality and intimacy are extremely personal issues, it is unlikely that many patients will be vocal about their wants or needs for sexual concerns. Various factors explain why cancer patients generally do not initiate a discussion related to their sexual concerns. These factors may be related to patients’ own beliefs about their ability to discuss sexuality or their perception of the HCPs’ response to discussing sexuality-related issues (Zimmaro et al., 2020). A study in breast cancer survivors found that women’s barriers to sexuality-related discussion with HCPs were largely related to their perception of their own lack of comfort or ability as opposed to that of their providers (Zimmaro et al., 2020). Another study found that the minority of cancer patients that actually do have the courage to ask oncology care providers about sexual problems have significantly greater interest in sexual activity as well as more sexual dysfunction than those that did not ask (Flynn et al., 2012). However, this does not mean that only the patients who contact HCPs are the ones with an existing or potential sexual problem. Not complaining does not necessarily signify a lack of a problem. The great majority of cancer patients do not raise the issue themselves; however, they expect the health professional to initiate the discussion (Hautamäki et al., 2013).

Taken together, it is evident that HCPs should initiate the discussion for the benefit of cancer survivors. Therefore, it is encouraging to see that findings of a recent study in Danish students in the health professions, including nurses, indicate that most students report a positive attitude toward addressing sexual health (Gerbild et al., 2021).

1.5 Adjusting to Sexual Changes after Cancer

1.5.1 Sexuality-related Concerns of Partners

Despite the importance of intimate relationships, the experience of partners during cancer is often neglected in cancer research on sexuality and intimacy. Intimate partners are also often overlooked in many patient-centered models of cancer care (Hawkins et al., 2009; Enzlin et al., 2017). Moreover, there is a paucity of studies that investigate the impact of cancer on the experience of sexuality and intimacy from the perspectives of both the patient and their partner (De Vocht, 2011). Because a partner can offer significant support and serve as an effective stress buffer during the adaptation to cancer, this inattention to the importance of intimate partners and the couple's experience is most regrettable (Duhamel & Dupuis, 2004; Di Mattei et al., 2020). Fortunately, there is growing acknowledgement of partner experiences and recognition of their unmet needs for support related to sexuality and intimacy (D'Ardenne, 2004; Gilbert et al., 2010; Ussher et al., 2012a; Ussher et al., 2014; Wittmann, 2016; Cohee et al., 2020).

The onset of cancer is reported to have various effects on intimate partners, such as decreased desire for sexual intimacy, fear of initiating sexual contact, cessation or decreased frequency of sex, and problems with sexual arousal (Hawkins et al., 2009; Perz, et al., 2013). In some instances, intimate partners associate these sexual changes with stress, weariness, and revised priorities including coping and survival (Canzona et al., 2019b). Moreover, changes in the dynamics of the intimate relationship that may occur in the cancer illness directly affect the partner. For instance, the intimate partner may act more as a caregiver than as a lover in the relationship, which may result in the de-sexualization of the woman with cancer (Gilbert et al., 2009; Hawkins et al., 2009). Some partners may become overprotective during the illness or deny the effects of cancer to try to avoid distress, further suppressing their own needs related to the intimate relationship (Perz et al., 2013). Furthermore, findings of a study on partners of cancer survivors revealed that many of the participants who reported on less or absent sexual activity also reported feelings of loss and sadness

(Ussher et al., 2011). Subsequently, some intimate partners may find it difficult to communicate about sexual matters in the context of cancer, and struggle with their own worries about their dissatisfaction with the sexual relationship (Canzona et al., 2019b.) In addition, partners may have feelings of guilt about their own sexual needs, sometimes because of what is considered appropriate in the cancer experience (Perz et al., 2013; Canzona et al., 2019b; Kuta, 2021).

1.5.2 Couple's Response to Sexual Changes After Cancer

Various relational dynamics may come to the forefront when a couple copes with cancer, and these dynamics may also affect the adaptation of the couple regarding changes in sexuality and intimacy. For instance, research suggests that couples show significant variation in how they adapt after cancer and whether the adaptation is experienced primarily in a positive or negative way (Ussher et al., 2010; Flynn et al., 2012; Bober & Varela, 2012; Badr & Krebs, 2013; Adorno et al., 2018).

When providing psychosexual intervention to couples facing cancer, gaining insight into how couples may react and adapt to sexual changes is valuable. It is particularly useful because individual couples do not adjust to these changes in a uniform way, thus suggesting the importance of a tailor-made approach when developing a couple-based intervention because there is most likely no "one size fits all" solution (Gorman et al., 2020).

1.5.2.1 Multiple „Truths"

There exists no absolute truth about how couples facing cancer may respond to changes following cancer. This is another important observation to consider when developing a couple-based intervention that is guided by a systemic theoretical framework (see Section 1.10). The post-modernist view of "objectivity in parentheses" emphasizes multiplicity; there are multiple views, realities, and lives (Wright & Bell, 2009; Shajani & Snell, 2019). In addition, the presence of one's partner influences how the couple experience the joint sessions with the nurse (Taylor & de Vocht, 2011). Finally, the presence of the nurse in the sessions with the couple may also influence how the couple perceive the effect of cancer on their intimate relationship.

According to the aforementioned post-modernist view, the description of the individual couple about their intimate relationship is "true" and the woman's account of the sexual relationship with her intimate partner is "true" as well even if it may differ from the "true" narrative of her partner (Taylor & de Vocht, 2011; Shajani & Snell, 2019). This notion of multiplicity of truth is acknowledged in that each patient has their own unique definition of sexuality (Southard & Keller, 2009). Thus, in joint sessions of therapeutic conversations with the couple, there are many “truths.” Again, this fact highlights the need to consider a tailor-made approach when developing an intervention for couples.

1.5.2.2 Cancer as a „We-disease”

In the past decades, a recurrent theme in research in the Western world is that couples who face the cancer illness together view it as a “we-disease,” and couples who can communicate their concerns and needs may have a more unified and stronger relationship to begin with (Traa et al., 2015; Manne et al., 2014). Therefore, Cairo Notari and colleagues (2017b) have suggested that it is incorrect to consider that caregiving is only a stressor or burden for the intimate partner because, in their opinion, perceiving cancer as a “we-disease” may mean that the only thing to do is to face the illness together. Furthermore, couples who are satisfied before cancer diagnosis may view the illness-related changes as temporary (Cairo Notari et al., 2017b). Notably, although the notion of having a sense of “we-disease” in cancer is commonly reported in research findings, research also shows that couples may have dissimilar opinions about what “we” encompasses (de Boer et al., 2018).

1.5.2.3 Closer or more apart?

The cancer experience may influence the dynamics of an intimate relationship in different ways. In terms of closeness or intimacy, some couples report that the cancer experience brought them closer together, whereas others report experiencing adjustment and communication difficulties, resulting in decreased intimacy and relationship strain (Ussher et al., 2010; Badr & Krebs, 2013). One study in patients diagnosed with diverse types of cancer found that 41.5% of the women participants reported that the illness had brought them closer to their partners (Préau et al., 2011). Préau and colleagues identified some factors that were independently associated with closer couple relationships in women who reported that the illness had brought them closer to their partners, such as regular sexual activity, satisfaction with information provided by HCPs, and specialized psychological support at the time of diagnosis (Préau et al., 2011).

1.5.2.4 Sexual Adjustment Pathways

Research suggests that each individual couple has their own unique sexual adjustment pathway in the cancer experience (Ussher et al., 2012a; Ussher et al., 2014; Benoot et al., 2017). Benoot and colleagues (2017) reviewed evidence from qualitative studies on the sexual adjustment process of couples after cancer with the specific aim of developing a theoretical model that could facilitate intervention designs. They identified three different pathways of sexual adjustment: as a grieving process, as a cognitive restructuring process, and as a rehabilitation process:

1. Couples displaying sexual adjustment as a grieving process exhibit minimization or avoidance of sexuality, sense of loss with related feelings of anger or depression, and subsequently, sexual acceptance.

2. When couples go through sexual adjustment as a cognitive restructuring process, according to Benoot et al., they initially adhere to sexual intercourse as the dominant sexuality discourse and struggle with a sexual identity crisis and eventually adapt by redefining sexuality and demonstrating flexibility in their sexual expression.

3. The third sexual adjustment pathway of rehabilitation is characterized by a focus primarily on the bodily changes because of sexual side effects of cancer. Here, the emphasis is on sexual dysfunction and restoration of sexual function, for example, by using medical aids.

According to Benoot and colleagues (2017), each pathway has its own advantages and disadvantages in helping a couple to cope with sexual changes. They suggest that it would be helpful if HCPs adopt a strengths-oriented approach in their couple-based interventions, integrate all three pathways, and simultaneously concentrate on the aspects that are unique for each couple.

1.5.2.5 Changes in Sexual Activity after Cancer

Sexual activity has various implications for emotional and physical well-being (Diamond & Huebner, 2012; Perz et al., 2013). When adjusting to changes in sexual activity after cancer, some couples find that non-sexual intimacy becomes an adequate substitute for sexual activity that is no longer possible, whereas other couples discover that loss of sexual activity is related to loss of emotional and physical intimacy altogether (Bober & Varela, 2012). Indeed, some individuals with cancer and their partners report that QOL and relationship satisfaction are attained through open communication and non-genital intimacy (Perz et al., 2013). Although sexual activity can change differently for couples following cancer, couple-based interventions addressing sexuality and intimacy may help maintain a sense of “normalcy” when facing cancer (Bondil et al., 2016).

Previous research by Flynn and colleagues (2011) reiterates these above-mentioned, sometimes opposing findings. In this study, cancer survivors with a wide range of cancer types reported that although most effects of cancer on sexual functioning were deemed as negative, many participants reported satisfaction with their sex life and intimacy despite decreased sexual function (Flynn et al., 2011). Participants in this study tended to fall into four categories regarding their view of emotional intimacy while experiencing sexual difficulties:

- intimacy declined without sexual activity,
- intimacy became an alternative to sexual activity,
- intimacy was sexual activity,
- increased intimacy led to an improvement in sexual activity

Cancer survivors in the last category were able to let changes in emotional intimacy induce improvement in their sexual relationship. In light of these findings, Flynn and colleagues (2011) advise HCPs against assuming that the level of sexual impairment determines sexual satisfaction and instead directly explore the cancer patients’ sexual concerns. This advice is important to consider when devising interventions to support couples adjusting to sexual changes after cancer.

1.5.2.6 Flexible Coping

Some couples struggle in the context of cancer and are unsuccessful in renegotiating sexuality and intimacy (Gilbert et al., 2010). However, couples who are more successful in their renegotiation and sexual recovery have a good and well-established “pre-cancer” relationship, communicate better with each other, and adhere less to the so-called “coital imperative” (the belief that penetrative sexual intercourse is the only right or viable way to be sexually intimate; Gilbert et al., 2010). In addition, couples who adjust better to sexual changes are able to redefine their experiences of sexual intimacy to include practices that were previously sidelined (Gilbert et al., 2010). According to Reese and colleagues (2010), couples who use flexible coping are more likely to have a better chance of adjusting to cancer-related changes in sexuality and intimacy. Couples who are able to shift their perspectives on sexuality and intimacy can better maintain their role as lovers, do better in their renegotiation of sexuality, and are more able to sustain intimacy (Reese, 2010).

Accordingly, it can be argued that a flexible view of sexual expression may be helpful when adjusting to sexual changes after cancer. An individual who views sexual function and activity in a flexible manner regards sexual intercourse, non-intercourse sexual activities, and non-sexual intimate activities all as a part of sexual expression (Reese et al., 2010; Reese, 2011). The idea that a flexible perception of sexual expression is helpful is supported by findings that show that, for many women with cancer, renegotiating sex involves exploring non-penetrative sexual practices and focusing on other ways to be intimate, such as massage, use of sexual aids such as a vibrator, kissing, cuddling, and touching (Ussher et al., 2014). Furthermore, the knowledge that couples in a well-functioning pre-cancer relationship may adjust better to sexual changes after cancer is valuable. It is a useful reminder of the fact that couples who are in a well-functioning relationship may benefit from sexual support interventions.

Taken together, all the above-mentioned factors highlight the importance of developing interventions that are likely to accommodate the different ways in which couples adapt to and cope with sexual changes after cancer. Furthermore, these factors underline the value of couple-based interventions in encouraging open dialogue (Canzona et al., 2019b).

1.6 Psychosocial Interventions for Couples after Cancer

The vast majority of couple-based psychosocial interventions for cancer have only been published in the last two decades suggesting they are in their early developmental stage (Baik & Adams, 2011; Brandao et al., 2014; Badr & Krebs, 2013; Regan et al., 2015). The term “couple-based intervention” refers to any psychosocial intervention in which two partners in a committed, romantic relationship are together seen by a therapist, interventionist, or health educator for assistance (Baucom et al., 2012, p. 61).

However, despite evidence that couple-based interventions may be at least as efficacious as patient-only interventions, they have neither been widely adopted nor been an often-sought option in cancer care (Brotto et al., 2010; Badr et al., 2019). One review suggested that multiple factors explain this lack of implementation; research on couple’s intervention suggests diverse outcomes and intervention strategies, which makes it difficult for clinicians to discern “best practice” recommendations (Badr & Krebs, 2013). In particular, many couple-based interventions for couples coping with cancer fail to describe the theoretical frameworks that are used, and dyadic theoretical frameworks are lacking (Li & Loke, 2014).

Couple-based interventions have been identified to be promising when couples are coping with chronic illness (Bradbury & Bodenmann, 2020). One review suggests that couple-based interventions tend to have the greatest impact in improving couple’s communication, psychological distress, and relationship functioning (Regan et al., 2012). However, this specific review excluded studies that focused on sexuality, stating that these were worthy of separate attention. In spite of this exclusion, Regan and colleagues concluded that interventions involving the couple are promising in reducing distress and improving coping and adjustment to a cancer diagnosis or cancer symptoms. Additionally, couple-based interventions may have important advantages compared with individual support for sexual concerns after cancer (Carroll et al., 2016). For example, one review of interventions for enhancing women’s sexual adjustment and body image after cancer established that interventions that produced stronger effects were couple focused (Scott and Kayser, 2009). Moreover, the effects of these interventions tended to be maintained longer than those of a patient-only intervention. The treatment components that focused on the couple included educating both partners on the woman’s diagnosis and treatment, promoting the mutual coping and support process of the couple, and using specific sexual therapy techniques that addressed the sexual and body image concerns (Scott & Kayser, 2009). Another advantage relates to addressing sexual concerns comprehensively. For instance, Carroll and colleagues (2016), in a more recent review on the efficacy of couple-based interventions in breast cancer survivors, found that these interventions were associated with enhancement of all major aspects of sexuality—sexual function, sexual relationship, and sexual identity.

The first study to show that adjustment in female cancer patients can be improved by a couple-based intervention was conducted in Australia (Scott, Halford and Ward, 2004). This study examined the effects of a couple-coping intervention (CanCOPE) for adjustment to an early-stage breast or gynecological cancer. The findings showed that the CanCOPE intervention significantly improved the couples' supportive communication, reduced psychological distress and coping effort, and improved sexual adjustment. The authors concluded that the couple-based intervention was more effective than individual support in facilitating adaptation to cancer (Scott, Halford and Ward, 2004).

Most couple-based interventions include the provision of some kind of emotional support, information, and resources, sometimes termed as "psychoeducation." Psychoeducational intervention is a term often used for interventions that involve education and elements of psychological, cognitive, and behavioral therapy to improve patients' acceptance of cancer and aid their recovery from the illness and treatment (Chow et al., 2012). Results of one review that examined the effects of couple-based interventions in cancer care found that intervention methods that aim at improving communication, reciprocal understanding, and intimacy in the couple appeared to reduce illness-related distress in one or both partners and to improve dyadic adjustment (Baik and Adams, 2011). Similarly, another review by Regan and colleagues (2015) suggested that intervention models that target relational processes such as open communication, intimacy, and self-efficacy to encourage dyadic coping after cancer have a larger impact on outcomes (Regan et al., 2015). Furthermore, a recent review found high-level evidence for the effectiveness of psychoeducational programs offered to women with gynecological cancer and their partners to improve physical aspects of sexual function related to long-term side effects of cancer treatment (Beesley et al., 2019).

As for guiding theoretical frameworks, overall, the structure and content of most couple-based interventions are influenced by two main theoretical frameworks—dyadic theories that originated from social psychology (e.g., relationship- or attachment-oriented theories) and theories focusing on the individual (e.g., cognitive–social processing or stress-coping framework; Baik & Adams, 2011). The widespread variability in research methods in couple-based intervention studies also makes it difficult to assess which interventions work for whom (Taylor et al., 2011). In addition, many methodological limitations are evident when searching the literature on effectiveness of couple-based interventions. One of the recommendations that is repeatedly highlighted is that this research may benefit from a control group especially because there is a strong placebo response (Brotto et al., 2010).

1.6.1 Couple-based Interventions addressing Sexuality and Intimacy

Research findings have established that one of the most consistent predictors of sexual health after cancer diagnosis is the relational health in intimate relationships (Emilee et al., 2010; Canzona et al., 2019b). Similarly, research on the relationship between sexual activity and illness indicates that sexual activity has various implications for emotional and physical well-being (Diamond & Huebner, 2012). In the case of cancer, sexual relations and the experience of intimacy has been shown to moderate cancer-related stress by providing a safe haven for expressing a range of emotions, stimulating inner resources and strengths, and affirming a deeper meaning of daily life, thus making the cancer experience more manageable (Ussher et al., 2012b; Graugaard et al., 2012; Schoebi & Randall, 2015). Furthermore, among women with cancer, perceived partner support and good relationship quality lowers the risk of sexual difficulties and enhances the sexual relationship, thus protecting against the detrimental effects of cancer treatment on sexuality and intimacy (Naaman et al., 2009; Gilbert et al., 2010; Golbasi & Erenel, 2012, Fang et al., 2015; Cairo Notari et al., 2017a; Kowalczyk et al., 2019; Parton, 2019). Consistent with these findings, other studies have shown that the main strategies related to couple-based interventions for sexual support involve creating opportunities for shared understanding of sexual changes after cancer and enhancing couples' communication (Milbury & Badr, 2013; Gorman et al., 2020). Therefore, to prevent misunderstanding and tension in the intimate relationship, there is a need for psychosexual support to encourage open dialogue (Canzona et al., 2019b).

Taken together, these findings underscore the importance of providing couples facing cancer with support and education for concerns related to sexuality and intimacy. Without support, such couples are left to struggle on their own in adjusting to changes in sexuality and intimacy (Parton, 2019). It is therefore disheartening that research on the development of couple-based interventions to support sexuality and intimacy after cancer is advancing at a slow rate and published interventions are few and far between, especially pertaining to women with cancer and their partners. Remarkably, a recent survey among Dutch breast cancer survivors found that most women preferred to get information about the effects of cancer on sexuality and intimacy from a nurse (66.4%), and the most preferred method of communication was conversation with an HCP together with their partner (51.6%; Den Ouden et al., 2019).

Only a handful of interventions for woman with cancer and their partners have been developed, tested, and reported, and the studies were conducted exclusively in the USA (Jonsdottir et al., 2018). This is a clear indication that more evidence-based interventions are needed in other countries for women with cancer and their partners. For example, currently, the literature includes only one study protocol, also from the USA, on a couple-based intervention that addresses sexual concerns of breast cancer survivors and is currently recruiting participants (Reese et al 2020).

The scarcity of evidence-based couple-based interventions to support changes related to sexuality and intimacy, especially among women with cancer and their partners, poses a challenge to advanced nurse practitioners who intend to improve SHC, but it can also be viewed as an opportunity in advancing clinical nursing practice.

1.7 Barriers and Facilitors among HCPs in addressing Sexuality-related Issues in Cancer Care

Nurses work in various health care setting with other HCP‘s, for example doctors, physiotherapists, radiologists and social workers in the overall care of cancer patients. Furthermore, organizational factors such as policy of the health care setting may influence nurses in addressing sexual concerns (Dyer & das Nair, 2013). Therefore it is pertinent to explore some of the general barriers and facilitators in addressing sexuality among doctors and nurses reported in the literature, and also specifically among HCP‘s working in cancer care.

A central and recurrent narrative has emerged from the research published in the past 40 years in the Western countries about SHC in clinical practice, affecting individuals living with chronic illness and disability (McGrath et al., 2020). This seemingly never-ending saga consists of three interconnecting themes and is also well known in the clinical care of cancer patients—nurses and doctors in oncology support discussing sexuality with patients; however, these discussions are not routine in clinical practice, and these professionals find it difficult to address the subject of sexuality in clinical practice (Stead et al., 2003; Park et al., 2009; Jonsdottir et al., 2016; Reese et al., 2017; Krouwel et al., 2019). For instance, Hautamäki and colleagues (2007) studied 215 health care professionals’ experiences of discussing sexuality-related issues with cancer patients; only 35% of providers initiated these discussions, and 98% of respondents reported that they talked about these issues with less than 50% of their patients. It is noteworthy that discussions of sexual concerns are especially uncommon among women with cancer (Reese et al., 2017). As a result, sexual issues often remain both under-addressed and undertreated in cancer care.

Not only do nurses and other HCPs find it difficult to address sexuality but patients may also be reluctant to express their sexual concerns. This situation can create a “two-way taboo” where sexual concerns are not addressed (Traumer et al., 2019). A recent review revealed that among HCPs working with patients after diagnosis of a chronic illness, personal and social barriers have the strongest effect on discussing sexual health, thus suggesting areas of needed support for HCPs (O'Connor et al., 2019). Likewise, the two most commonly cited explanations by doctors and nurses in oncology for avoiding addressing sexual issues are personal discomfort with the subject of sexuality and a lack of training in sexual health (Jonsdottir et al., 2016). The former explanation has also been corroborated in a previous study showing that majority of HCPs in cancer care find it personally confronting to raise these issues, and feelings of personal vulnerability and uncertainty drove them away from the topic of sexuality and intimacy (Hordern and Street, 2007b).

The literature on sexuality and cancer repeatedly mentions lack of education and training as one of the major reasons why HCPs, including nurses, are reluctant to initiate sexuality-related discussions with cancer patients despite acknowledging the importance of addressing sexual concerns (Hautamäki et al., 2007; Kotronoulas et al., 2009). Indeed, education and training have been shown to improve the knowledge and confidence of HCPs to initiate discussions on sexual matters with cancer patients (Hautamäki et al., 2007; Saunamäki et al., 2010; Wang et al., 2015; Bober et al., 2016; Reese et al., 2017; Carter et al., 2018; Albers et al., 2020b). A recent review verifies these findings and reports that nurses with training in sexual health hold more positive attitudes toward discussing sexuality-related issues with patients (Verrastro et al., 2020). In contrast, another recent review of educational interventions for HCPs to improve SHC provision concluded that there was insufficient evidence to make an overall recommendation about these interventions, mostly owing to the small number of studies and data heterogeneity (Albers et al., 2020b).

Because HCPs in cancer care inconsistently address the subject of sexuality in clinical practice, researchers have attempted to study the barriers and facilitators to this task in detail (Hordern & Street, 2007b; de Vocht 2011; Ussher et al., 2013; Reese et al., 2017; Canzona et al., 2018; Annerstedt & Glasdam, 2019; Hjalmarsson & Lindroth, 2020). For instance, Ussher and colleagues (2013) interviewed 38 HCPs working across a range of professions involved in cancer care to examine how they perceive sexuality following cancer. They identified many personal, patient-centered, and situational barriers in discussing sexual issues with patients (Ussher et al., 2013). For instance, HCPs may perceive discussion of sex as irrelevant or inappropriate; other barriers include the following: "We are not as equipped as we would like to be" (personal factor), "It is much easier to talk about sex with certain patient groups than others" (patient-centered factor) and "time constraints and the lack of privacy" (situational context) (Ussher et al., 2013).

Yet another prominent barrier in discussing sexuality-related issues in clinical practice involves the difference in how patients and HCPs perceive sexuality and intimacy (Hordern & Street, 2007 b). This was one of the major findings in a study by Hordern and Street (2007b) that included HCPs, mainly nurses and doctors in cancer and palliative care. While patients prefer open communication on topics of intimacy and sexuality after cancer diagnosis, medical professionals prefer to focus on combating the disease, thus largely enforcing a medical perspective, which results in the neglect of psychological, relational, or social components of sexual difficulties or sexual concerns after cancer (De Vocht, 2011; White et al., 2013; Ussher et al., 2013; Wang et al., 2018). Furthermore, according to Hordern (2008), implicit in this medical perspective is the belief that HCPs assume that they know what concerns the patient most and that the patient shares their one-dimensional focus. This medical perspective can also influence fellow coworkers, including nurses who often work in interdisciplinary cancer care teams (Annerstedt & Glasdam, 2019). Remarkably, however, there is some research that suggests that HCPs with a nursing, psychology, or social work background are more likely than medical staff to report discussing sexuality with patients (Ussher et al., 2013). However, in a range of settings, barriers to integration of sexuality into nursing practice continue to exist (Mcleod & Nahmo-Murie, 2016).

Dyer and das Nair (2013) concluded that, to improve addressing sexuality issues, three kinds of factors need to be considered: structural, organizational, and personal factors. All three types of factors are intricately linked and have a combined effect on HCPs' decision about whether to initiate a sexuality discussion with patients (Dyer & das Nair, 2013):

- Structural factors relate to aspects of wider society over which health professionals have less personal control, for example, political and economic aspects or dominant societal discourses such as the view of heterosexuality being the "norm."
- Organizational factors are, for example, policy of the health institution and training of staff and resources such as the possibility of referral pathways if needed.
- Personal factors relate to the knowledge, motivation, and personal attitude of the individual health professional.

Sociopolitical–cultural factors influence the attitude of all individuals, patients and HCPs alike, toward sexuality-related discussions in the context of clinical cancer care (Butcher et al., 2016; Williams et al., 2017). These attitudes are embedded in the dominant cultural discourses around sexuality and intimacy in every culture. Therefore, researchers have emphasized that this discussion may be more difficult for HCPs in certain cultures than in others, with consequent challenges related to SHC in cancer (Shell, 2007; Wazqar, 2020). For instance, one study among Canadian and African HCPs in cancer care found similarities in terms of discomfort with the topic of sexuality, but the African nurses reported substantial cultural barriers influencing sexuality discussions with cancer patients in comparison with Canadian nurses (Maree & Fitch, 2019).

Although it is well established that appropriate education and training of HCPs is important for effectively addressing sexuality-related issues in cancer care, very few studies have tested interventions to improve the competency of HCPs to deliver sexual health (Wang et al., 2015; Jonsdottir et al., 2016). In one study by Jonsdottir and colleagues (2016), HCPs working in cancer care, including nurses, were offered a training program on SHC, as part of a 2-year project, with the goal to improve communication and counseling on sexuality and cancer and integrate it into the daily care of cancer patients (Jonsdottir et al., 2016). Overall, this project had a certain impact with regard to a change in attitudes and important practice issues. Furthermore, those who participated in specific workshops discussed the issue more frequently than those who did not participate (Jonsdottir et al., 2016). The authors concluded that it is essential to provide ongoing educational opportunities in conducting such discussions as well as to address the issues from as many angles as possible and include structural, organizational, and personal factors (Jonsdottir et al., 2016).

1.8 Barriers and Facilitators among Nurses in Addressing Sexuality

The previously mentioned general pattern of HCPs having difficulty addressing sexuality in clinical care has also been identified among nurses (Ekstrom et al., 2016; Fennell & Grant, 2019; Papdopoulou et al., 2019). For instance, a recent review confirmed this pattern among nurses; the majority of them had a positive attitude toward discussing sexual health with patients, whereas 60% felt that such discussions were uncomfortable and that the nurses could only discuss sexual issues if the discussion was initiated by the patient (Nurjannah & Hartini, 2020). Similarly, another study found that over

90% of nurses were aware how disease and medical treatment may affect patient's sexuality, but the majority (60%) did not feel confident in their ability to address sexuality-related concerns (Saunamäki et al., 2010). Furthermore, a recent study in oncological nurses showed that support and communication related to sexual health had low priority from the perspective of clinical care, and the nurses' view on sexual health was influenced by medical logic with an emphasis on the physical aspects of sex and pharmacological treatment of sexual problems (Annerstedt & Glasdam, 2019).

The nursing profession has the potential to develop competency in addressing SHC, but this progress is slow, and the above-mentioned barriers are repeatedly observed in nursing practice. For instance, Fennell and Grant (2019) reviewed the current evidence on the influencing factors of provision of SHC by nurses. They reviewed 532 studies, including ten studies in nurses with diverse specializations, for example, within oncology. The review highlighted four main factors that influenced provision of SHC by nurses in clinical practice: lack of knowledge about sexual health, belief that sexual health is private and not a priority, nurses' own discomfort about sexuality-related discussions, and perceived barriers related to organizational factors.

In light of the above findings, further research is required to understand what support nurses need to be able to overcome obstacles that prevent them from raising sexual issues with their patients (Saunamäki et al., 2010; Olsson et al., 2012; 2014; Depke & Onitilo, 2015). Numerous factors influence nurses in developing and conducting sexuality-related interventions, and findings from several studies have provided valuable insight on many of these factors (Saunamäki et al., 2010; Olson, 2012; Williams et al., 2017; Annerstedt & Glasdam, 2019). For example, Williams and colleagues (2017) examined the influencing factors of provision of psychosexual care by nurses for women with gynecological cancer and identified five themes: the use of various strategies by nurses to aid conversations about sexuality, unique psychosexual needs of women, personal and professional experiences of nurses, system-related factors within the health care setting, and societal influences related to attitudes around sexuality. Not unexpectedly, one key important factor used by almost all nurses was the perceived necessity of first establishing a trusting and therapeutic relationship with women with cancer to promote a level of comfort when discussing sexual concerns (Williams et al., 2017).

Nurses with the required competency level and appropriate training in SHC are in an ideal position to offer interventions related to sexuality and intimacy for women with cancer and their partners. These qualifications are crucial because couple-based interventions are complex, for example, owing to the intimate nature of the subject of sexuality and intimacy and the need for understanding the couple as a unit. However, the full integration of sexuality-related interventions into cancer care has a long way to go, and the development of nurse-managed couple-based interventions is still in its infancy (White et al., 2007). Nevertheless, it is encouraging that nurses with higher education and those who have undergone further training more often provide sexual counseling than nurses with an undergraduate education and that nurses have participated in the development of multidisciplinary sexual health programs in cancer care (Varela & Bober, 2013; Krouwel et al., 2015; Walker et al., 2021). In this regard, it is also encouraging that recent research in breast cancer patients and their partners suggests that nurses were the most preferred cancer care provider for a discussion about sexuality (Albers et al., 2019).

Study findings suggest that nurses in cancer care that actually discuss sexual issues with patients seem to share certain characteristics such as being both knowledgeable and confident with the subject of sexuality, both professionally and personally (Olsson et al., 2012; Krouwel et al., 2015). This suggests that raising the topic of sexuality-related issues requires the cancer nurse to have not only knowledge and training in SHC but also maturity. Indeed, one study revealed that the few nurses who sometimes talked with patients about sexuality described personal maturity and comfort with their own sexuality as prerequisites for the discussions (Olsson et al., 2012). These findings are consistent with findings by Saunamäki et al. who studied the attitudes and beliefs of nurses toward discussing sexuality with patients and found that nurses who had a more positive attitude toward such discussions were older nurses and nurses with further education (Saunamäki et al., 2010).

Furthermore, above-mentioned professional confidence is consistent with findings by De Vocht (2011); she states that HCPs in cancer care need to view the patient as a person “including their emotional layer and a real life in the world ‘out there’ with everything that comes with it” (2011a, p. 95) so that they are able to use a person-oriented approach regarding SHC, which is preferred by patients (De Vocht, 2011). The above-mentioned professional outlook—seeing the whole person—has been used in the conceptualization of the so-called “stepped skills model” in delivering SHC in cancer (De Vocht et al., 2011). Team members in cancer care are trained to develop the competencies according to their corresponding roles and responsibilities. A team member with a minimum competency level (called “a spotter”) can, for example, provide minimal information about sexual side effects of cancer treatment. An HCP who can relate, within the professional role, to patients on a personal level and is confident and comfortable in discussing sexual and intimate issues assumes the role of a “skilled companion”. This is a patient-driven or patient-oriented model that acknowledges that patients and their partners are the true experts of their lives, including the sexuality aspect (De Vocht, 2011).

1.9 Advancement in Sexual Health Cancer Care

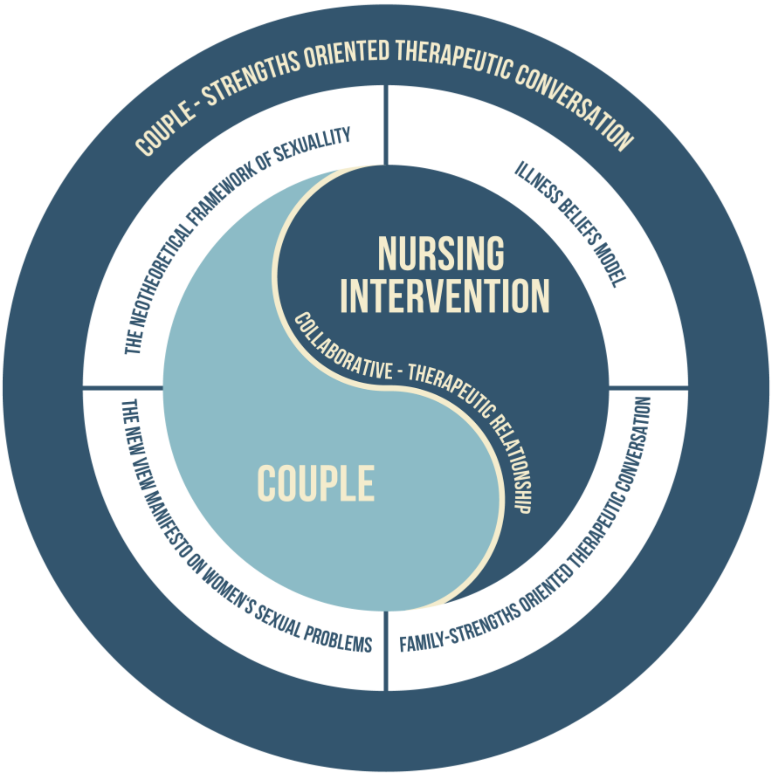
Three influential developments that positively affect the advancement of Sexual Health Cancer Care (SHCC) have emerged in the past decades. First, the creation of oncosexology as a new subspeciality of medical sexology is a significant milestone in advancing sexual health in cancer patients (Gianotten, 2003; Post et al., 2008; Mulhall et al., 2011; Gianotten & Reisman, 2017). This is an important step because it helps balance the two equally important issues of fighting the cancer (the medical perspective; adding years to life) and improving QOL (the illness narrative; adding life to years).

The second development includes the provision of specialized SHC programs for cancer survivors, in which multi-disciplinary teams offer comprehensive SHC (Krychman, 2006; Barbera et al., 2011; Tracy et al., 2016; Walker et al., 2021; Verrastro et al., 2020; Duimering et al., 2020; Nisbet et al., 2021). Various initiatives have been undertaken to offer specialized SHC and rehabilitation to cancer survivors. The sexual medicine program at the Memorial Sloan-Kettering Cancer Center in New York in the United States provides one of the most comprehensive SHC services available for all cancer survivors. The program has been developed around four cornerstones: clinical care, patient education and support, research, and education and training for health professionals (Krychman, 2006). In Canada, a specialized sexual health and rehabilitation clinic was started (Barbera et al., 2011) for survivors of gynecological cancer. One of the key lessons in developing and implementing that clinic was that strong and persistent leadership and dedicated personnel was required for its success. Likewise, a feasibility study of a sexual health clinic within cancer care was conducted in Canada (Tracy et al., 2016); this sexual health clinic was led by a cancer nurse who received a specialized training in sexual health. The clinic was found to be feasible, and welcomed by cancer survivors.

The third important development is the creation of an interdisciplinary network of clinicians, researchers, and healthcare professionals: the Scientific Network on Female Sexual Health and Cancer with the aim to promote sexual well-being in women and girls affected by cancer by advancing evidence-based education and practice (Goldfarb et al., 2013). This kind of networking is both timely and appropriate for HCPs, including nurses in clinical cancer care who wish to promote sexual health provision among women with cancer.

1.10 Theoretical Frameworks guiding the Couple-Strengths Oriented Therapeutic Conversation

It is important that nurses have access to theoretical frameworks built on a strong empirical data within the field of nursing when devising a new couple-based intervention. The couple-strengths oriented therapeutic conversation (CO-SOTC) intervention addressed in this doctoral thesis is the Family-strengths Oriented Therapeutic Conversation (FAM-SOTC) intervention, a family nursing intervention developed and tested in clinical settings (Gisladottir et al., 2017; Petursdottir & Svavarsdottir, 2019; Svavarsdottir & Gisladottir, 2019). The FAM-SOTC intervention is based on four models: the Calgary family assessment model (CFAM), the Calgary family assessment intervention Model (CFIM), the Illness Beliefs Model (IBM), and the resilience component of the Resiliency model (Wright & Leahey, 2013; Wright & Bell, 2009; McCubbin et al., 1996). The IBM, which is an advanced clinical model and a component of the FAM-SOTC intervention, forms the theoretical backbone of the CO-SOTC intervention. The background necessary for a comprehensive understanding of the multiple factors that shape women’s sexuality is provided by the Neo-theoretical Framework of Sexuality (Cleary & Hegarty, 2011) and the New View Manifesto, a theoretical framework offering a woman-centered understanding of sexual problems (Tiefer & Kaschak, 2001). The theoretical frameworks that guide the CO-SOTC intervention are described in subsequent sections.



- **The Family-Strengths Oriented Therapeutic Conversation** (FAM-SOTC) emphasizes the illness narrative, collaborative therapeutic relationship, and a systemic understanding of the couple's experience
- **The Illness Beliefs Model** centers around creating a context for changing beliefs, distinguishing illness beliefs, challenging constraining beliefs, and strengthening facilitating beliefs
- **The Neotheoretical Framework of Sexuality** underlines that all major domains of sexuality need to be assessed and understood
- **The New View Manifesto on women's sexual problems** offers a women's centered definition of women's sexual problems

Figure 2: The theoretical frameworks guiding the Couple-strengths Oriented Therapeutic Conversation (CO-SOTC) intervention

1.10.1 The Illness Beliefs Model (IBM)

The predominant theoretical framework for the CO-SOTC intervention is the IBM, which is a clinical practice model grounded in post-modernism, a worldview developed on the basis of the biology of cognition theory (Maturana & Varela, 1992) and grand theories such as general systems theory (von Bertanalaffy, 1968), communication theory (Watzlawick et al., 1974), cybernetic theory (Tomm, 1980), and change theory (Bateson, 1979) along with midrange theories from family nursing (Shajani & Snell, 2019;

Wright & Leahey, 2013). The clinical application of IBM in the intervention is described in Section 3.6.3.

1.10.1.1 Biology of Cognition Theory

The key component of Maturana and Varela's biology of cognition theory (1992) is the concept "structural determinism," which outlines that changes (that are always occurring whether or not we are aware of them) in a living system are determined by the present structure of that living system (such as a person). Otherwise, everyone would respond in exactly the same manner to the same stimulus (Maturana & Varela, 1992). Accordingly, an effective intervention is that for which a fit exists between the intervention offered by the nurse and the bio-psychosocial-spiritual structure of the woman and her partner (Wright & Bell, 2009). Furthermore, the nurse does not know beforehand whether the intervention will succeed in creating a fit (Leyland, 1998).

1.10.1.2 Grand theories

Apart from the biology of cognition theory, several grand theories influence the IBM, for instance, the general systems theory (von Bertanalaffy, 1968), which has been applied by health professionals for many years, including nurses, and has been highly influential with family social science frameworks (Smith & Parker, 2015; Shajani & Snell, 2019). Its principal focus is on discovering patterns between and among the interacting components of a system and moving the focus from individual parts to the whole system (Shajani & Snell, 2019). Applied to families or subsystem of families—the couple—this theory assumes that concerns, symptoms, or problems are the result of recurring patterns of interaction between family members. The nurse that applies a systems theory approach uses three approaches in therapeutic conversations with couples; hypothesizing, circularity and neutrality (Shajani & Snell, 2019).

Other grand theories influencing IBM are communication theory, cybernetic theory, and change theory (Watzlawick et al., 1974; Tomm, 1980; 1987; 1988; Bateson, 1979). Communication theory places an emphasis on how individuals communicate and interact with each other (Watzlawick et al., 1974). Its key concepts are that all communication—both verbal and non-verbal—is meaningful and is always observed on two levels: what is being said (content) and what the communication reveals about the nature of the relationship (Shajani & Snell, 2019). In addition, communication theory embraces the idea that dyadic relationships exhibit varying degrees of symmetry and complementarity, which are useful in identifying interaction patterns (Jackson, 1973). Cybernetic theory (Tomm, 1980; 1987; 1988) postulates that family systems can self-regulate via feedback loops that exist simultaneously at several system levels within families. The components of IBM support this self-regulation aspect of family systems. Finally, the change theory (Bateson, 1979) describes how and why a desired change is expected to happen (Shajani & Snell, 2019). Bateson offered the valuable idea that, with regard to perception of change, the mind can only perceive information of differences over time. This idea fits well together with Maturana and Varela's (1992) emphasis that human systems (persons) bring forth reality through language and that change is determined by the present structure of that human system.

1.10.2 Theoretical Frameworks for Sexuality

The use of systemic and psychodynamic theories and theories reflecting social constructionism have been useful in the exploration of sexual expression, sexuality-related problems, and therapy (Doan, 2004; Jurich, 1998; Kleinplatz, 2012; Tiefer, 2006; Woody, 1992, Træen, 2008). The primary reason is the fact that sexual expression is a system of communication and are understood only within relational and situational contexts and with respect to the prevalent attitudes in society toward sexuality. Sexual expression and sexual problems are embedded within the sexual relationship. Therefore, the smallest, most realistic unit to work with in any therapeutic effort related to sexual expression is preferably the couple rather than the individual (Jonsdottir, 2009).

The CO-SOTC intervention utilizes the neo-theoretical framework of sexuality (Cleary & Hegarty, 2011). When trying to understand the ramifications of an illness on sexuality, focusing only on the sexual response (sexual function; desire, arousal, and orgasm), which primarily involves a physical component, is considered limited according to the neo-theoretical framework. It is necessary to also address the other two major dimensions of sexuality: sexual relationship (communication and intimacy), and sexual identity (body image, sexual esteem, and sexual self-schema. This framework is also valuable for preparing the evidence-based educational information that is offered to the couple after the conclusion of the first session. When all domains of the neo-theoretical framework of sexuality are addressed, it increases the likelihood of a thorough understanding of what comprises successful adjustment of sexual life after cancer.

In addition to cancer diagnosis and treatment, numerous interrelated factors may influence the sexual life of women with cancer. The CO-SOTC intervention has been primarily developed to address sexual changes after cancer; therefore, it is necessary to consider these factors when preparing for the therapeutic conversations with the couple. The New View Manifesto on women's sexual problems extends beyond the Neo-theoretical framework of understanding on how women's sexuality may be influenced and what may become a sexual problem for them (Tiefer & Kaschak, 2001). In this manifesto, a sexual problem is defined as dissatisfaction with any emotional, physical, or relational attribute of the sexual experience, which may arise in one or more interconnected aspects of women's sexual lives: (a) sociocultural, political, or economic factors, such as inadequate sex education or lack of SHC services; (b) partner and relationship factors such as distress resulting from betrayal or partner abuse; (c) psychological factors such as mistrust due to past traumatic experiences or depression; and (d) medical factors such as side effects of medications or medical conditions affecting the body. The manifesto is a theoretical framework and classification system for women's sexual problems, which is grounded in sexual rights and provides an all-encompassing framework for women's sexuality. According to the World Association for Sexual Health (2008), the sexual rights of all individuals must be respected, protected, and fulfilled so that sexual health can be attained and maintained.

1.11 Context and Rationale for the Study

Nurses with suitable competency levels are in an ideal position to provide interventions for sexuality-related concerns, and have an important role in promoting sexual health (International Family Nursing Association, 2017; Papadopoulou et al., 2019). The importance of promoting sexual health is highlighted in the “Sexual Health for the Millennium” declaration, in which eight millennium development goals are specified. These goals emphasize, for example, that to achieve sexual health, all individuals must have access to sexual health information and services, and because sexual concerns and problems impact QOL, it is crucial to identify, prevent, and treat sexual concerns and problems (World Association for Sexual Health, 2008).

However, the millennium development goals to support sexual health in women with cancer and their partners have not received sufficient attention in cancer care, with various consequences. For instance, as perceived partner support and sexual intimacy is shown to moderate cancer-related stress related to sexual changes in women with cancer, this inattention to interventions for couples results in missed opportunities that could reduce cancer-related stress in couples facing cancer. Taken together, this thesis demonstrates the need for generating and testing new evidence that nurses can use in advancing sexual health in cancer care.

This doctoral thesis has two major components. First, it presents the findings of a systematic literature review of the characteristics of couple-based intervention studies addressing sexuality following cancer care, which indicate substantial gaps in nurse-managed interventions for sexual concerns among women with cancer and their partners. Second, it describes the development and testing of a novel theoretically based couple-based intervention that addresses sexual changes in women with cancer and their intimate partners. Outcome measures assessed changes in sexual concerns, illness interference on daily life in women with cancer, and confidence about illness beliefs related to sexuality and intimacy following cancer and relationship quality in women and intimate partners.

The overall findings of this intervention study may help in addressing the evident gaps in providing appropriate interventions for women with cancer and their intimate partners and thereby encourage the promotion of sexual health in cancer care.

2 Aims

The overall aim of the thesis was twofold: to describe the characteristics of couple-based intervention studies that address sexuality after cancer and to develop and test the effectiveness of a novel couple-based intervention (CO-SOTC) for women with diverse types of cancer and in active cancer treatment and their intimate partners. This thesis is based on three studies published as three research papers (Figure 1, Table 2).

> The specific aims of the three studies were as follows:
>
> Study I (systematic review): This study aimed to explore, describe, and synthesize the characteristics of couple-based intervention studies addressing sexuality following cancer; to determine areas for improvement for research in this area; and to discuss how the results of the review may benefit clinical care (Paper I).
>
> Study II (quasi-experimental single-group pre-post-follow-up design): This study aimed to evaluate the effectiveness of the CO-SOTC intervention among women undergoing cancer treatment regarding concerns related to sexual adverse effects of cancer treatment, sexual concerns related to intimate partners, and concerns related to communication with healthcare providers about sexual issues and to assess the changes in illness intrusiveness in daily life, specifically, in illness intrusiveness on intimacy (Paper II).
>
> Study III (quasi-experimental single-group pre-post-follow-up design): This study aimed to evaluate the effectiveness of the dyadic CO-SOTC intervention on confidence about how illness beliefs affect sexuality and intimacy and on perceived relationship quality among women in active cancer treatment and their intimate partners (Paper III).

Table 2: Aims, designs, variables, data sources, and analysis of Studies I, II, and III

	Study I	Study II	Study II
Aim	To explore, describe and synthesize the characteristics of couple-based intervention studies addressing sexuality following cancer	To evaluate the effect of the CO-SOTC intervention on sexual concerns among women undergoing cancer treatment and to assess the changes in illness intrusiveness in daily life, specifically with respect to illness intrusiveness on intimacy	To evaluate the effect of the CO-SOTC intervention on confidence about how illness beliefs affect sexuality and intimacy, and on perceived relationship quality among women in active cancer treatment and their intimate partners
Design	Systematic literature review	Quasi-experimental single-group pre-post-follow-up trial	Quasi-experimental single-group pre-post-follow-up trial
Study eligibility criteria (Study I)	Studies that included: Adult females and males with any type of cancer and their intimate partners, and in any phase of cancer after diagnosis, all couple-based interventions with the possibility of integration into sexual health care in cancer, and including different modes of delivery, studies reporting at least one measure presenting one of the three main sexuality components of the neotheoretical framework		
Variables (Study II and III)		CO-SOTC intervention (independent variable) Dependent variables: Women's sexual concerns related to sexual adverse effects associated with cancer treatment and sexual concerns relating to their partners, concerns related to communication with healthcare providers in relation to sexual concerns, illness interference with meaningful activities or interests in daily life (relationship with one's intimate partner and sex life, social relations and personal development, respondents' health, work, active recreation, and their financial situation	CO-SOTC intervention (independent variable) Dependent variables: Confidence about facilitating beliefs and constraining beliefs regarding sexuality and intimacy, relationship quality
Data	Exploratory search in 3 databases (Cochrane and JBI database, Google Scholar), comprehensive electronic literature search in PubMed, CINAHL and PsychINFO databases, citation tracking and inspection of	Questionnaire answers of woman with cancer (N=60) before receiving the intervention, after receiving two sessions, and after the third and final follow-up session	Questionnaire answers of woman with cancer (N=60) and their intimate partners (N=60) before receiving the intervention, after receiving two sessions, and after the third and final follow-up session

	reference lists of included study articles, contact to		
Analysis	Narrative analysis guided by following checklists for quantitative research evidence in the Joanna Briggs Institute (JBI) Reviewer's Manual: PRISMA statement; Preferred Reporting Items for Systematic Reviews and Meta-Analyses, MAStARI; JBI-Meta Analysis of Statistics Assessment and Review Instrument to evaluate risk bias in relation to study design and application of its method, TIDieR; The template for intervention description and replication to evaluate the reporting of interventions	Repeated measures ANOVA A paired t test Greenhouse-Geisser formula to correct deviation from sphericity Eta squared to assess effect size	Repeated measures ANOVA A paired t test Greenhouse-Geisser to correct the violations of sphericity Eta squared to assess effect size F-test to assess dyadic difference scores

2.1 Research question in Study I

The following research question was investigated in Study I:

"What are the characteristics of couple-based intervention studies in existing quantitative research that aim to enhance sexual function, sexual relationship, and sexual self-concept of patients with cancer and their partners?"

2.2 Hypotheses and Research question in Study II

Hypotheses:

On the basis of a literature review and the theoretical frameworks that guided the thesis, it was hypothesized that (1) women diagnosed with cancer in general and (2) with breast cancer in particular who are in active cancer treatment and receive the dyadic CO-SOTC intervention will report significantly lower concerns over time in relation to

a. Sexual adverse effects of cancer treatment
b. Sexual concerns related to intimate partners
c. Concerns related to communication with healthcare providers about sexual issues

Research question of Study II:

“Do any differences emerge over time (at baseline, after the second session, and after the 3-month booster session) in the degree to which illness intrudes in daily life, particularly with respect to intimacy and sex life, of women undergoing active cancer treatment and diagnosed with cancer in general and breast cancer in particular?”

2.3 Hypotheses and Research question in Study III

Hypotheses:

On the basis of the treatment literature review and the theoretical frameworks that guided this study, it was hypothesized that

1. Women diagnosed with cancer who are undergoing active cancer treatment will report a) increased confidence about how illness beliefs (facilitating or hindering beliefs) affect sexuality and intimacy and b) higher relationship quality after the dyadic CO-SOTC intervention.

2. Intimate partners will report a) increased confidence about how illness beliefs (facilitating or hindering beliefs) affect sexuality and intimacy and b) higher relationship quality after the dyadic CO-SOTC intervention.

The following research question was addressed:

“Is there a significant difference between women’s and their partners’ confidence about how illness beliefs (facilitating or hindering beliefs) affect sexuality and intimacy (dyadic difference scores) and perceived relationship quality at each time point (at baseline, after the second session, and after the 3-month booster session)?”

3 Patients and Methods

3.1 Design of Studies I, II and III

Study I was a systematic literature review with the aim of assessing the characteristics of couple-based intervention studies that addressed sexuality following cancer (Table 2). The study findings are reported in paper I, including five supplementary tables available online (Jonsdottir et al., 2018). Study II had a quasi-experimental single-group pre-post-follow-up design and aimed to assess the effectiveness of a nurse-managed CO-SOTC intervention regarding (a) women's sexual concerns and (b) illness intrusiveness of cancer on women's daily life and intimacy (Table 2). Study III also had a quasi-experimental single-group pre-post-follow-up design and aimed to examine the effects of a nurse-managed dyadic CO-SOTC intervention on (a) the confidence about how illness beliefs (facilitating or hindering beliefs) affect sexuality and intimacy and (b) the perceived relationship quality among women in active cancer treatment and their intimate partners. (Table 2).

3.1.1 Search Methods in Study I

Multiple search methods were used to identify studies eligible for the systematic literature review:

- Exploratory search in three databases (Cochrane database, Joanna Briggs Institute [JBI] database, and Google Scholar) with extensive free-text terms without restrictions on publications period, for instance, "sexuality," "intimacy," "intervention," "couple," and "cancer"
- Comprehensive electronic literature search in PubMed, CINAHL, and PsychINFO databases where search terms were chosen after running a sensitivity test on various free-text sentences, MeSH terms, and key words
- Review of the reference lists of included studies

In addition, more papers were identified by doing citation tracking of included articles; authors of published study protocols were contacted to inquire whether their study had been completed and were asked to share their preliminary results. In situations where additional information was needed for the analysis of the data, primary researchers were contacted.

The eligibility criteria for including studies were as follows:

- All studies on adult (≥18 years) cancer survivors (all types of cancer and in any phase of cancer after diagnosis) and their partners (both heterosexual and homosexual couples).
- All quantitative couple-based intervention studies reporting at least one of the major domains of sexuality according to the neo-theoretical framework (Cleary & Hegarty, 2010).
- All types of couple-based interventions with the possibility of integration into SHC and including different modes of delivery such as face-to-face on site, by telephone, web based, group sessions.
- Studies in English and published from January 1, 2009, to December 31, 2016.

Studies focusing only on medical and invasive interventions were excluded. In addition, studies published before January 1, 2009, were excluded because they had already been reported in other reviews (Brotto et al., 2010; Chambers et al., 2011; Scott & Kayser, 2009; Taylor et al., 2011).

3.1.2 Reporting of Study I

The reporting of the systematic literature review was guided by checklists for quantitative research evidence in the JBI Reviewer's Manual (Joanna Briggs Institute, 2014) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—PRISMA statement (Liberati et al., 2009). JBI–Meta Analysis of Statistics Assessment and Review Instrument (MAStARI) was used to assess risk bias in relation to study design and application of its method. The template for intervention description and replication was used to assess the reporting of interventions (Hoffmann et al., 2014).

A pronounced difference in outcome measures and various methods across intervention studies that were included in the systematic literature review precluded quantitative synthesis. Therefore, the findings were summarized narratively in paper I. Five tables describing the main results (including an extensive matrix describing the characteristics of couple-based interventions for sexuality following cancer) were included in an online supplementary file, whereas a shorter version of three of those online tables was presented in Paper I.

3.2 Design, Setting, Intervention, and Participants in Studies II and III

The CO-SOTC intervention study was designed and performed as a randomized controlled trial with a wait-list control group (receiving delayed intervention; Figure 3). Participants were allocated by simple randomization to experimental group or wait-list control group. However, considerable differences in clinical and demographic variables were observed between the experimental group and the control group. Therefore, the groups were merged into one group and the data were analyzed considering that it was a repeated measure, quasi-experimental single-group pre-post-follow-up study design, assessing the data of women with cancer and their partners over three time points (at baseline, after the second session, and after the 3-month booster session) over 3 months.

CONSORT
TRANSPARENT REPORTING of TRIALS

Fig. 3 CONSORT Flow Diagram

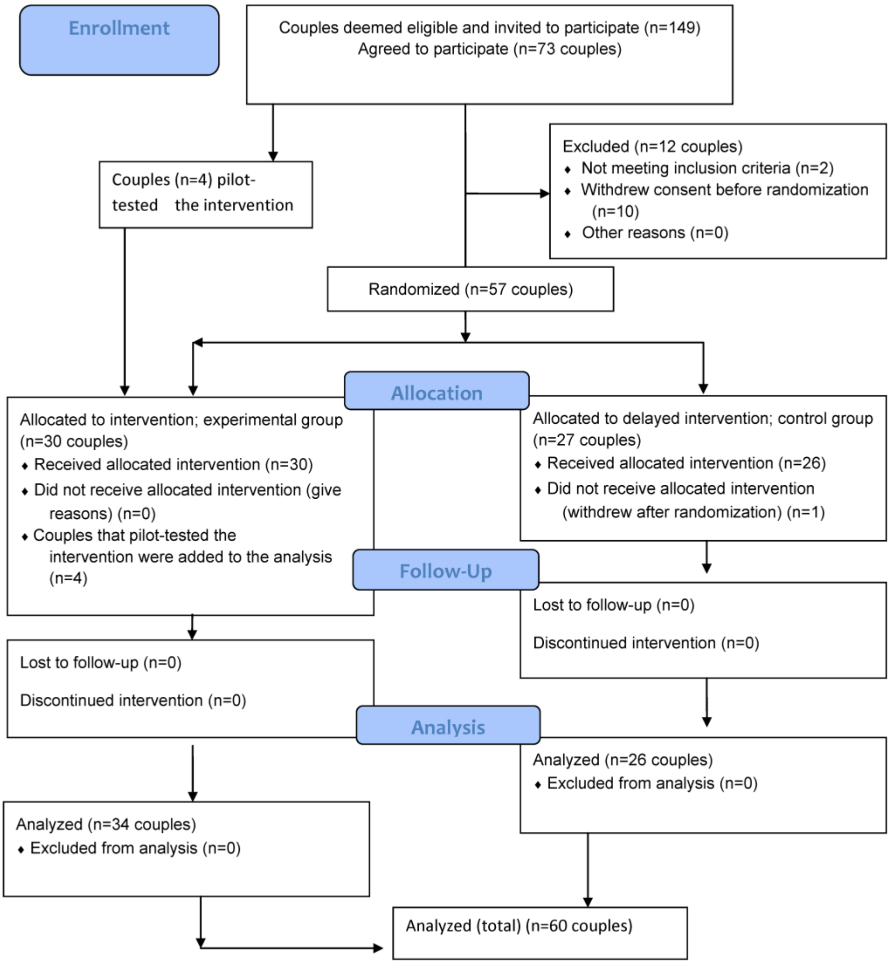


Figure 3: Consort Flow Diagram

The CO-SOTC intervention was developed at the School of Health Sciences, Faculty of Nursing, at the University of Iceland in 2015–2016 and registered at clinicaltrials.gov (entry NCT03936400).

3.3 Development of Therapeutic Conversation with Females Diagnosed with Cancer and Their Partners.

The theoretical models guiding the CO-SOTC intervention development and session components are described in Section 1.10. The full details of the intervention protocol are presented in Appendix I.

Study participants were recruited at Landspitali—The National University Hospital of Iceland, where female patients were approached by clinical nurses and radiologists. Eligible participants were women who met the following criteria: 18 years or older, diagnosed with cancer (any type and stage of cancer), in active cancer treatment, in an intimate relationship, and able to effortlessly write and speak the Icelandic language.

The CO-SOTC intervention was delivered in a neutral setting outside the Landspitali National University hospital between 2017 and 2019. Sixty women and their intimate partners (N = 120) participated in the intervention.

Women characteristic	Mean	%	Median	SD	Range
Age (years)					
Total (n=60)	52.0		53.5	10.74	30–70
Breast (n=46)	52.6		54.0	10.48	33–70
Other types of cancer (n=14)	50.3		52.0	11.75	30–67
Marital status					
Married (n=53)		88.3			
Cohabitation (n=7)		11.7			
Length of present relationship (years) (n=59)	25.1		24.0	13.32	2–50
Type of cancer					
Breast (n =46)		76.7			
Blood (n=7)		11.7			
Lung (n=3)		5.0			
Gastrointestinal (n =3)		5.0			
Brain (n=1)		1.6			
Time since diagnosis (months)	12.0		6.0	19.1	1–115
Previous cancer diagnosis					
Yes (n=11)		18.6			
No (n=48)		81.4			
No answer (n=1)					
Stage					
Local (n=40)		72.7			
Advanced (n=15)		27.3			
No answer (n=5)					
Treatment					
Surgery (n=46)		76.7			
Chemotherapy (n=45)		75.0			
Radiation therapy (n=45)		75.0			
Endocrine therapy (n=27)		45.0			
Other treatment (n=6)		10.0			
Comorbidity (n=23)					
Arthritis (n=9)		39.1			
Hypertension (n=7)		30.4			
Mental illness (n=4)		17.4			
Lung disease (n=2)		8.7			
Cardiovascular disease (n=1)		4.3			
Gastrointestinal disease (n=1)		4.3			
Diabetes (n=1)		4.3			
Other (n=6)		26.1			
Currently on sick leave					
Yes (n=37)		62.7			
No (n=22)		37.3			
No answer (n=1)					
Education completed					
Primary school education (n=3)		5.0			
Secondary school education (n=13)		22.1			
University level education (n=43)		72.9			

Table 3: Characteristics of participants

Partner characteristics				
Age (years)				
Total (n=60)	54.3		10.78	30-75
Employment				
Works overtime – two jobs (n=17)		28.8		
Full time employed (n=30)		50.8		
Part time employed (n=4)		6.8		
Disabled (n=5)		8.5		
Pensioner (n=53)		5.1		
Currently on sick leave				
Yes (n=3)		5.4		
No (n=53)		94.6		
Education completed				
Primary school (n=5)		9.8		
Secondary school (n=24)		47.0		
University level (n=30)		43.2		

The doctoral student, a nurse with a postgraduate degree in sexuality education and training in systemic therapy and family system nursing and authorized as a specialist in clinical sexology delivered all the sessions in the intervention to all 60 couples. After completing the first session, the couples were provided access to evidence-based information (references provided in Appendix II) on a secure website that was created for the study and hosted by Landspitali—The National University Hospital of Iceland (Appendix II). The webpage was 40 pages long and included information about the most common sexual side effects of cancer treatment, such as vaginal dryness, loss of sexual desire, and pain related to sexual activity and the possible solutions.

All 60 couples provided at least one preintervention and two postintervention assessments over a 3-month period. The couples who were randomized to the wait-list control group provided two preintervention assessments before receiving the delayed intervention. Each individual couple completed all three sessions of the CO-SOTC, resulting in a 100% adherence rate.

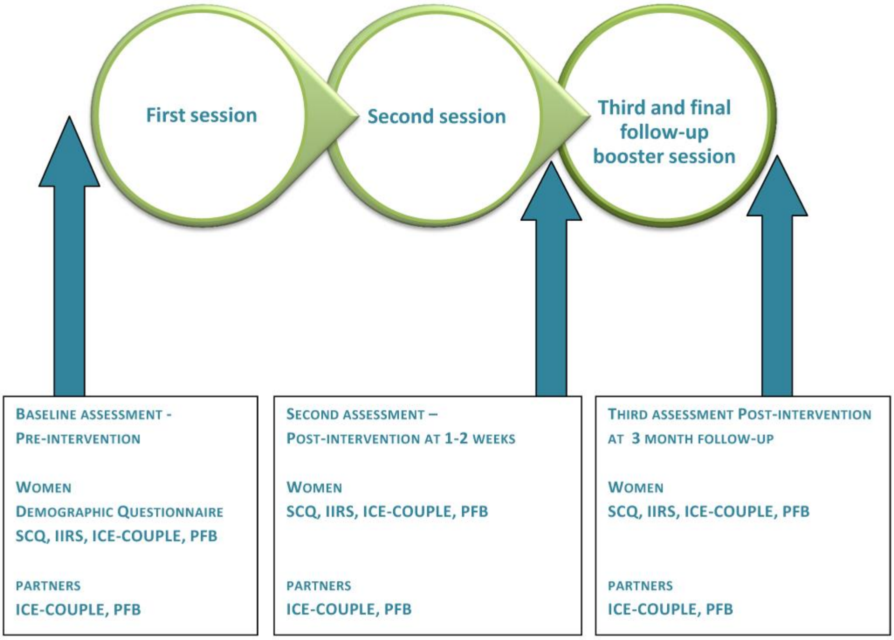


Figure 4: Timeline of Intervention delivery and Assessments

3.4 Outcomes and Quantitative Assessments Made in Studies II and III

3.4.1 Outcomes and Quantitative Assessments Made in Study II

The outcomes were as follows: 1) women’s sexual concerns related to sexual adverse effects associated with cancer treatment, 2) women’s sexual concerns related to their partners, 3) communication with healthcare providers in relation to women‘s sexual concerns, and 4) illness interference with meaningful activities or interests in daily life, measured preintervention at baseline (T1), postintervention after receiving two sessions of the intervention (T2), and after follow-up booster session after 3 months (T3).

In Study II, the Sexual Concerns Questionnaire (SCQ; Abbott-Anderson, 2015) and Illness Intrusiveness Rating Scale (IIRS; Devins, 2010) were administered to the participating women prior to the first session at baseline (T1), postintervention (T2), and after the follow-up (booster session; T3).

1. **Sexual Concerns Questionnaire (SCQ)**

The SCQ was derived from the Sexual Concerns Questionnaire-Gynecological Cancer (SCQ-GC) questionnaire that assesses sexual concerns after gynecological cancer diagnosis. Only a slight adaptation was necessary to ensure its applicability to women diagnosed with any type of cancer.

The SCQ is a 42 question 5-point Likert scale (0 = not concerned at all, 5 = extremely concerned) cancer-specific questionnaire reflecting an integrative biopsychosocial approach and therefore feasible to use in this study (Abbott-Anderson, 2015; Abbott-Anderson & Kwekkeboom, 2012). The SCQ contains four subscales and two open-ended questions about other sexual concerns or other issues the participant may want to share.

The first subscale is a 22-item scale that measures sexual concerns related to sexual adverse effects associated with cancer treatment, such as diminished interest in sexual activity or associated pain. The second subscale is a 10-item scale that measures the women's sexual concerns related to their partners, such as worries that their partners do not find them sexually attractive or their experiences of not feeling emotionally close to their partners. The third subscale includes five items concerning communication with healthcare providers in relation to sexual concerns, including the healthcare providers' perceived discomfort in discussing sexuality. Because the fourth subscale of the questionnaire is aimed at women currently without partners, it was omitted from this study. The participating women were required to answer how concerned they were since the cancer treatment began on items included in each subscale. A total score was calculated for each subscale. Higher scores indicate greater concerns.

A previous study reported Cronbach's α of 0.78 for the entire questionnaire and test–retest reliability of 0.89 and 0.99 at 2 weeks and 3–4 weeks, respectively. Cronbach's α was 0.89, 0.83, and 0.93 for the first, second, and third subscale, respectively (Abbott-Anderson, 2015).

2. Illness Intrusiveness Rating Scale (IIRS)

The IIRS is a 13-item self-report questionnaire with a 7-point Likert scale (1 = not very much and 7 = very much) and three subscales measuring the extent to which illness interferes with meaningful activities or interests in daily life (Devins, 2010). The first subscale—social relations and personal development— contains six questions about family relations, other social relations, passive recreation (such as reading), self-expression, religious expression, and community and civic involvement. The second subscale—intimacy—contains two questions about the relationship with one's intimate partner and sex life. The third subscale—instrumental—comprises four questions about the respondents' health, work, active recreation (for instance, physical exercise), and their financial situation. A total score is calculated by summing the ratings of all items, and a mean is calculated for each subscale. The lower the sum of scores in a subscale, the lesser is the illness intrusiveness in that domain.

The IIRS has been used among various patient groups including breast cancer patients and has been found to be valid and reliable (Devins, 2010). For the Icelandic version of the questionnaire, Cronbach's α was 0.933 for the entire questionnaire, 0.901 for the subscale social relations and personal development, 0.793 for the intimacy subscale, and 0.842 for the instrumental subscale (Jonsdottir et al., 2015).

Demographic Questionnaire

The women who participated in the CO-SOTC intervention answered all four main questionnaires (SCQ, IIRS, ICE-Couple, PFB) and a demographic questionnaire. The demographic questionnaire included 16 questions covering topics such as age of the woman and her partner, marital status, length of intimate relationship, education completed, work, sick leave, time since cancer diagnosis, stage of cancer, type of cancer treatment, and comorbidities (Table 3).

A single-item screener for self-reported sexual problems proposed by the PROMIS group and the Scientific Network on Female Sexual Health and Cancer (FSHC) was added as the last question in the demographic questionnaire (Flynn et al., 2015). The rationale behind the recommendation of the PROMIS group and FSHC network is that when individuals are asked about these issues as a global yes/no style question, 1 in 10 women reported having a sexual problem or concern (Flynn et al., 2015). However, according to Flynn and colleagues, when women are asked to report specific sexual problems or concerns, approximately 1 in 2.5 women reported at least one sexual problem.

The single-item screening question asks the participants whether they experienced any of eight different sexual problems or concerns for 3 months or more in the past 12 months, for example, "You wanted to feel more interest in sexual activity," "You had pain during or after sexual activity," "Some other sexual problem or concern," and "No sexual problems or concerns." The participating women were asked to check all items that applied.

3.4.2 Outcomes and Quantitative Assessments made in Study III

The outcomes used were as follows: 1) confidence about how the illness beliefs affect sexuality and intimacy with regard to cause, control, effect, suffering, and support and 2) relationship quality, measured preintervention at baseline (T1), after receiving two sessions of the intervention (T2), and after the 3-month follow-up (booster) session (T3).

In Study III, the ICE-Couple outcome measure (Svavarsdottir and Jonsdottir, 2016) and Partnership Questionnaire (Partnerschaftsfragebogen [PFB]; Hahlweg, 1996) were administered to the participating women and their partners at T1, T2, and T3.

1. Ice-Beliefs Questionnaire for Couples (ICE-Couple)

The ICE-Couple outcome measure (Svavarsdottir and Jonsdottir, 2016) was developed specifically for this study on the basis of the Ice-Beliefs Questionnaire (ICE-Beliefs), originally created by one of the authors (Svavarsdottir, 2011, 2014). The original ICE-Beliefs questionnaire is a self-report measure of an individual's beliefs about illness and was derived from the IBM (Wright & Bell, 2009).

The ICE-Couple measures a couple's perception of how both individuals deal with changes in sexuality and intimacy following cancer diagnosis and treatment. The questionnaire was used to measure changes in facilitating or hindering beliefs following the CO-SOTC intervention. In the context of sexual changes following cancer, hindering beliefs are beliefs that obstruct finding solutions to distress or concerns (e.g., "All affectionate touching is off limits because sexual intercourse is no longer possible"), whereas facilitating beliefs are beliefs that open a possibility for a diversity of solutions (e.g., "We can learn to live with changes in our sex life and still be intimate").

Participants report the degree to which they believe the illness affects sexuality and intimacy with regard to cause, control, effect, suffering, and support on seven items using a 5-point Likert scale (1 = never to 5 = always) and eight open-ended questions. Higher scores indicate more confidence about facilitating beliefs versus constraining beliefs regarding sexuality and intimacy. The instrument has been found to be both valid and reliable (Cronbach's α = 0.780–0.789; Gisladottir and Svavarsdottir, 2017). Good internal consistency was observed for the ICE-Couple measure in the present study as Cronbach's α was 0.82 for the women and 0.80 for their intimate partners.

2. Partnership Questionnaire (PFB)

The PFB is a 30-item outcome measure that assesses relationship quality (Hahlweg, 1996). The PFB contains three subscales (conflict, tenderness, and communication) with ten items each: subscale Q (quarreling or conflict), T (tenderness), and C (communication). For instance, one of the quarreling subscale items is “He/she keeps bringing up mistakes that I have made in the past;” a tenderness item is “He/she makes an effort to be attentive to my wishes and fulfills them when the opportunity arises,” and a communication item is “He/she shares his/her thoughts and feelings openly with me.”

All scale items of the PFB are scored using a 4-point Likert scale (Never/very rarely [0], rarely [1], often [2], very often [3]). The PFB can be used to assess the relationship quality using subscales; the subscale scores are combined to generate a PFB total score (Cronbach’s α = 0.95). The total score can be used to reliably differentiate between distressed and non-distressed couples and monitor changes resulting from couple therapy (Total PFB-T score = (30 − Scale Q) + Scale T + Scale C). A total PFB score of <53 is regarded as a threshold for low marital quality. Good to very good reliability coefficients were confirmed for the three subscales (conflict behavior: α = 0.88, tenderness: α = 0.91, communication: α = 0.85, total scale: α = 0.93; Hinz et al., 2001; Kliem et al., 2012.). In the present study, Cronbach’s α for the participating women and their partners was, respectively, 0.85 and 0.89 for conflict behavior, 0.89 and 0.88 for tenderness, 0.89 and 0.84 for communication, and 0.93 and 0.93 for the whole scale.

3.5 Data analysis of Studies II and III

In Studies II and III, the Statistical Package for the Social Sciences (SPSS) version 26.0 was used for descriptive statistics and statistical analyses (IBM Corp). Descriptive statistics were used to report background variables in Studies II and III.

In both Studies II and III, repeated measures ANOVA was used for an overall assessment of outcome differences over time. Kolmogorov-Smirnov test was used to assess normality before the intervention, at baseline. Effect size was assessed with Eta squared (η2) where a value above 0.01, 0.06, and 0.14 denotes a small, intermediate, and large effect, respectively (Field, 2009).

Sample size requirements were based on the dyadic analysis, which showed that, considering repeated measures tests of mean differences and an average effect size of 0.5 (based on Cohen’s D), the sample size (number of couples) required for 80% and 90% statistical power was 27 and 36, respectively (Kraemer, 1987). The number of participating couples was 60, which is well beyond the minimum number of couples required for adequate statistical power.

In Study II, the treatment effect over the three time points was assessed using an F test, and a paired t test was used to further compare the outcomes of the CO-SOTC intervention between measurements from T1–T2, and T2–T3. Mauchly's test generally showed deviations from sphericity for the outcomes of both the SCQ and IIRS scales. Therefore, the Greenhouse-Geisser formula was used to correct the deviations from sphericity. The significance value for the difference between means was set at $p < 0.05$.

In Study III, the treatment effect over the three time points was assessed using an F test, and a paired t test was used to further compare the outcomes of the CO-SOTC intervention between measurements from T1–T2, T2–T3, and T1–T3. The assumption of sphericity was tested using Mauchly's test of sphericity, which showed deviations from sphericity for the outcomes of both ICE-Couple and PFB. Therefore, the Greenhouse-Geisser formula was used to correct the deviations from sphericity. Dyadic difference scores between the participating women and their intimate partners were computed to assess whether the couples differed on the outcome measures over time, using an F test with p values set at <0.05.

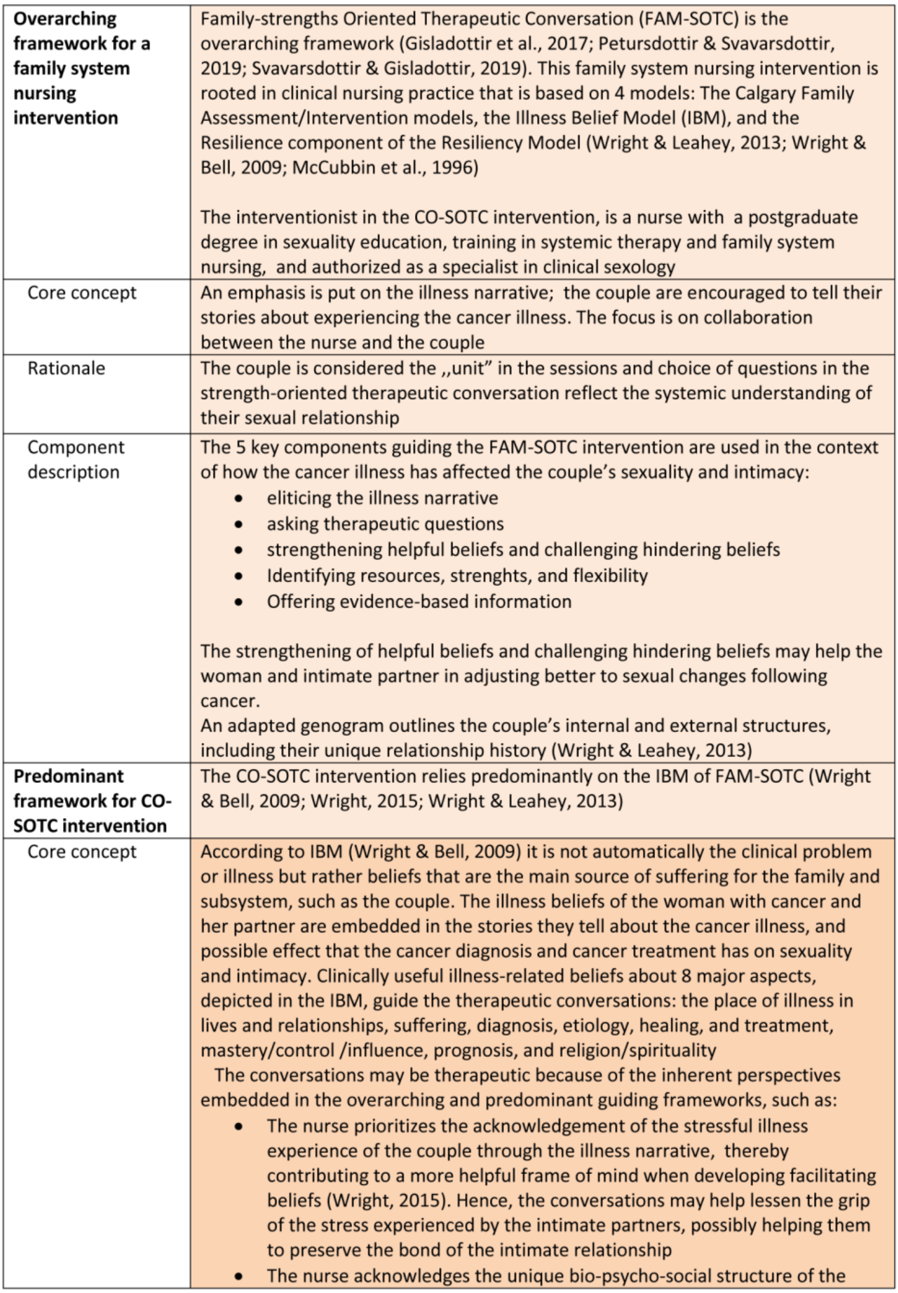
3.6 The Couple-strengths Oriented Therapeutic Conversation Intervention (CO-SOTC)

3.6.1 Components of CO-SOTC intervention

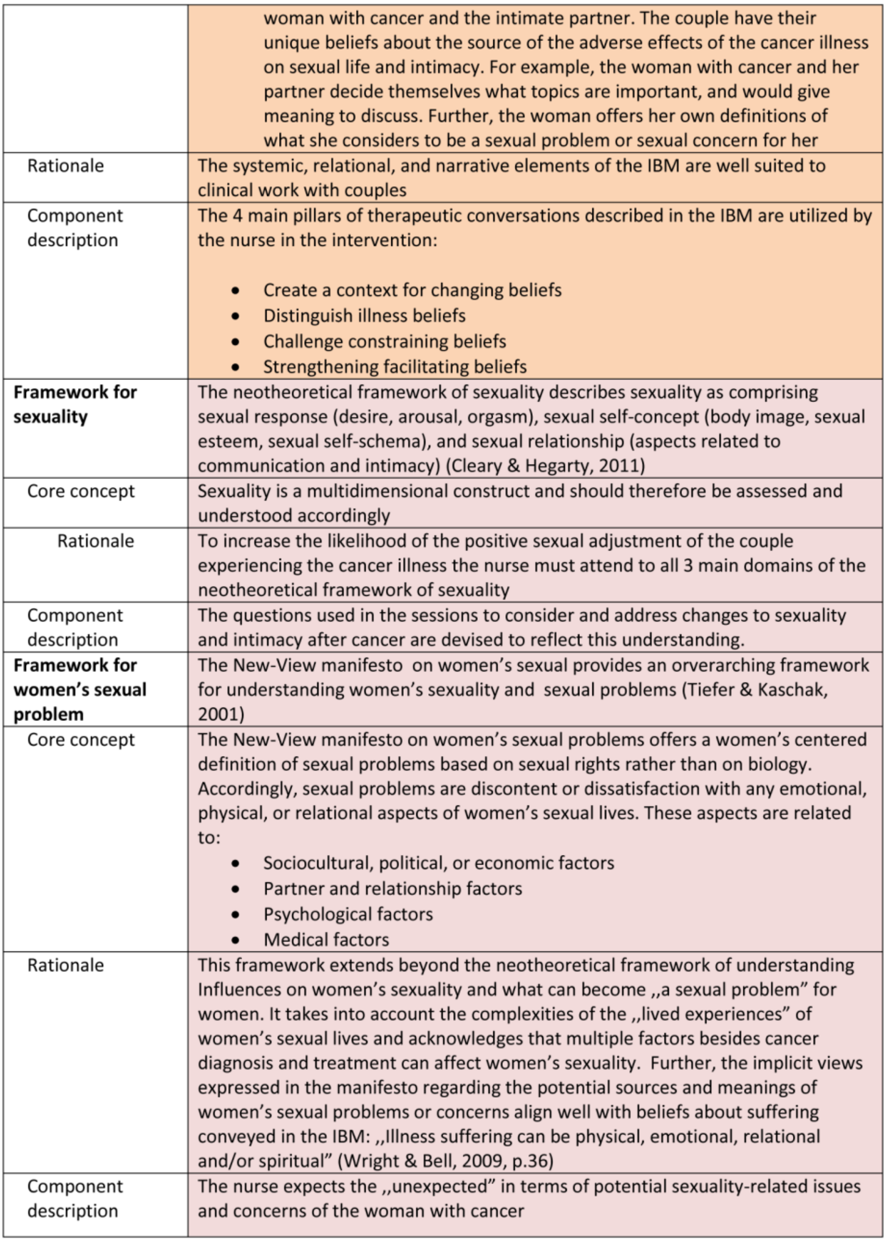
The CO-SOTC intervention has two components: strengths oriented therapeutic conversations (see Appendix I; CO-SOTC intervention protocol) and information provision (see Appendix II; Evidence-based educational information available on the website).

The CO-SOTC intervention consists of three strengths oriented therapeutic conversations provided in three 50 min face-to-face sessions with the participating women with cancer and their partners at a neutral setting outside the Landspitali hospital. The first two sessions were scheduled 1–2 weeks apart, and the final session was conducted approximately 3 months after the first session. A maximum period of 2 weeks between the first two sessions was chosen purposely to promote the therapeutic conversations' effect and maintain the therapeutic relationship's bond with the woman and her partner while also minimizing disturbances due to possible side effects of cancer treatment. The third session, which was a booster session, was scheduled at 3 months after the first session to give the couple time to reflect on their experience of participating in the intervention. All 60 couples provided at least one preintervention and two postintervention assessments over a 3-month period.

Table 4: Intervention guideline: theoretical frameworks, rationale, and utilization of the Couple-strengths Oriented Therapeutic Conversation (CO-SOTC) intervention in clinical practice



Overarching framework for a family system nursing intervention	Family-strengths Oriented Therapeutic Conversation (FAM-SOTC) is the overarching framework (Gisladottir et al., 2017; Petursdottir & Svavarsdottir, 2019; Svavarsdottir & Gisladottir, 2019). This family system nursing intervention is rooted in clinical nursing practice that is based on 4 models: The Calgary Family Assessment/Intervention models, the Illness Belief Model (IBM), and the Resilience component of the Resiliency Model (Wright & Leahey, 2013; Wright & Bell, 2009; McCubbin et al., 1996) The interventionist in the CO-SOTC intervention, is a nurse with a postgraduate degree in sexuality education, training in systemic therapy and family system nursing, and authorized as a specialist in clinical sexology
Core concept	An emphasis is put on the illness narrative; the couple are encouraged to tell their stories about experiencing the cancer illness. The focus is on collaboration between the nurse and the couple
Rationale	The couple is considered the ,,unit" in the sessions and choice of questions in the strength-oriented therapeutic conversation reflect the systemic understanding of their sexual relationship
Component description	The 5 key components guiding the FAM-SOTC intervention are used in the context of how the cancer illness has affected the couple's sexuality and intimacy: • eliticing the illness narrative • asking therapeutic questions • strengthening helpful beliefs and challenging hindering beliefs • Identifying resources, strenghts, and flexibility • Offering evidence-based information The strengthening of helpful beliefs and challenging hindering beliefs may help the woman and intimate partner in adjusting better to sexual changes following cancer. An adapted genogram outlines the couple's internal and external structures, including their unique relationship history (Wright & Leahey, 2013)
Predominant framework for CO-SOTC intervention	The CO-SOTC intervention relies predominantly on the IBM of FAM-SOTC (Wright & Bell, 2009; Wright, 2015; Wright & Leahey, 2013)
Core concept	According to IBM (Wright & Bell, 2009) it is not automatically the clinical problem or illness but rather beliefs that are the main source of suffering for the family and subsystem, such as the couple. The illness beliefs of the woman with cancer and her partner are embedded in the stories they tell about the cancer illness, and possible effect that the cancer diagnosis and cancer treatment has on sexuality and intimacy. Clinically useful illness-related beliefs about 8 major aspects, depicted in the IBM, guide the therapeutic conversations: the place of illness in lives and relationships, suffering, diagnosis, etiology, healing, and treatment, mastery/control /influence, prognosis, and religion/spirituality The conversations may be therapeutic because of the inherent perspectives embedded in the overarching and predominant guiding frameworks, such as: • The nurse prioritizes the acknowledgement of the stressful illness experience of the couple through the illness narrative, thereby contributing to a more helpful frame of mind when developing facilitating beliefs (Wright, 2015). Hence, the conversations may help lessen the grip of the stress experienced by the intimate partners, possibly helping them to preserve the bond of the intimate relationship • The nurse acknowledges the unique bio-psycho-social structure of the



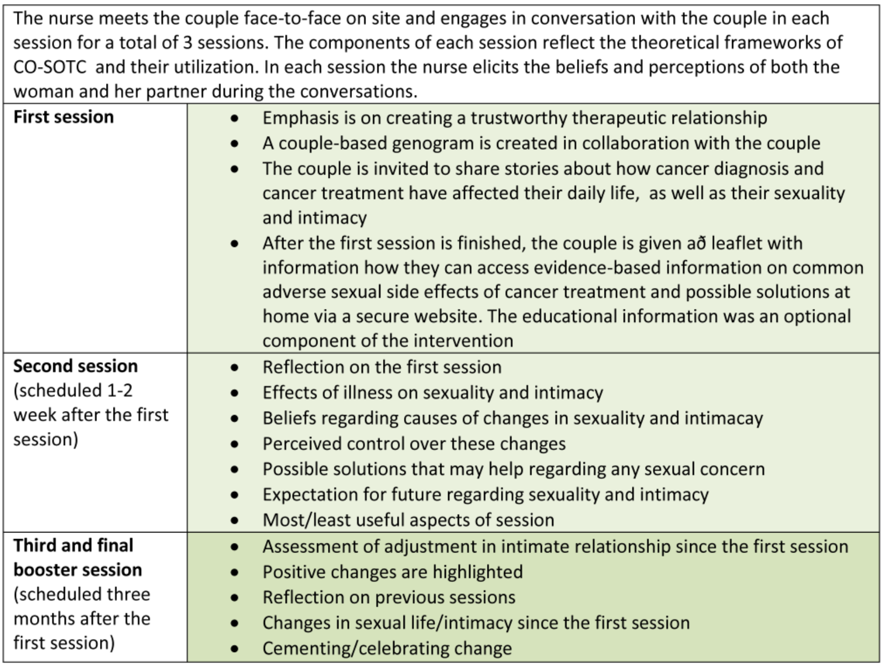
	woman with cancer and the intimate partner. The couple have their unique beliefs about the source of the adverse effects of the cancer illness on sexual life and intimacy. For example, the woman with cancer and her partner decide themselves what topics are important, and would give meaning to discuss. Further, the woman offers her own definitions of what she considers to be a sexual problem or sexual concern for her
Rationale	The systemic, relational, and narrative elements of the IBM are well suited to clinical work with couples
Component description	The 4 main pillars of therapeutic conversations described in the IBM are utilized by the nurse in the intervention: • Create a context for changing beliefs • Distinguish illness beliefs • Challenge constraining beliefs • Strengthening facilitating beliefs
Framework for sexuality	The neotheoretical framework of sexuality describes sexuality as comprising sexual response (desire, arousal, orgasm), sexual self-concept (body image, sexual esteem, sexual self-schema), and sexual relationship (aspects related to communication and intimacy) (Cleary & Hegarty, 2011)
Core concept	Sexuality is a multidimensional construct and should therefore be assessed and understood accordingly
Rationale	To increase the likelihood of the positive sexual adjustment of the couple experiencing the cancer illness the nurse must attend to all 3 main domains of the neotheoretical framework of sexuality
Component description	The questions used in the sessions to consider and address changes to sexuality and intimacy after cancer are devised to reflect this understanding.
Framework for women's sexual problem	The New-View manifesto on women's sexual provides an orverarching framework for understanding women's sexuality and sexual problems (Tiefer & Kaschak, 2001)
Core concept	The New-View manifesto on women's sexual problems offers a women's centered definition of sexual problems based on sexual rights rather than on biology. Accordingly, sexual problems are discontent or dissatisfaction with any emotional, physical, or relational aspects of women's sexual lives. These aspects are related to: • Sociocultural, political, or economic factors • Partner and relationship factors • Psychological factors • Medical factors
Rationale	This framework extends beyond the neotheoretical framework of understanding Influences on women's sexuality and what can become ,,a sexual problem" for women. It takes into account the complexities of the ,,lived experiences" of women's sexual lives and acknowledges that multiple factors besides cancer diagnosis and treatment can affect women's sexuality. Further, the implicit views expressed in the manifesto regarding the potential sources and meanings of women's sexual problems or concerns align well with beliefs about suffering conveyed in the IBM: ,,Illness suffering can be physical, emotional, relational and/or spiritual" (Wright & Bell, 2009, p.36)
Component description	The nurse expects the ,,unexpected" in terms of potential sexuality-related issues and concerns of the woman with cancer

After completing the first session, the couple were handed a sheet on how to access non-interactive, evidence-based, educational information on a secure website (see Appendix II). The use of the educational information on the website was an optional part of the CO-SOTC intervention; however, the value of providing information, for instance, in written form is well established (Lubotzky et al., 2019). The decision to keep the information material optional was primarily influenced by the notion presented by Maturana and Varela (1992) that one cannot perform an instructive intervention, for example, in an attempt to make a woman or her partner comply to certain solutions that, according to the nurse, will increase their sexual well-being. Although the educational material on the website was optional, information about sexual side effects of cancer treatment and possible solutions was provided by the interventionist during the sessions as needed.

3.6.2 Delivery of the CO-SOTC Intervention

The interventionist who delivered all sessions in the study intervention to the study participants is a doctoral student and a nurse authorized in clinical sexology. The intervention protocol and therapeutic conversation sessions of the CO-SOTC intervention are described in Appendix I. The components of this intervention protocol were developed for the CO-SOTC intervention as a part of a doctoral research project named “Development of strengths-oriented therapeutic conversations with females with cancer and their partners and evaluation of effect regarding adjustment of sexuality and intimacy.”

Table 5: Session components of Couple-strengths Oriented Therapeutic Conversation (CO-SOTC)



The nurse meets the couple face-to-face on site and engages in conversation with the couple in each session for a total of 3 sessions. The components of each session reflect the theoretical frameworks of CO-SOTC and their utilization. In each session the nurse elicits the beliefs and perceptions of both the woman and her partner during the conversations.	
First session	• Emphasis is on creating a trustworthy therapeutic relationship • A couple-based genogram is created in collaboration with the couple • The couple is invited to share stories about how cancer diagnosis and cancer treatment have affected their daily life, as well as their sexuality and intimacy • After the first session is finished, the couple is given að leaflet with information how they can access evidence-based information on common adverse sexual side effects of cancer treatment and possible solutions at home via a secure website. The educational information was an optional component of the intervention
Second session (scheduled 1-2 week after the first session)	• Reflection on the first session • Effects of illness on sexuality and intimacy • Beliefs regarding causes of changes in sexuality and intimacay • Perceived control over these changes • Possible solutions that may help regarding any sexual concern • Expectation for future regarding sexuality and intimacy • Most/least useful aspects of session
Third and final booster session (scheduled three months after the first session)	• Assessment of adjustment in intimate relationship since the first session • Positive changes are highlighted • Reflection on previous sessions • Changes in sexual life/intimacy since the first session • Cementing/celebrating change

3.6.3 Clinical application of IBM in the CO-SOTC intervention

The central concept of the IBM is that it is not necessarily the illness or clinical symptoms but rather the beliefs about the illness and clinical symptoms that are the primary source of concern for the family and family subsystems such as couples (Wright & Bell, 2009). But what are “beliefs”, why are they significant for an intervention offered to the couple, and how do they emerge? According to the creators of the IBM, “Our beliefs are the lenses through which we view the world, guiding the choices we make, the behaviors we choose, and the feelings with which we respond. Our beliefs are the blueprint from which we construct our lives and intertwine them with the lives of others” (Wright & Bell, 2009, p. 19).

Consequently, the primary goal of the therapeutic interventions in the CO-SOTC intervention is to identify and challenge constraining beliefs regarding sexuality and intimacy and support facilitating beliefs among partners of the couple dyad. There are eight specific illness beliefs the creators of the IBM have found to be useful in clinical work with individuals and families (Wright & Bell, 2009). According to the authors, these are illness beliefs about suffering, diagnosis, etiology, healing and treatment, mastery/control/influence, prognosis, religion/spirituality, and the place of illness in lives and relationships. Each of these illness beliefs can be recognized in the CO-SOTC intervention protocol (Appendix I).

Another central feature of the IBM is that it focuses explicitly on the illness narrative as opposed to the medical narrative (Wright and Bell, 2009). Therefore, in the therapeutic conversations of CO-SOTC, the subjective impact for both partners is emphasized and how the cancer affects the couple's sexual relationship is explored in collaboration with the nurse.

It is also expected that various factors other than the cancer diagnosis and treatment can affect their well-being and intimate relationship. This viewpoint necessitates that nurses are able to understand sexuality and women's sexual problems simultaneously through the neo-theoretical framework of sexuality and New View Manifesto framework (see Section 10.1.2).

Finally, it can be helpful to consider the concept of maladaptive and adaptive emotional distress response. Research has suggested that emotional distress, signified by elevated distress scores, often serves as an adaptive purpose (Zwhalen et al., 2017; Baker-Glenn et al., 2011). For instance, research suggests that elevated distress does not necessarily coincide with the patients' perceived need for help, nor with the desire of the patients for referral to psychological or psychosocial treatment (Zwhalen et al., 2017; Baker-Glenn et al., 2011). Instead, patients may primarily be in need of support from their loved ones such as their intimate partner and primary HCPs such as oncologists and cancer nurses. Emotional responses only become maladaptive if they persist over time or become extreme and unstable (Dekker et al., 2017). In the intervention study described in this thesis, the nurse interventionist does not know beforehand which woman will have or develop an adaptive or maladaptive emotional response regarding her sexual concerns. However, one purpose of the CO-SOTC intervention is to prevent a maladaptive response that may persist and provide support that may be conducive to an adaptive emotional response. Increased confidence about the effect of illness beliefs (facilitating beliefs and hindering beliefs) on changes related to sexuality and intimacy following cancer may support an adaptive emotional response. Specifically, this increased confidence is based on the notion that facilitative beliefs can overcome hindering beliefs.

3.7 Ethical Approval

The study was granted ethical approval by the Scientific Ethics Board at Landspitali—the National University Hospital of Iceland (No. 23/2016), which also notified the National Bioethics Committee about the study. The study was approved by the chief executives of nursing and medicine and head nurses in the participating wards at Landspitali—the National University Hospital of Iceland.

4 Results

4.1 Study I

Fourteen intervention studies addressing sexuality following cancer were included and analyzed in the systematic literature review, and a total of 1,726 individuals (863 couples, range 14–189) participated. All studies had been conducted in English-speaking countries, and most were pilot studies (N = 8).

4.1.1 Type of cancer diagnosis and couples' sexual orientation

Ten of the fourteen intervention studies focused on prostate cancer survivors. The remaining four studies focused on patients with breast cancer (N = 2), colorectal cancer (N = 1), and advanced gastrointestinal cancer (N = 1). Homosexual couples participated in two of the fourteen studies.

4.1.2 Mode of intervention delivery

The results showed a wide variety in terms of mode of delivery of the included intervention studies. The intervention was delivered face to face (N = 6), in group (N = 4), by telephone (N = 2), via the internet (N = 1), or through a videoconference session (N = 1). The duration and number of sessions varied. For instance, the group-based interventions were offered as a single half-day intervention or a 3 day-long intervention. The number of face-to-face sessions was most often three, with each session lasting 50–90 min.

4.1.3 Methodological limitations

The most common limitations concerned randomization, blinding, concealment, and inadequate description of outcomes in couples who withdrew from the intervention. Four studies reported the rate of adherence to the intervention, which ranged from 64–85%; three studies reported the drop-out rate, which ranged from 15–33%. Moreover, four out of eleven studies with "care as usual" control groups did not clarify what usual care implied.

4.1.4 Theoretical frameworks and components of interventions

Most intervention studies had used cognitive behavioral therapy as their guiding theoretical framework. The content of the included interventions was diverse but shared common threads of enhancing communication skills, confronting the adverse effects of cancer treatment on sexuality, relationship adjustment, and reorganization of negative beliefs about sexual activities (see Paper I Supplemental online information; Table S3).

4.1.5 Outcomes

All included studies reported at least one positive outcome of participation in a couple-based intervention addressing sexuality after cancer, demonstrated in terms of significance and effect size. Those studies that showed statistical significance (N = 7) included more participants or more couples with low sexual function or with fewer relationship resources at baseline. Furthermore, consistent with previous findings, the results of Study I indicated that couple-based interventions are more likely to result in positive adjustment to sexual changes after cancer if they are tailored to the needs of the couple (Martire, 2013; Regan et al., 2012).

The use of outcome measures showed a wide disparity in how sexual concerns are conceptualized and measured. For instance, most of the outcome measures covered only one of the three main components of sexuality according to the neo-theoretical framework of sexuality (Cleary & Hegarty, 2011). Furthermore, six of the 27 outcome measures that were used in the included studies to assess sexuality were cancer specific.

4.1.6 Interventionists

A wide difference was seen in the competencies and professions that provided the couple-based interventions. Four studies included more than one profession in the team of interventionists. No intervention was nurse-managed; however, in two studies, nurses were among a team of interventionists. Furthermore, only four studies reported that the interventionist had received specific training in delivering interventions for SHC or had prior training in couples' therapy.

Overall, the findings from Study I demonstrate a lack of consensus about how couple-based interventions addressing sexuality after cancer are provided and evaluated. The findings revealed weaknesses in the methodology and reporting of research studies targeting sexuality and intimacy among couples facing cancer. However, Study I provided valuable insights into areas of further improvement, for example, the need to develop cancer-specific outcome measures that encompass all main domains of sexuality; moreover, couple-based interventions for women with cancer and their intimate partners are especially scarce, and all included studies on interventions were from English-speaking countries

4.2 Studies II and III

The sample used in Studies II and III consisted of 60 women and their intimate partners (all males; N = 120) who participated in the CO-SOTC intervention comprising three strengths-oriented therapeutic conversations. Most of the participating women had been diagnosed with breast cancer (76.7%; Table 3). At the onset of the CO-SOTC intervention, each woman participant was receiving one or more cancer treatments (surgery, chemotherapy, radiation therapy, or endocrine therapy). The average age of the women was 52 years, average length of the current relationship was 25 years, and 72.9% had completed university-level education.

A total of 56 women answered a single-item screening question in the demographic questionnaire. The screening question asked about eight different sexual problems or concerns experienced for a period of 3 months or more in the previous 12 months. The number and percentage of the women that answered each of the items was as follows:

- You wanted to feel more interest in sexual activity (n = 35) 62.5%
- Your vagina felt too dry (n = 29) 51.8%
- You had pain during or after sexual activity (n = 16) 28.6%
- You had difficulty having an orgasm (n = 18) 32.1%
- You felt anxious about sexual activity (n = 8) 14.3%
- You did not enjoy sexual activity (n = 12) 21.4%
- Some other sexual problem or concern (n = 11) 19.6%
- No sexual problems or concerns (n = 13) 23.2%

Median time since diagnosis was 6 months (SD = 19.1 months, range = 1–115 months; Table 3). The answers to the single-item screener show that a substantial number of participating women had experienced sexual problems or concerns in the past 12 months; some indicated having experienced more than one problem or concern. The two most common items were lack of interest in sexual activity and vaginal dryness. Taken together, the answers to the single-item screener underline concerns in all main domains of sexuality (sexual function, sexual relationship and sexual identity). Furthermore, these results give an indication of the prevalence of sexual concerns among women with cancer and how these concerns may affect their intimate relationship.

After the third follow-up session, the women were asked to complete a short questionnaire on the usefulness* of the evidence-based educational information on a secure website that they were given access to after the first session (* "not useful," "slightly useful," "neutral," "rather useful," "useful"). Thirty-six (60%) women reported that they had read one or more of the information materials. The women who reported having read one or more information materials found the following information "rather useful" or "useful" (combined answers):

- Vaginal dryness (93.9%; N = 33)
- Lubricants (90.6%; N = 32)
- Vaginal moisturizers (86.7%; N = 30)
- Couples and sexual well-being (86.7%; N = 30)
- Decreased sexual desire (84.8%; N = 33)
- Partner's sexual concerns (80.0%; N = 25)
- Fatigue (77.4%; N = 31)
- Vaginal narrowing (59.2%; N = 27)
- Changes in body image (57.1%; N = 28)
- Vaginal dilation (28.0%; N = 25)

4.2.1 Study II

The main results of Study II demonstrated that all women with cancer reported significantly less sexual concerns related to sexual adverse effects of cancer treatment over time as measured by the first subscale of SCQ from baseline (T1) to post-intervention (T2; p = 0.003) and also at the follow-up session (T2–T3; p = 0.012), supporting hypothesis 1a about the sexual adverse effects of cancer treatment. In the subgroup of women with breast cancer (Table 6), these sexual concerns were significantly reduced from T1 to T2, but no statistical difference was observed from T2 to T3; thus, the findings partly supported hypothesis 2a.

The women's sexual concerns related to intimate partners were significantly reduced from T1 to T2 (p = 0.001) in all women with cancer and in the subgroup of women with breast cancer (p = 0.005) but not from T2 to T3, which partly supports hypotheses 1b and 2b about sexual concerns related to intimate partners (Table 6).

Regarding concerns related to communication with HCPs about sexuality-related issues, the total group of women reported significantly reduced concerns from T1 to T2 (p = 0.021) but not from T2 to T3, which partly supports hypothesis 1c about concerns related to communication with HCPs about sexuality-related issues (Table 6). In the subgroup of women with breast cancer, the findings did not support this hypothesis.

Results on intervention effect size (η2) over time indicated a large effect for the total group of women (η2 = 0.194) and subgroup of women with breast cancer (η2 = 0.163) for sexual concerns related to sexual side effects of cancer treatment (Table 6). A large effect was also observed for the total group of women (η2 = 0.169) and subgroup of women with breast cancer (η2 = 0.150) for sexual concerns related to intimate partner (Table 6). The substantial positive effects suggest that the intervention was relevant for these sexual concerns. Regarding concerns related to communication with HCPs about sexuality-related issues, the intervention effect was small for the total group of women (η2 = 0.090) and intermediate for the subgroup of women with breast cancer (η2 = 0.076; Table 6). The most likely explanation of the weak effect size for this concern is that the primary aim of the intervention was to aid adjustment to changes in sexuality and intimacy but not communication with HCPs about sexuality-related issues in general.

Table 6: Differences in mean of Sexual Concerns Questionnaire (SCQ) between time points using repeated measures ANOVA

Variables (n)	Baseline (T1) Mean (SD)	Post-intervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	F (P value)	Time T1 versus T2 P value	Time T2 versus T3 P value	Eta-Squared (η2)
Sexual concerns related to the sexual side effects of cancer treatment							
All women (n=59)	35.3 (24.8)	30.8 (25.8)	25.9 (22.9)	2619 (0.000) [a]	0.003	0.012	0.194
Subgroup of women with breast cancer (n= 45)	32.1 (24.8)	27.7 (24.5)	23.8 (22.5)	1579 (0.000)	0.010	0.064	0.163
Sexual concerns with partner							
All women (n=59)	12.1 (11.6)	8.8 (9.9)	7.9 (9.9)	559 (0.000) [a]	0.001	0.242	0.169
Subgroup of women with breast cancer (n=45)	11.0 (11.4)	7.7 (8.9)	7.0 (9.8)	416 (0.001) [a]	0.005	0.481	0.150
Concerns related to communication with health care provider about sexuality-related issues							
All women (n=57)	3.9 (4.1)	2.8 (3.4)	2.5 (3.0)	62 (0.009) [a]	0.021	0.362	0.090
Subgroup of women with breast cancer (n=43)	3.7 (4.1)	3.0 (3.7)	2.5 (3.1)	33 (0.036)	0.133	0.195	0.076

[a] Greenhouse-Geisser correction

The results for the research question of Study II show that the total group of women and subgroup of women with breast cancer perceived no significant difference over time in the illness intrusiveness on the intimacy or instrumental subscales (Table 7). These results indicate that the intervention may have had certain protective effect related to intimacy.

The total group of women perceived significantly more illness intrusiveness regarding items on the social relations and personal development subscale from T1 to T2 ($p = 0.035$), but the results on this subscale for the subgroup of women with breast cancer were not significant ($p = 0.057$). Results for treatment effect size (η2) over time showed an intermediate intervention effect for the total group of women (η2 = 0.086) and a small effect for the subgroup of women with breast cancer (η2 = 0.035) regarding illness intrusiveness with respect to items on the social relations and personal development subscale (Table 7). The total group of women and subgroup of women with breast cancer perceived no significant illness intrusiveness on the intimacy or instrumental subscales (Table 7.) Overall, the results on illness intrusiveness indicate that the specific aim of the intervention (supporting adjustment to changes in sexuality and intimacy) may have had some protective effect related to items associated with illness intrusiveness on the intimacy subscale.

Table 7: Difference in mean of Illness Intrusiveness Rating Scale (IIRS) between time points using repeated measures ANOVA

Variables (n)	Baseline (T1) Mean (SD)	Post-intervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	F (P value)	Time T1 versus T2 P value	Time T2 versus T3 P value	Eta-Squared (η2)
Social relations and personal development							
All women (n=53)	2.4 (1.2)	2.7 (1.3)	2.8 (1.4)	5.80 (0.009)	0.035	0.375	0.086
Subgroup of women with breast cancer (n=40)	2.3 (1.3)	2.7 (1.4)	2.7 (1.5)	4.14 (0.035)	0.057	0.669	0.035
Intimacy							
All women (n=55)	3.5 (1.9)	3.5 (1.9)	3.5 (2.0)	0.20 (0.820) ^{a}	-	-	-
Subgroup of women with breast cancer (n=41)	3.4 (1.9)	3.5 (1.9)	3.3 (2.1)	0.74(0.545) ^{a}	-	-	-
Instrumental							
All women (n=55)	4.4 (1.5)	4.4 (1.5)	4.4 (1.6)	0.13 (0.864) ^{a}	-	-	-
Subgroup of women with breast cancer (n=42)	4.3 (1.6)	4.3 (1.6)	4.2 (1.7)	0.11(0.882) ^{a}	-	-	-

[a] Greenhouse-Geisser correction

The overall findings of Study II are encouraging because they demonstrate the potential of a novel nurse-managed couple-based intervention on addressing concerns related to sexuality and intimacy among women in active cancer treatment. The findings also demonstrate the feasibility of developing a novel intervention and integrating empirical knowledge of family nursing with theories about sexuality to improve sexual health outcomes for couples facing cancer. The 100% adherence rate to the intervention is also motivating as it indicates that the intervention was well received by women with cancer and their intimate partners.

4.2.2 Study III

The main results of Study III were that women in active cancer treatment (total group) reported significantly increased confidence about how illness beliefs (facilitating beliefs and hindering beliefs) affect sexuality and intimacy over time, from T1 to T2 ($p = 0.000$) and from T1 to T3 ($p = 0.000$), thus supporting hypothesis 1a (Table 8). Likewise, intimate partners reported significantly increased confidence about how illness beliefs affect sexuality and intimacy over time; from T1-T2 ($p = 0.005$) and T1-T3 ($p = 0.000$), which supports hypothesis 2a (Table 8).

Results on intervention effect size (η2) for confidence about illness beliefs related to sexuality and intimacy found a large effect size for participating women (η2 = 0.155) and an intermediate effect size for their intimate partners (η2 = 0.114; Table 8). For overall relationship quality, effect size was intermediate for women (η2 = 0.016) and their partners (η2 = 0.012; Table 9). The magnitude of the effect size suggests that the elements of the dyadic CO-SOTC intervention influenced couples in a meaningful way, especially regarding increased confidence about their illness beliefs.

Table 8: Difference in mean on illness beliefs about sexuality and intimacy for couples using repeated measures ANOVA

Variables (n)	Baseline (T1) Mean (SD)	Post-intervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	F (P value)	Time T1 versus T2 P value	 T2 versus T3 P value	 T1 versus T3 P value	Eta-Squared (η2)
Confidence about facilitating beliefs versus constraining beliefs about sexuality and intimacy								
Women (n*=52)	24.2 (6.0)	27.1.8 (5.9)	28.0 (5.1)	420.50 (0.000) [a]	0.000	0.135	0.000	0.155
Intimate partner (n=56)	24.1 (5.4)	26.0 (5.7)	27.4 (4.5)	307.21 (0.000) [a]	0.005	0.042	0.000	0.114

[a] Sphericity Assumed, *n varies due to missing data

The total group of women reported increased relationship quality over time, from T1 to T2 (p = 0.022) and from T1 to T3 (p = 0.005), which supports hypothesis 1b about higher relationship quality after the dyadic CO-SOTC intervention (Table 9). Similarly, intimate partners reported increased relationship quality over time, from T1 to T2 (p = 0.037) and from T1 to T3 (p = 0.047), which supports hypothesis 2b about higher relationship quality after the dyadic CO-SOTC intervention (Table 9).

Table 9: Difference in mean of relationship quality for couples using repeated measures ANOVA

Variables (n)	Baseline (T1)	Post-intervention (T2)	Follow-up (T3)	F (P value)	Time T1 versus T2	T2 versus T3	T1 versus T3	Eta-squared (η2)
	Mean (SD)	Mean (SD)	Mean (SD)		P value	P value	P value	
Overall relationship quality								
Women (n*=58)	69.2 (14.4)	70.8 (13.5)	71.8 (13.6)	198.61 (0.010) [b]	0.022	0.263	0.005	0.016
Intimate partner (n=48)	64.2 (13.6)	65.9 (13.9)	66.5 (15.3)	132.08 (0.058) [b]	0.037	0.587	0.047	0.012
Subscales								
Conflict								
Women (n=58)	4.2 (4.5)	3.9 (4.6)	3.7 (4.7)	8.08 (0.220) [a]	0.322	0.424	0.105	-
Intimate partner (n=50)	5.2 (5.6)	4.6 (5.6)	5.0 (6.3)	9.88 (0.198) [a]	0.060	0.302	0.471	-
Tenderness								
Women (n=59)	21.5 (6.4)	22.6 (5.8)	22.9 (5.4)	64.72 (0.007) [b]	0.001	0.487	0.005	0.026
Intimate partner (n=53)	18.5 (5.9)	19.2 (5.8)	19.4 (5.6)	21.29 (0.139) [b]	0.071	0.734	0.101	-
Communication								
Women (n=59)	22.1 (6.2)	22.3 (5.8)	22.5 (5.9)	5.0 (0.599) [a]	0.514	0.671	0.363	-
Intimate partner (n=51)	21.4 (4.3)	21.7 (4.6)	22.0 (4.9)	10.04 (0.364) [a]	0.424	0.469	0.212	-

[a] Sphericity Assumed, [b] Greenhouse-Geisser correction, *n varies due to missing data

Table 10: Dyadic difference scores on illness beliefs about sexuality and intimacy and relationship quality using a F-test

Variables (n)	Baseline (T1)	Post-intervention (T2)	Follow-up (T3)	Dyadic difference scores	Time
	Mean (SD)	Mean (SD)	Mean (SD)	Timepoint (n) Mean (SD)	F (P value)
Confidence about facilitating beliefs versus constraining beliefs about sexuality and intimacy					
Women (n*=49)	24.5 (6.1)	27.3 (6.0)	28.2 (5.1)	T1 (n=49) 0.10 (5.72)	0.680 (0.444)
Intimate partner (n=49)	24.4 (5.1)	26.1 (5.5)	29.0 (13.9)	T2 (n=49) 1.19 (5.63)	
				T3 (n=49) -0.82 (15.25)	
Overall relationship quality					
Women (n=47)	68.1 (14.7)	69.9 (13.9)	71.0 (13.4)	T1 (n=47) 4.11 (11.52)	0.245 (0.783)
Intimate partner (n=47)	64.0 (13.6)	65.5 (13.7)	66.0 (15.2)	T2 (n=47) 4.36 (10.90)	
				T3 (n=47) 4.97 (11.26)	

*n varies due to missing data

An F test of the research question on dyadic difference scores between the participating women and their intimate partners showed no statistically significant differences over time in illness beliefs about sexuality and intimacy or overall relationship quality (Table 10). This indicates that the participating women and their partners scored similarly on the outcome measures and that their experience of the CO-SOTC intervention was similar.

Overall, tests of normality showed limited deviation from normality, most specifically for sexual concerns related to sexual adverse effects of cancer treatment, illness beliefs, and relationship quality. However, normality tests showed significant deviation from normality for sexual concerns regarding intimate partners ($p = 0.001$) and for concerns related to communication with HCPs about sexuality-related issues ($p = 0.000$). This indicates that the reported sexual concerns of women related to intimate partners and concerns related to communication with HCPs were somewhat clustered at baseline.

Taken together, findings from Study III demonstrate that the dyadic CO-SOTC intervention is effective in supporting sexual adjustment among women in active cancer treatment and their intimate partners. The CO-SOTC intervention adds new empirical evidence to the limited data on couple-based interventions addressing sexuality and intimacy among women with cancer and their partners. Moreover, to the best of our knowledge, this is the first nurse-managed intervention to report on the outcomes of a short-term dyadic intervention addressing sexuality and intimacy after cancer.

5 Discussion

The overall aim of this doctoral thesis was twofold: to describe the characteristics of couple-based intervention studies that address sexuality after cancer and to develop and test the effectiveness of a novel couple-based intervention (CO-SOTC) for women with diverse types of cancer in active cancer treatment and their intimate partners.

Findings of Study I in the first phase of the doctoral research revealed important gaps and methodological concerns regarding couple-based interventions addressing sexuality after cancer. The results showed that there is no clear consensus in the literature about how couple-based interventions addressing sexuality after cancer are best structured, suggesting limited empirical data to guide clinical nursing practice. The results offer speculative evidence on how the quality of future research can be improved and how knowledge can benefit clinical practice. For example, the results identified the need for further research on outcome measures related to sexual health. The findings of Study partly guided phase II involving the development of the CO-SOTC intervention. For instance, findings showed that nurses were part of a team of interventionists in two of the 14 included interventions, and both interventions were for prostate cancer survivors and their intimate partners. Thus, the findings of Study I support recent review findings that indicate that nurses have neither conducted research studies on the development and testing of couple-based interventions addressing sexuality after cancer nor published such research (Charalambous et al., 2018; Papadopoulou et al., 2019). This indicates a strong need to enhance knowledge, clinical skills, and training among nurses so that they can be more proactive in the provision of sexual health in cancer care. The scarcity of evidence-based couple-based interventions to support changes related to sexuality and intimacy, especially among women with cancer and their partners clearly poses a challenge to nurses who want to improve SHC; however, it can also be viewed as an opportunity to improve QOL aspects in clinical care. This opportunity is highlighted in a recent narrative review on the state of dyadic interventions for cancer survivors where Badr and colleagues (2019) concluded that when nurses view the dyad as a unit of care, this may improve several aspects of QOL. They urged nurses to include cancer survivors and their intimate partner when formulating supportive care protocols. This suggestion is consistent with recent clinical cancer care guidelines that recommend providing couple-based interventions to partnered women to address intimacy and relationship issues (Barbera et al., 2017; Carter et al., 2018). In addition, findings of Study I revealed that only a handful of interventions have been developed, tested and reported for women with cancer and their partners, and such studies have been conducted only in USA. This is a clear indication that more evidence-based interventions are needed in other countries for women with cancer and their partners. For example, currently, the research literature reports on only one study protocol, also from the USA, of a couple-based intervention addressing sexual concerns among breast cancer survivors, and this study is currently recruiting participants (Reese et al 2020).

The main results of Studies II and III are that women with cancer and their intimate partners who participated in the novel CO-SOTC intervention reported benefits related to sexuality and their intimate relationship, thus providing the couples with an opportunity to address cancer-related stressors that affect sexuality and intimacy. Results of Study II revealed that over time the women participating in a strengths-oriented therapeutic conversation intervention reported significantly less sexual concerns related to adverse sexual side effects of cancer treatment, sexual concerns related to their intimate partners, and concerns regarding communication with HCPs about sexuality-related issues. Moreover, illness interference on intimacy did not significantly change over time. The hypotheses related to sexual concerns were supported or partly supported by the findings but were most reliable when the total number of participants was considered as a higher number increased the likelihood of detecting significant results. The findings supported the idea that the CO-SOTC intervention may have lessened the perceived illness intrusiveness of cancer, particularly with respect to intimacy. Furthermore, the overall findings in Study II on sexual concerns and illness intrusiveness highlight that the main focus of the CO-SOTC intervention was on supporting adjustment to changes in sexuality and intimacy after cancer, and not on social support in general.

Results of Study III showed that the women with cancer and their intimate partners reported significant improvements over time in relationship quality and confidence about how their illness beliefs (facilitating beliefs and hindering beliefs) affect sexuality and intimacy. The significant improvement in confidence related to illness beliefs among intimate partners is particularly striking and encouraging, suggesting that the collaborative therapeutic aspect of the CO-SOTC intervention was also relevant for the partners. In addition, the magnitude of effect sizes on illness beliefs and relationship quality shows that the components of the CO-SOTC intervention influenced the couples in a meaningful way, especially regarding increased confidence about their illness beliefs related to sexuality and intimacy. Finally, the results on illness interference with intimacy among the women demonstrate that no significant changes were found over time, possibly indicating protective effect of the CO-SOTC intervention owing to which the women may have believed that they were in more control of the extent to which their illness influenced their intimate relationship.

The overall positive findings of Studies II and III are consistent with previous findings showing that the chief strategies related to couple-based interventions for sexual support involve creating opportunities for shared understanding of sexual changes after cancer and enhancing couples' communication (Milbury & Badr, 2013; Canzona et al., 2019b; Gorman et al., 2020). Furthermore, the overall results of Studies II and III demonstrate that positive changes were not only short term but also persisted over the 3-month period of the study, even though the participating women were undergoing cancer treatment and nearly one-third of them reported advanced illness. The reported benefits among the total group of women and the subgroup of women with breast cancer regarding their sexual concerns regarding their intimate partners were short term. Although this shows that improvement of partner-related sexual concerns was not lasting during the study period, it is perhaps not an unexpected finding and may be explained in two ways. First, it has been previously recognized that in some couples facing cancer, the illness brings the partners closer together, which may have affected the reported outcomes among partners (Dorval et al., 2005). Second, the participating couples may already have had relationships of above-average quality, which may have prevented the continuous enhancement of sexual concerns regarding intimate partners. The latter explanation is corroborated by normality tests that showed significant deviation from normality related to sexual concerns regarding intimate partners ($p = 0.001$).

The study presents a rare example of a tested couple-based intervention that provides support related to sexuality and intimacy. The 100% adherence rate confirms that the CO-SOTC intervention was well received by the women and their intimate partners, suggesting that the intervention had several advantages in addressing sexuality and intimacy. First, it underlined the collaborative aspect between the couple and the nurse. Second, the intervention openly avoided "one-size-fits-all" approach in favor of discovering the unique "sexual fingerprint" of a woman and her partner through therapeutic conversations. Third, the structure and contents helped in building trust, a vital cornerstone of conversations about sexuality and intimacy.

Additionally, this intervention study demonstrates that nurses who intend to provide a couple-based intervention must have appropriate knowledge of sexual health and training in clinical sexology and be able to use relevant empirical data of nursing frameworks when devising these interventions. The importance of having a certain competency is highlighted in various proposed competency levels for SHC included in cancer care and within the family nursing profession (World Association for Sexual Health, 2008; International Family Nursing Association, 2017; Papadopoulou et al., 2019). To address the persistent problem of sub-optimal nurse-managed provision of sexual health in cancer care Papadopoulou and colleagues (2019) propose a two-level international SHC competency chart for nurses: an entry level and a champion level. Nurses at the champion level not only have a personal interest in SHC, experience in the provision of SHC, and post-graduate training but they are essentially nurses with expert knowledge and skills required to address patient's sexual concerns based on evidence (Papadopoulou et al., 2019).

Developing and conducting a nurse-managed couple-based intervention study is challenging not only because it is inherently a time-consuming process but also because of the complex nature of such intervention; it is a therapeutic process involving two individuals—the woman with cancer and her intimate partner—and involves addressing diverse aspects such as the multiple barriers to the subject of sexuality in health care settings and in society and vulnerability of the patients participating in the study. Furthermore, only one interventionist delivered all sessions to the couples. Despite these previously mentioned challenges, the whole study process described in this thesis demonstrates that nurses can improve the inadequate empirical data of nurse-managed couple-based interventions addressing sexual changes after cancer.

5.1 Reflections on the CO-SOTC Intervention

The CO-SOTC intervention is the first nurse-managed couple-based intervention addressing sexuality and intimacy after cancer to be developed and tested for effectiveness and provides substantial evidence for offering such nurse-managed interventions. The overall favorable outcomes and the 100% adherence rate of the CO-SOTC intervention are reassuring and suggest that the theoretical frameworks guiding the intervention components were suitable and relevant for the participants. Several distinct features of the CO-SOTC intervention may explain what makes the intervention therapeutic (Figure 5).

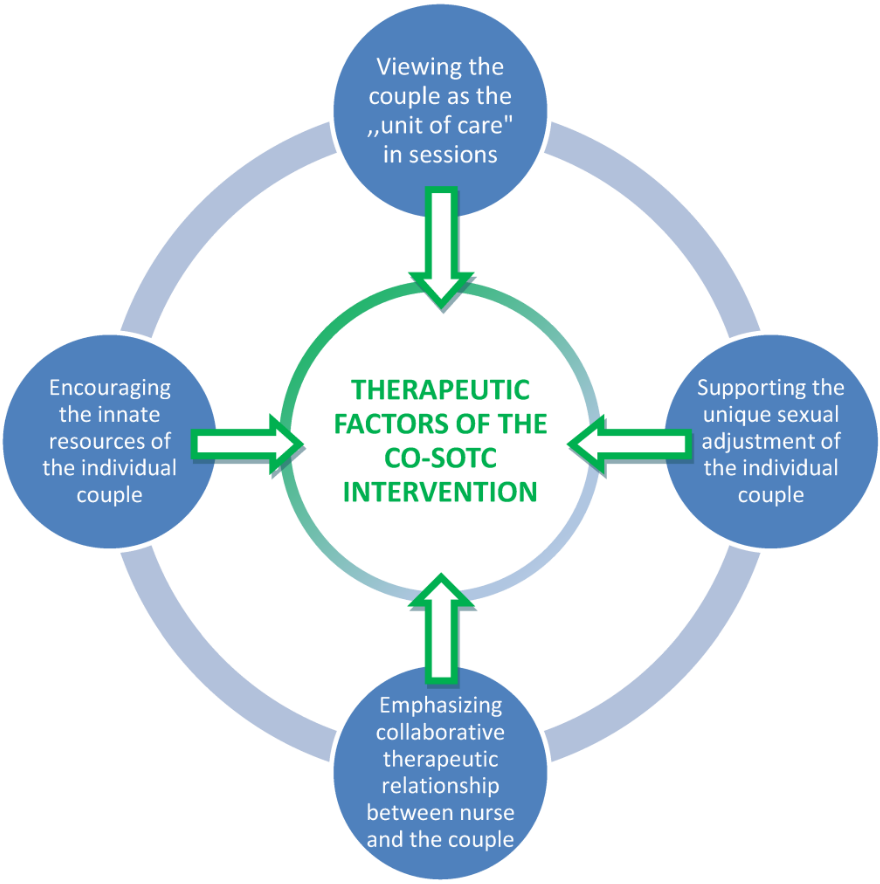


Figure 5: Therapeutic factors of the CO-SOTC intervention

First, the results support other study findings showing that interventions that include the patients’ intimate partners are more likely than interventions that do not include partners to produce significant effects related to adjusting to sexual changes after cancer (Taylor et al., 2011; Carroll et al., 2016).

Second, the substantial impact of the CO-SOTC intervention suggests that the intervention may have the potential to address the aspects of changes in sexuality and intimacy after cancer that are unique for each couple. Specifically, the ability of the CO-SOTC intervention to influence the couples in a meaningful way regardless of each individual couple’s distinctive sexual adjustment process suggests that it offers a person-centered, tailor-made approach, which is known to be welcomed by couples (Benoot et al., 2017; Albers et al., 2020; Bradbury & Bodenmann, 2020). Third, the strengths-oriented approach of the CO-SOTC intervention emphasizes motivating the innate resources of the individual couple by supporting facilitating beliefs. Such an approach, in and of itself, may improve their coping strategies in adjusting to sexual changes after cancer (Gorman et al., 2020). In addition, the findings of a recent review by Badr (2017) suggesting that therapeutic questions that elicit reflection on couples’ unique strengths may help enhance the impact of couple-based interventions in cancer. However, it must be highlighted that although the CO-SOTC intervention focuses on strengths, it first acknowledges the stressful experience of the individual couple, thereby possibly alleviating some of the cancer-related stress and contributing to a more helpful frame of mind when supporting facilitating beliefs (Wright, 2015). Fourth, the chief components of the CO-SOTC intervention—collaborative therapeutic relationship with the nurse, active listening, and validation of the individual couple narrative—appear to be advantageous in helping couples adjust to sexual changes after cancer. In addition, this emphasis on collaboration helps to promote a level of comfort that is indispensable when discussing sexual concerns (Williams et al., 2017). Such collaborative focus, which is a vital component of the CO-SOTC intervention, may sometimes be underrated as an important therapeutic influence in nurse-managed interventions. For instance, research findings have established that therapeutic alliance as perceived by the patient is a common factor among interventionists who are considered efficacious (Charman, 2004).

The four main features mentioned above which possibly explain the therapeutic effect of CO-SOTC also align well with research demonstrating that open communication about sexual concerns after cancer lessens the impact of uncertainty of the intimate relationship and enhances the perceived quality of the relationship (Canzona et al., 2019a; Gorman et al., 2020). Taken together, the overall findings indicate that the strengths-oriented therapeutic conversations of the CO-SOTC intervention reduce cancer-related stress affecting sexuality and intimacy, thus supporting sexual adjustment and installing a renewed sense of hope in maintaining the intimate bond.

5.2 Challenges in Conducting Research on Sexuality and Intimacy among Women Cancer Surviors and their Intimate Partners

The subject of sexuality and intimacy is innately both private and personal, and this fact alone suggests that many challenges await researchers intending to conduct sexuality-related research. Therefore, it is necessary to consider some of the ethical and methodological considerations when embarking on research involving the intimate lives of couples.

However, this does not mean that the subjects of sexuality and intimacy should be omitted from research endeavors. On the contrary, if these subjects are excluded from being the focus of research, it can make it more difficult for patients to access evidence-based information and support when adjusting to changes in sexuality after cancer. According to the World Health Organization, sexual rights are part of human rights, for example, the right to SHC services based on the best scientific evidence (2000).

A key ethical concern is how the personal or private life of couples participating in a study on sexuality and intimacy can be best protected (Guidelines for Research Ethics, 2014, p. 4). The privacy of the participating couples in this study was ensured by various means:

- Confidentiality and anonymity were ensured on all the paper questionnaires. This ensured participants' anonymity in consequent data extraction by staff at the Social Science Research Institute.
- The intervention was delivered in face-to-face sessions with the individual couple and not in groups, as group participation could increase the risk of compromising their personal or private life.
- Participants were offered access to a secure website (hosted by the Landspitali hospital) that they could access in the privacy of their homes, and the use of the website was optional.
- All outcome measures were on paper questionnaires. Therefore, data were not gathered electronically (some participants expressed gratitude that the questionnaires were on paper and not electronic). This can be viewed as another way to respect the personal life and intimate relationship of the couple.

- The interventionist/researcher was not involved in the recruitment process, and this was one way of honoring the ethical criterion of clear role description. After the couples were randomized, the actual names of the women and their partners were only known to the researcher, who also provided the intervention.
- The interventionist/researcher was not allowed access to the hospital records and therefore had no previous knowledge about the women with cancer. This reduced the possible treatment bias of the interventionist, and the interventionist first met the women with cancer and their partners when the intervention started.
- To protect personally identifiable information, paper questionnaires that had been completed were stored in a locked cabinet and destroyed after all data extraction and analysis. Session notes written by the interventionist/researcher were also kept in a safe place.

To minimize or prevent harm, it was necessary for participants to be informed about any risks/benefits involved in participating in the study. Therefore, a clause in the informed consent letter stated that “participation ensures no guarantee of benefit other than potential improvement in the well-being of you and your partner. Women who have been diagnosed with cancer and seek health-care services at Landspitali in the future may benefit from your participation. Likewise, this research can lead to a better understanding on how HCPs can better support women with cancer.” The interventionist was also aware of the fact that the participants constituted a vulnerable population as the cancer might progress with unforeseen consequences despite (or because of) active cancer treatment and cause unforeseen distress to the participating women and their partners. Furthermore, participants had free-of-charge access to further sessions provided by an independent therapist, after completing the intervention, which was stated in the informed consent letter. The implication that the woman and her partner may need more sessions than the intervention offered in the research project may have been considered a potential risk. None of the participating couples requested this additional support.

To support the right to self-determination, the participants were not required to have a certain level of sexual distress to be considered eligible to participate in the study. The women and their intimate partners had the right to decide whether they wanted to participate in the study, for whatever reason. Some couples stated that they were grateful for the hospital services and cancer treatment, and this gratitude was one of the reasons they decided to participate in the research; they wanted to “give back” to the health care system. Thus, it seems that gratitude or altruism played a role in the decision of some couples to join the research project. This is an interesting side of self-determination regarding the decision to consent to participate in couple-based research on sexuality and intimacy.

However, for some individuals, the perceived burden associated with participating in a study can result in diminished participation rate in psychosocial research. Implicit in the ethical criteria of the right to self-determination is respecting the will of individuals to not participate in the research or their wish to withdraw from participation. This means avoiding coercion and pressure in any way while recruiting participants and respecting their decision to withdraw before or after the study begins. The informed consent letter, presented by clinical nurses, and radiologists in participating wards, clearly stated that if the participants wished to withdraw their consent or stop at any time during the research project, it would have no consequences at all regarding the hospital services they received. Nevertheless, some participants were hard to reach after they had given their consent to participate in the intervention study. They did not answer phone calls or e-mail. A decision needed to be made about the appropriate number of attempts required to get in contact with a couple who had already provided their consent. The interventionist reached the conclusion that four attempts were maximum; if a couple had not answered by then, it was concluded that, for whatever reason, they were not going to participate. Women who had agreed to participate and provided a written consent could withdraw their consent at any time; a few women did withdraw their consent before coming to the first session, most often due to their deteriorating health.

Finally, one ethical criterion that needed to be considered was to support diversity, thereby ensuring not to exclude minority groups. The interventionist decided to include lesbian couples as potential participants; however, participation by lesbian couples was associated with the risk of confounding the data analysis as it would be not be possible to compare outcomes from a few lesbian couples with those from a larger group of heterosexual couples.

5.3 Methodological Strengths and Limitations

5.3.1 Study I

Owing to the insufficient quality of reporting of the included studies, it was not feasible to provide an overall recommendation on how to implement couple-based interventions addressing sexuality-related issues in cancer care. Nevertheless, Study I offered some suggestions for how to conduct such studies.

5.3.2 Study II and Study III

The studies had two noteworthy strengths. First, women with different types of cancer and stage of cancer participated, suggesting the potential use of the intervention regardless of the type of cancer. Second, the adherence rate to the CO-SOTC intervention was 100% as there was no attrition among the women or their intimate partners during the intervention, showing that it was well received by the women with cancer and their intimate partners.

The main limitation of both Study II and III is the quasi-experimental single-group pre-post follow-up design, posing a threat to the validity of the overall findings. The research was initially designed and conducted as a randomized controlled study with a control group receiving delayed intervention. All assessments over the study period were completed before the data analysis was performed. However, substantial differences were observed in both clinical and demographic variables at baseline between the experimental and control groups, preventing comparisons of outcome measures between the groups as initially planned. The women in the control group were on average 3 years younger, had fewer co-morbidities, and more often had cancers other than breast cancer. Considering this unsuccessful randomization, we chose to combine the groups and analyze them as a single group to identify changes over time from preintervention to postintervention to follow-up. Therefore, to reduce the risk of sample heterogeneity, future studies should employ a randomized controlled design and stratified recruitment of participants. However, our experience from the study suggests that sample stratification is perhaps achievable only in a larger population than in the Icelandic population. For example, the process of sample stratification may extend over a couple of years which may be unrealistic in terms of research resources.

The absence of women with gynecological cancer and lesbian couples among participants was disappointing and, as a result, it is unclear whether the CO-SOTC intervention is beneficial for these women. Ensuring their participation would have required a considerably longer time frame of recruiting participants. The recruitment process and delivery of the CO-SOTC intervention to the 60 participating couples lasted over 2 years. Therefore, the longer time frame needed to ensure the inclusion of women with gynecological cancer and lesbian couples would have been challenging considering the number of individuals diagnosed with cancer in a small country such as Iceland.

The study had several other limitations. For instance, this study was performed in the context of the Icelandic health care system. This may be a factor influencing the replication in and translation to health care systems in other countries. In addition, the participants were highly educated, precluding generalization of findings to women that have completed only primary or secondary education. Furthermore, it has been shown that the effects of the intervention tend to be weaker in actual clinical practice than in controlled studies (Bradbury & Bodenmann, 2020). Therefore, it is unknown whether the promising effects of the CO-SOTC intervention would show similar results in these two different contexts. Finally, only one nurse delivered the intervention, possibly resulting in a so called “therapist effect” influencing the study outcomes. Nevertheless, having only one interventionist ensured consistency in delivering the intervention.

6 Conclusions

The overall aim of the thesis was to describe the characteristics of couple-based intervention studies that address sexuality after cancer and develop and test the effectiveness of a novel couple-based intervention (CO-SOTC) for women with diverse types of cancer and in active cancer treatment and their intimate partners. This doctoral research involved two distinct study phases (Figure 1) that collectively addressed the overall aim of this thesis. The findings of the three studies included in this thesis contribute to the limited empirical data on couple-based studies addressing sexuality and intimacy among women with cancer and their partners.

The findings of the systematic literature review verified the lack of nurse-managed couple-based interventions and identified the need for further work on outcome measures related to sexual health.

The CO-SOTC intervention was offered to women who were in active cancer treatment—regardless of the type and stage of cancer—and their partners; the adherence rate was exceptional (100%). After receiving the intervention, the participating women reported a reduction in sexual concerns related to cancer treatment and to their intimate partner and concerns regarding communication with HCPs about sexuality-related issues. Moreover, although the women were in active cancer treatment and therefore at risk of experiencing adverse sexual side effects, they perceived no difference over time in illness intrusiveness on intimacy after receiving the intervention, suggesting a protective effect of participation in the CO-SOTC intervention. Furthermore, the couples who participated in the intervention had increased confidence about how illness beliefs affect sexuality and intimacy and improved relationship quality over time after receiving the intervention.

The development of the CO-SOTC components was inspired by the strengths-oriented therapeutic conversations used in previously reported FAM-SOTC interventions. Moreover, the ICE-COUPLE outcome measure was developed from an outcome measure previously used in FAM-SOTC interventions. Consequently, the findings of the CO-SOTC intervention contribute to the existing rich empirical data obtained using FAM-SOTC as the overarching framework. Furthermore, this novel nurse-managed intervention achieved the task of providing couples an opportunity to address cancer-related stressors that affect sexuality and intimacy using a new intervention protocol. Given the centrality of intimate relationships in people's lives and the perceived importance of partner support when experiencing cancer, it is highly appropriate that nurses can offer evidence-based interventions related to sexuality and intimacy.

The overall findings of the study presented in this thesis demonstrate the effectiveness of the CO-SOTC intervention and potential applicability of the intervention to a vulnerable group of patients and their intimate partners.

6.1 Future Direction

Because the CO-SOTC is a new intervention, it remains to be replicated and tested among other subgroups within cancer care to further validate the effectiveness of the intervention. For instance, the CO-SOTC intervention needs to be tested among women with gynecological cancer and lesbian couples and remains to be replicated by other nurses involved in cancer care.

The findings of this study indicate that the CO-SOTC intervention is promising in addressing the unique sexual adjustment pathways of women with cancer and their partners. Therefore, it may be feasible to use the intervention protocol as a template and test the intervention among patients experiencing chronic illnesses other than cancer.

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Original publications

Paper I

Accepted: 19 September 2017

DOI: 10.1111/jan.13470

REVIEW PAPER

WILEY JAN Informing Practice and Policy Worldwide through Research and Scholarship

A systematic review of characteristics of couple-based intervention studies addressing sexuality following cancer

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Funding information
This study was supported by the grants received by Jóna Ingibjörg Jónsdóttir from the following institutions: Ingibjörg R. Magnúsdóttir Research Fund and The Icelandic Nurses' Association Scientific Fund. The funding sources had no involvement in the data analysis and interpretation of results

Abstract

Aim: To describe the characteristics of couple-based intervention studies that address sexuality following cancer.

Background: Sexuality-related problems are common among cancer survivors and their partners.

Design: Systematic literature review with a narrative summary of results.

Data sources: Electronic searches were conducted in PubMed, CINAHL and PsychINFO. We included studies published from 1 January 2009 - 31 December 2016. Additional information was retrieved by scrutinizing reference lists, conducting citation tracking and contacting authors. We included all types of quantitative intervention studies published in the English language which contained outcome measures corresponding to the neo-theoretical framework of sexuality—sexual function, sexual relationship and sexual self-concept.

Review Methods: Our review was guided by the Joanna Briggs Institute reviewer's manual. Data were extracted and appraised using the standardized checklists for quantitative studies. This assessment was conducted independently by two reviewers. A third reviewer was involved if consensus could not be reached.

Results: Fourteen studies were included. Interventions were delivered face-to-face, by telephone or via the Internet. Sessions ranged from 1-8, with a duration from 2-22 weeks. Most studies offered ≥3 sessions. Interventions addressed unique concerns and/or provided general education. There was little agreement on the use of outcome measures. Most studies inadequately described fidelity to the study protocol and the training of interventionists.

Conclusion: There was no clear consensus about how couple-based interventions are best structured. The results provide tentative evidence for how the quality of future research studies can be improved and how knowledge can be used in clinical practice.

KEYWORDS
cancer, couple-based interventions, intimacy, narrative summary, nursing, oncology, oncosexology, partners, sexuality, systematic review

1 | INTRODUCTION

Sexual well-being and the experience of intimacy with one's partner have been described in the literature as a "safe haven" that provides relief in the experience of cancer (Manne & Badr, 2008; Manne, Siegel, Kashy, & Heckman, 2014; Naaman, Radwan, & Johnson, 2009; Ussher, Perz, & Gilbert, 2014). This psychological buffer is likely to be interrupted during the course of disease (Hawkins et al., 2009). In this review, we define sexuality according to the neo-theoretical framework (Cleary & Hegarty, 2011): (1) *Sexual function*, encompassing desire, arousal/excitement and orgasm which are the main components of the sexual response cycle; (2) *Sexual relationship* comprising aspects related to communication and intimacy; and (3) *Sexual self-concept* related to the person's self-perceived sexual identity including body image, sexual esteem and thoughts about oneself as a sexual person. We also use the neo-theoretical framework to locate and critically appraise existing studies where couple-based interventions for sexuality have been provided.

1.1 | Background

Problems related to sexuality are common among cancer survivors and often occur because of inadequate ways of adjusting to new challenges (Hill et al., 2011; Holm et al., 2012). It is well-known that chemotherapy and other cancer treatments such as radiation, surgery and hormonal therapies frequently cause disruption in the sexual well-being of patients (Bober & Varela, 2012). Depending on the type of treatment, females experience changes in sexual desire, vaginal dryness and/or dyspareunia, difficulties in sexual arousal and/or orgasm, body image concerns, vaginal obstruction and/or stenosis (Bober & Varela, 2012; Falk, Ganz, & Vora, 2016). In males, some side-effects of treatment include erectile dysfunction, loss of libido, changes in orgasm, inability to ejaculate and reduced penile length (Bober & Varela, 2012; Dizon, Ganz, & Vora, 2017). The sexual relationship and sexual identity may also be adversely affected (Cleary & Hegarty, 2011; Sadovsky et al., 2010; Ussher, Perz, & Gilbert, 2015).

Considering that sexual relationships inherently involve a partner makes it highly relevant to include "the unity of the couple" when supporting sexual adaptation (D'Ardenne, 2004; Ussher et al., 2014; Walker, Wassersug, & Robinson, 2015). Sexual counselling improves sexual relationships, independent of the partner being present but benefits tend to increase with the involvement of the partner (Bober & Varela, 2012; Brotto, Yule, & Breckon, 2010). Nevertheless, partners are rarely included in interventions that are provided to maintain and improve sexual relations and intimacy after cancer (Schover et al., 2012).

After a cancer diagnosis, couples act differently concerning sexuality. Some couples believe that the cancer experience brings them closer together while others grow more distant from one another—the latter intrinsically bringing about communication problems and reduced intimacy (Badr & Krebs, 2013; Gilbert, Ussher, & Perz, 2010). These adverse changes in the sexual relationship are often linked to feelings of rejection, self-blame, sadness, isolation, resentment towards one's partner and decreased sexual satisfaction (Gilbert et al., 2010). A positive adjustment process may be facilitated by sexual counselling, which can serve as a catalyst for contemplating and responding in a constructive way to these challenges (Manne, 2011).

Research on couple-based interventions for sexual concerns has adopted a wide-ranging approach encompassing relational, psychological and educational support and has used different ways of delivering the interventions, for example, face-to-face, written information, telephone calls and web-based learning (Brotto et al., 2010; Kim, Yang, & Hwang, 2015; Scott & Kayser, 2009). Previous reviews have mainly included couples with prostate and breast cancer, and no systematic review has specifically addressed the study characteristics of couple-based interventions regarding sexuality concerns that include all cancer types (Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011; Scott & Kayser, 2009; Taylor, Harley, Ziegler, Brown, & Velikova, 2011). Potentially, such knowledge would provide a feasible structure that could be used when deciding how to implement interventions in the most fruitful way in clinical settings and when designing future intervention studies.

Given this background, we set out to explore the following research question: "What are the characteristics of couple-based interventions in existing quantitative research studies which aim to improve sexual function, sexual relationship and sexual self-concept of patients with cancer and their partners?"

Why is this review needed?

- Including partners in education and counselling about sexuality and intimacy can accentuate the benefits of counselling and promote the well-being of patients with cancer and their partners.
- No systematic review has specifically addressed study characteristics of couple-based interventions related to sexuality across different cancer types.

What are the key findings?

- We demonstrated existing limitations in couple-based interventions for cancer, for instance, a disproportionate emphasis on outcomes related to sexual functioning in male cancer patients and heterosexual couples.
- The findings identified shortcomings in the methodology and reporting of research studies focusing on couple-based interventions following cancer.

How should the findings be used to influence policy/practice/research/education?

- The paper demonstrates an urgent need to advance and validate alternate outcome measures that are built on sound theoretical constructs, such as the neo-theoretical framework of sexuality, to evaluate the improvement of multiple aspects of sexual concerns for couples receiving interventions following cancer.
- The results provide a firm foundation to enhance the design and reporting of future intervention studies addressing sexuality following cancer.

2 | THE REVIEW

2.1 | Aims

- To explore, describe and synthesize the characteristics and results of studies that investigate the effectiveness of couple-based interventions following cancer.
- To determine areas for improvement of research studies in this area.
- To discuss ways in which the results of the review might benefit clinical care.

2.2 | Design

We systematically reviewed the literature, guided by the checklists for quantitative research evidence in the Joanna Briggs Institute (JBI) Reviewer's Manual (2014). To accomplish transparent reporting of the results, we also followed advice from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—PRISMA statement (Liberati et al., 2009).

2.3 | Search methods

First, we conducted an exploratory search without time restrictions, encompassing free-text terms such as "sexuality," "intimacy," "cancer," intervention and "couple*" and various constellations of those, in the Cochrane database for systematic reviews, in the JBI database and on Google Scholar, to ascertain that no similar review existed (JJ). Then, we conducted a comprehensive electronic literature search in PubMed, CINAHL and PsychINFO including studies published from 1 January 2009 to 31 December 2016. The search terms, their levels and combinations were chosen after running a sensitivity test on a wide variety of possible free-text sentences, key words and MeSH terms. In accordance with the suggestion of a prior review (Klinke, Hafsteinsdóttir, Hjaltason, & Jónsdóttir, 2015), we only included new terms or combinations if they yielded at least one new potential article. The same criteria were applied when deciding on further inclusion of databases. Hence, adding more databases, such as Scopus and Embase, did not produce more eligible studies. For an example of a complete search strategy and results in PubMed, see S1. Additional papers were identified by carrying out citation tracking of included articles in Google Scholar and by scrutinizing the reference lists of eligible studies. We also contacted the authors of published study protocols to enquire whether their study had been completed and/or to ask them to share their preliminary results. Primary researchers were contacted in situations where additional information was needed.

2.3.1 | Review process and selection of included studies

Stage 1: Titles were screened for fit with predetermined eligibility criteria, see Table 1. If uncertainties existed regarding inclusion, the study continued to the next stage. Stage 2: Abstracts were screened by two authors after duplicates had been eliminated within and between each database. Stage 3: Full-text articles were evaluated as to whether they fulfilled the eligibility criteria. Consensus discussions involved a third author if doubts existed with regard to inclusion. Studies obtained from other sources also went through the above stages.

TABLE 1 Eligibility criteria used for including studies

Items	Eligibility criteria
Types of participants	All adult cancer survivors and their partners (all types of cancer in both heterosexual and homosexual couples) in any phase of cancer after diagnosis
Study designs	All quantitative intervention studies
Language	Studies in English
Date of search	Studies published from 1 January 2009-31 December 2016 Studies published prior to 1 January 2009, were excluded since they were already reported in other reviews (Brotto et al., 2010; Chambers et al., 2011; Scott & Kayser, 2009; Taylor et al., 2011)
Types of interventions	All couple-based interventions with the potential of integration into sexual health care and including different modes of delivery (face-to-face, telephone, web-based, group sessions, etc.) were included. Studies merely focusing on medical and invasive interventions were excluded
Types of outcome measures	Studies had to report at least one measure reflecting one of the major sexuality components according to the neo-theoretical framework (Cleary and Hegarty, 2010)

2.4 | Search outcome

The initial search yielded 1,348 studies. Eight additional records were identified by other sources. Two of those fulfilled the criteria for inclusion. After screening all the titles for relevance and eliminating duplicates within and between databases, 101 abstracts remained to be scrutinized further against the eligibility criteria. Ultimately, this left 26 full-text articles to be assessed. Out of those, 14 were included. For a flow chart of the study selection process, see Figure 1. In the search process, four authors were contacted to obtain additional information or to enable a decision on inclusion.

2.5 | Quality appraisal and reporting of interventions

Risk bias in relation to the study design and application of its method was evaluated independently by two reviewers using the JBI-Meta Analysis of Statistics Assessment and Review Instrument (MAStARI) (JJ/MEK) (see S2). No study was excluded based on this assessment. Rather, the results of the appraisal were used to provide recommendations for improvement. There was a high discrepancy in the initial evaluation; therefore, consensus was reached by involving a third reviewer (HJ). We used the template for intervention description and replication (TIDieR) checklist to evaluate the reporting of interventions (Hoffmann et al., 2014).

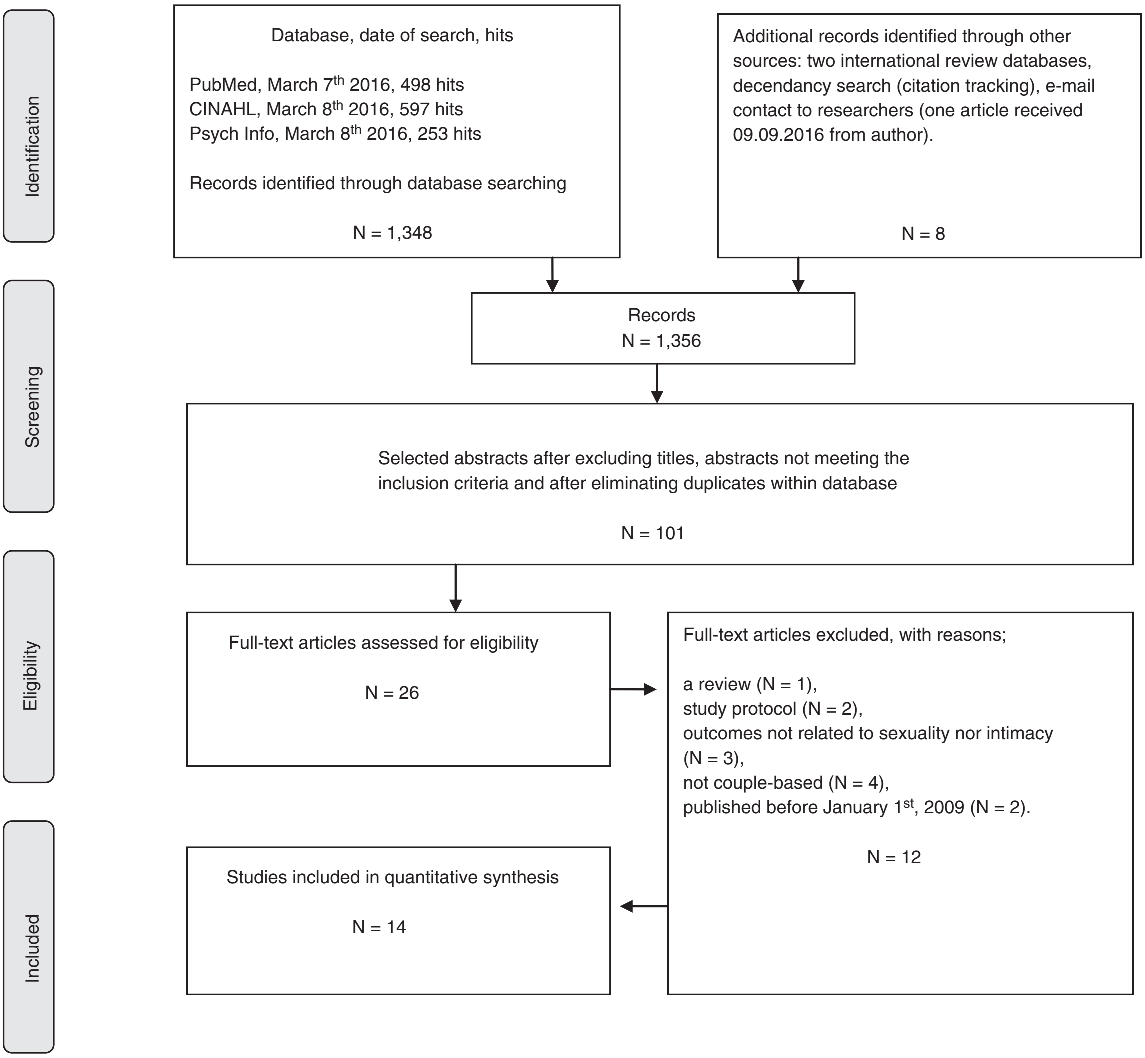

FIGURE 1 Adapted PRISMA flow diagram of the study selection process

2.6 | Data abstraction

Data related to source, country, setting, timing, participants, types of cancer, design, intervention and control group, couples, delivery mode, therapists, description of intervention and outcome measures of relevance for sexuality and results were extracted by the first author. A second author confirmed the correctness of data extraction.

2.7 | Synthesis

Due to the marked differences in chosen outcome measures and the incompatibility in the use of methods across studies, it was inappropriate to pool results by means of quantitative data synthesis. Therefore, the findings were summarized narratively. For a short overview of the included studies see Table 2.

3 | RESULTS

3.1 | Participants

A total of 1,726 individuals (863 couples, range 14–189) participated in the 14 studies. Out of those, a total of 572 couples (range 8–125) received an experimental intervention; the remaining couples functioned as controls. For an extensive overview of the characteristics of couple-based interventions, see S3. All studies, apart from four, focused on couple-based interventions for prostate cancer survivors (*N* = 10). The residual studies involved patients with breast cancer (*N* = 2) (Baucom et al., 2009; Decker, Pais, Miller, Goulet, & Fifea, 2012), colorectal cancer (*N* = 1) (Reese et al., 2014) and advanced gastrointestinal cancer (*N* = 1) (Porter et al., 2016). Although four studies welcomed same-sex couples (Hampton, Walker, Beck, &

TABLE 2 Short overview of included studies[a]

				Couples		
Source	**Intervention type**	**Setting**	**Cancer type**	**Experimental**	**Control**	**Intensity**
Studies with control group—single RCT, pilot RCT and quasi-experimental						
Baucom et al. (2009)	Face-to-face	Outpatient care	Breast	N = 8	N = 6	~7.5 hrs
Chambers et al. (2015)	Telephone	Private clinics, public hospitals	Prostate	Arm 1: N = 63 Arm 2: N = 62	N = 64	Arm one: ~8 calls Arm two: ~ 6 calls
Decker et al. (2012)	Face-to-face, telephone	One cancer centre	Breast	N = 26 face-to-face N = 14 telephone	N = 25	~3.0 hrs
Hampton et al. (2013)	Group based	Multi-site	Prostate	N = 24	N = 14	~3.5 hrs
Lyons et al. (2016)	Group based	Multi-site	Prostate	N = 32	N = 32	~48 hrs
Manne et al. (2011)	Face-to-face	Two cancer centres	Prostate	N = 37	N = 34	~7.5 hrs
Porter et al. (2016)	Videoconference	One outpatient cancer clinic Cancer registry	Gastrointestinal	N = 32	N = 17	~6 hrs
Reese et al. (2014)	Telephone	One cancer clinic	Colorectal	N = 13	N = 10	~3.3 hrs
Robertson et al. (2016)	Face-to-face	One clinic	Prostate	N = 21	N = 22	~5 hrs
Schover et al. (2012)	Face-to-face Web-based	Multi-site	Prostate	N = 60 face-to-face N = 55 Web-based	N = 71	~3.5 hrs
Walker et al. (2013)	Information face-to-face	Two cancer centres	Prostate	N = 14	N = 13	~1 hr
Studies with no control group—pre–post study design						
Song et al. (2015)	Web-based	Two cancer centres	Prostate	N = 26		~1.2–2.3 hrs
Walker et al. (2016)	Group-based	Urology clinic and one cancer centre	Prostate	N = 59		~3.5 hrs
Wittmann et al. (2013)	Group-based	One cancer centre	Prostate	N = 26		~6–8 hrs

[a] An extensive table describing the characteristics of couple-based interventions for sexuality following cancer can be found in online supplementary file.

Robinson, 2013; Manne et al., 2011; Robertson et al., 2016; Walker, Hampton, Wassersug, Thomas, & Robinson, 2013), they were only included in two instances (Manne et al., 2011; Robertson et al., 2016). In contrast, three studies excluded same-sex couples (Baucom et al., 2009; Chambers et al., 2015; Schover et al., 2012). With regard to partners' health status, three studies excluded those who had a diagnosis of cancer, active psychosis and dementia and those with hearing impairments (Manne et al., 2011; Porter et al., 2016; Song et al., 2015).

3.2 | Design and quality appraisal

Eight studies were pilot studies. Seven of those were pilot RCTs (Baucom et al., 2009; Manne et al., 2011; Porter et al., 2016; Reese et al., 2014; Robertson et al., 2016; Schover et al., 2012; Walker et al., 2013) and one study was a quasi-experimental pilot (Wittmann et al., 2013). In the remaining six studies, two were RCTs (Chambers et al., 2015; Lyons, Winters-Stone, Bennett, & Beer, 2016), two were quasi-experimental (Decker et al., 2012; Hampton et al., 2013) and two had a pre–post design (Song et al., 2015; Walker, King, Kwasny, & Robinson, 2016). Quality appraisal showed highly diverse results; see S2. The most common weaknesses in eight studies were related to randomization, blinding, concealment and insufficient description of outcomes in those couples who withdrew from the intervention (Baucom et al. 2009; Chambers et al., 2015; Decker et al., 2012; Hampton et al., 2013; Lyons et al., 2016; Manne et al., 2011; Porter et al., 2016; Reese et al., 2014; Robertson et al., 2016; Schover et al., 2012; Walker et al., 2013). However, the overall strengths across all studies were suitable ways of measuring outcomes, appropriate statistical analysis and providing data on partners.

3.3 | Country and setting

The studies were conducted in English-speaking countries: nine in the United States, three in Canada, one in Australia and one in the United Kingdom. Most interventions began after completion of primary cancer treatment (Hampton et al., 2013; Lyons et al., 2016; Reese et al., 2014; Robertson et al., 2016; Schover et al., 2012; Song et al., 2015; Walker et al., 2016; Wittmann et al., 2013). Six studies included patients from single-site specialized cancer centres or outpatient clinics (Baucom et al., 2009; Decker et al., 2012; Porter et al., 2016; Reese et al., 2014; Robertson et al., 2016; Wittmann et al., 2013). However, eight studies recruited participants more broadly, such as from a cancer registry, multiple cancer centres and support groups (Chambers et al., 2015; Hampton et al., 2013; Lyons et al., 2016; Manne et al., 2011; Porter et al., 2016; Schover et al., 2012; Song et al., 2015; Walker et al., 2013).

3.4 | Structure and results of couple-based intervention

A wide disparity was seen in the competencies and professions that provided the interventions; see S4. Only four of the studies reported that the interventionist(s) had received specific training in sexual health care or had prior training in couple's therapy (Baucom et al., 2009; Decker et al., 2012; Porter et al., 2016; Robertson et al., 2016).

All the studies reported at least one positive result of applying couple-based interventions, either mirrored in effect sizes, elucidating the direction of effect (Baucom et al., 2009; Hampton et al., 2013; Porter et al., 2016; Reese et al., 2014; Song et al., 2015; Walker et al., 2013, 2016) or statistical significance with *p*-values, indicating an absolute effect (Chambers et al., 2015; Lyons et al., 2016; Manne et al., 2011; Robertson et al., 2016; Schover et al., 2012; Walker et al., 2016; Wittmann et al., 2013). Demonstrating absolute effects seemed to apply to studies that included more participants (Lyons et al., 2016; Manne et al., 2011; Robertson et al., 2016; Walker et al. 2013; Wittmann et al., 2013) or studies that included couples with "less" relationship resources or low sexual function at baseline, hence providing a wider possibility for detecting change (Manne et al., 2011; Schover et al., 2012). Only two of the studies that reported statistical p-values had supported this with corresponding confidence intervals (Manne et al., 2011; Robertson et al., 2016). In the subsequent four sections, the main characteristics of interventions and results are described.

3.4.1 | Face-to-face interventions

Six studies involved face-to-face interventions where the duration ranged from 1-7.5 hrs with a mean of 4.6 hr (Baucom et al., 2009; Decker et al., 2012; Manne et al., 2011; Robertson et al., 2016; Schover et al., 2012; Walker et al., 2013). In four of the studies, the intervention was delivered face-to-face and in some instances also included home assignments in between sessions, for example, communication or sensate focus exercises (Baucom et al., 2009; Manne et al., 2011; Robertson et al., 2016). Two studies combined the face-to-face intervention with either telephone call(s) (Decker et al., 2012) or web-based information/interaction (Schover et al., 2012).

The exclusive face-to-face interventions diverged. In the study conducted by Baucom et al. (2009), the couples were taught effective communication to help them with sharing emotions and involving their partner in problem solving. Positive changes were found in satisfaction with relationship, sexual functioning and acceptance of bodily changes, both immediately and at the 1-year follow-up. Akin to this, Manne et al. (2011) also offered a similar intervention and found significant improvements in relationship satisfaction, communication and intimacy after the intervention was completed, in particular for couples that were "less resourceful" at the study outset.

A dissimilar way of face-to-face education was provided by Walker et al. (2013). Couples were given a 2-week home assignment of studying the contents of an educational booklet, with a single educational follow-up meeting. Positive changes were found in intimacy and relationship adjustment. Also, couples in the intervention group were more sexually active at the 6-month follow-up.

Following a face-to-face psycho-educational intervention, Robertson et al. (2016) found that participants were significantly less troubled by sexual concerns. However, at the 6-month follow-up, outcome measures had returned to baseline. After supporting effective communication, intimacy/sexual well-being and dyadic coping, using either face-to-face meetings or phone calls, Decker et al. (2012) found positive changes in relationship functioning and intimacy, using both modes of delivery. Finally, Schover et al. (2012) compared face-to-face counselling with a similar web-based intervention. Written material was provided for the face-to-face group (printed material from the website). Patients showed a significant improvement of erectile functioning, and better sexual function was reported by their partners.

3.4.2 | Group interventions

Four studies employed a group-based intervention (Hampton et al., 2013; Lyons et al., 2016; Walker et al., 2016; Wittmann et al., 2013). Three of them gathered the participants in a single, half to whole-day workshop and one study offered 6-month regular strength-training exercise for couples in groups (Lyons et al., 2016). The content of the group-based interventions differed. Wittmann et al. (2013) found a significant improvement in couples' communication about sexual problems, and there were positive changes among patients as regards approaching their partners about their sexual needs. The intervention emphasized the couple as a team in the process of sexual recovery and participants received information on sexual functioning aids, the concept of "satisfying sexuality" and how to counterbalance adverse effects of prostate cancer surgery and menopause.

The workshop by Hampton et al. (2013) focused on sexual changes after prostate cancer treatment, communication strategies, sensate focus exercises, value clarification and developing a plan as a couple to enhance the sexual relationship. A positive result was a reduced impact of prostate cancer treatment on sexual activity. Improved sexual interest and function was also found among partners. Support in relation to sexual changes following cancer treatment, preservation of sexual intimacy, value clarification and developing a plan together were also objectives in the workshop provided by Walker et al. (2016). Their results also revealed a tendency towards improved sexual relationship, satisfaction and orgasms. Finally, the study results from Lyons et al. (2016) showed a significant increase in affectionate behaviour among wives after the couple had been offered physical training exercises to enhance dyadic collaboration.

3.4.3 | Telephone interventions

Two studies delivered the intervention by telephone, where the number of phone calls ranged from four to eight (Chambers et al., 2015; Reese et al., 2014). In the study by Reese et al. (2014), telephone sessions focused on enhancing sexual communication, addressing constraining thoughts, broadening the range of both non-sexual and sexual activities and assigning sensate focus exercises. Sessions were supplemented with educational handouts. Improvements were found in intimacy and sexual function for couples regarding sexual communication. Chambers et al. (2015) provided an intervention consisting of support calls by nurses, covering the subjects of communication skills, conjoint coping, tip sheets on sexuality, behavioural homework and supplementary DVD or telephone calls provided by peers. The peer-supported group began their phone calls prior to prostate surgery, whereas the nurses initiated contact after surgery. The participants in both interventions significantly more often used medical treatment for erectile dysfunction.

3.4.4 | Other modes of delivery

Two studies used other modes of delivery, a pure web-based intervention for couples (Song et al., 2015) and videoconference sessions (Porter et al., 2016). After providing seven web-based educational modules, Song et al. (2015) found improvement in sexual function in partners. Two modules were mandatory, (1) couple communication and (2) survivorship. The remaining five modules were optional and encompassed information on how to manage diverse prostate cancer symptoms such as those related to sexual difficulties. In contrast, Porter et al. (2016) focused exclusively on communication training skills in their videoconference sessions, supplemented by homework assignments and educational handouts. The results indicated increased relationship satisfaction for couples as well as an improvement in perceived intimacy for partners.

3.5 | Consent, completion and fidelity

The acceptance rate for participation was described in six studies and ranged from 13% to 51% (Baucom et al., 2009; Decker et al., 2012; Manne et al. 2011; Reese et al., 2014; Robertson et al., 2016; Song et al., 2015). In two of those studies, the subsequent reasons given for non-participation were as follows: being too far from the hospital, lack of time, sexual problems not relevant, discomfort about discussing sex and feeling too ill (Baucom et al., 2009; Reese et al., 2014). Adherence to the intervention was described in four studies and ranged from 63.5% to 85% (Chambers et al., 2015; Porter et al., 2016; Walker et al., 2016; Wittmann et al., 2013). The drop-out rate was reported in three studies and ranged from 15% to 33% (Hampton et al., 2013; Porter et al., 2016; Schover et al., 2012).

In eight studies, various approaches were used to ensure therapists' compliance with the treatment in terms of the delivery of the content. For example, checklists were used or therapists were invited to discuss challenges they had encountered while providing the intervention and they reflected on possible solutions (Baucom et al., 2009; Chambers et al., 2015; Decker et al., 2012; Manne et al., 2011; Porter et al., 2016; Robertson et al., 2016; Schover et al., 2012; Walker et al., 2013).

3.6 | Control group

Four out of the 11 studies with a "care as usual" control group attempted to clarify the content of usual care (Baucom et al., 2009; Chambers et al., 2015; Manne et al., 2011; Robertson et al., 2016). Usual care was described as provision of available patient information materials (Chambers et al., 2015), making available to patients a list of community resources (Baucom et al., 2009), routine medical management/psychosocial services or referral to specialized services (Manne et al., 2011; Robertson et al., 2016). In one study, the control group received a delayed intervention (Reese et al., 2014), and in two instances, the control group received a different intervention (Porter et al., 2016; Schover et al., 2012). Four studies did not provide any explanation of "usual care" (Decker et al., 2012; Hampton et al., 2013; Lyons et al., 2016; Walker et al., 2013).

3.7 | Outcome measures

Most of the outcome measures only covered one of the three components of sexuality according to the neo-theoretical framework of sexuality (Cleary & Hegarty, 2011). The sexual relationship was addressed in 18 of 27 measures, sexual function in nine measures and sexual identity in five measures. The most comprehensive of the reported measures in relation to sexual concerns was the Psychological Impact of Erectile Dysfunction-Sexual Experiences scale, which assessed some components, albeit not in depth, in all three areas of the neo-theoretical model of sexuality (Chambers et al., 2015). Six of the outcome measures used to assess sexuality were cancer specific (Table 3).

Eight of these 27 outcome measures were used in more than one study (Chambers et al., 2015; Hampton et al., 2013; Manne et al., 2011; Porter et al., 2016; Reese et al., 2014; Robertson et al., 2016; Schover et al., 2012; Song et al., 2015; Walker et al., 2013, 2016; Wittmann et al., 2013). Collectively, the use of outcome measures reveals a wide disparity in how sexual concerns have been conceptualized and measured.

4 | DISCUSSION

In this systematic review, we identified study characteristics and results of couple-based interventions for sexuality-related concerns after cancer. Health professionals may benefit from the findings because they provide important suggestions for issues that should be addressed when planning on clinical interventions or research studies.

We had not anticipated that couple-based intervention studies would be so few, given the recent explosion in published literature that overall has highlighted the need for providing interventions to help couples deal with sexual concerns following cancer (D'Ardenne, 2004; Hawkins et al., 2009; Manne & Badr, 2008; Ussher et al., 2015). The issue of sexuality in patients with cancer has been addressed in previous reviews. However, they have mainly included

TABLE 3 Outcome measures, in included studies, related to sexuality

		Items covered according to the ternary neo-theoretical framework (Cleary and Hegarty, 2011) and cancer specificity			
Measure	**Description**	**Sexual relationship (communication/ intimacy)**	**Sexual function (including sexual desire)**	**Sexual self-concept (body image, sexual esteem and sexual self schema)**	**Cancer specific**
BIS-15 (Decker et al., 2012)	Body Image Scale, a 15-item scale that measures self-perception of body image developed for breast cancer survivors			✓	✓
DAS (Manne et al., 2011; Walker et al., 2013) DAS-A (Schover et al., 2012) RDAS (Chambers et al., 2015; Porter et al., 2016; Walker et al., 2016)	Dyadic Adjustment Scale, a 32-item self-report scale. Measures couple satisfaction; how each partner within the couple perceives his or her relationship. Dyadic Adjustment Scale-Abbreviated and Revised Dyadic Adjustment Scale (14-item) are both shorter versions of the Dyadic Adjustment Scale	(✓)			
DSCS-13 (Reese et al., 2014)	Dyadic Sexual Communication Scale, a 13-item Likert type scale that measures how respondents perceive the discussion of sexual matters with their partners	✓			
DSFI-SR (Baucom et al., 2009)	Derogatis Sexual Functioning Inventory—Self-Report measures constructs of current sexual functioning (e.g. drive, body image, sexual satisfaction) and indicators of general-well-being		✓		
HS-Q (Chambers et al., 2015; Wittmann et al., 2013)	Help Seeking-Questionnaire measures attitudes and beliefs that are potentially important in influencing men's help-seeking for ED		(✓)		
EPIC (Robertson et al., 2016; Song et al., 2015)	Expanded Prostate Cancer Index Composite, a 26-item scale constructed to measure urinary incontinence, urinary irritation, and the bowel, sexual and hormonal health-related quality of life domains		✓		✓
FACT-G (Song et al., 2015)	Functional Assessment of Chronic Illness Therapy-General, a 27-item scale that measures general quality of life and quality of life in physical, social/family, functional and emotional well-being	(✓)			
FSFI (Chambers et al., 2015; Reese et al., 2014; Schover et al., 2012)	Female Sexual Function Index, a 19-item Likert type measure that measures six domains of sexual function in females; desire, arousal, lubrication, orgasm, satisfaction and pain		✓		
HIR (Decker et al., 2012)	Heatherington Intimate Relationship scale, a 19-item Likert-type scale initially developed for assessment of postpartum couples and modified to assess changes in intimacy and sexuality	✓			
IIEF (Chambers et al., 2015; Reese et al., 2014; Schover et al., 2012)	International Index of Erectile Function, a 15-item standardized scale that measures the quality of male sexual function in five domains (erectile function, orgasmic function, sexual desire, sexual satisfaction, and overall satisfaction). Originally developed in conjunction with clinical trials for sildenafil		✓		

(Continues)

TABLE 3 (Continued)

		Items covered according to the ternary neo-theoretical framework (Cleary and Hegarty, 2011) and cancer specificity			
Measure	**Description**	**Sexual relationship (communication/ intimacy)**	**Sexual function (including sexual desire)**	**Sexual self-concept (body image, sexual esteem and sexual self schema)**	**Cancer specific**
ISS (Reese et al., 2014)	Index of Sexual Satisfaction, a 25-item Likert-type scale that measures the degree of dissatisfaction in the sexual component of a dyadic relationship	✓			
MSIS (Chambers et al., 2015; Porter et al., 2016; Reese et al., 2014; Song et al., 2015)	Miller Social Intimacy Scale, a 17-item measure of intimacy	✓			
MIS (Song et al., 2015)	Mutuality and Interpersonal Sensitivity Scale is a 32-item 5-point Likert-type scale consisting of two subscales; sensitivity and mutuality. Measures illness-related communication	✓			
MSES (Chambers et al., 2015)	Masculine Self-Esteem scale, a scale that was initially developed to assess outcomes of treatment for early prostate cancer. Measures men's appraisal of their masculinity			✓	✓
MSI-R (Porter et al., 2016)	Marital Satisfaction Inventory-Revised assesses the nature and extent of conflict within a marriage or relationship. Two subscales were used; Problem Solving Communication and Affective Communication	✓			
MS-15 (Lyons et al., 2016)	Mutuality Scale-15 item measures enduring quality in a relationship consisting of love, shared pleasurable activities, shared values, and reciprocity	✓			
QMI (Baucom et al., 2009)	Quality of Marriage Index, a six-item measure of marital quality on a 7-point Likert-type scale	✓			
PAIR (Manne et al., 2011; Walker et al., 2013)	Personal Assessment of Intimacy in Relationships, a 36-item measure developed asses intimacy in relationships, both actual and ideal levels	✓			
PIBS (Lyons)	Physical intimacy Behaviour Scale	✓			
PBS (Wittmann)	The Protective Buffering Scale. Measurers hiding concerns and avoiding disagreements, motivation to protect, received buffering	✓			
PIED-SE (Chambers)	Psychological Impact of Erectile Dysfunction-Sexual Experience scale measures the impact of erectile dysfunction on the sexual experience and on patient emotional life	✓	✓	✓	
RAS (Song)	Relationship Assessment Scale, a 7-item scale designed to measure individual's satisfaction with their relationship satisfaction, using a Likert 5-point scale	✓			
SFQ (Hampton et al., 2013; Reese et al., 2014; Walker et al., 2016)	Sexual Function Questionnaire, a 30-item questionnaire specifically developed for cancer survivors that measures sexual interest, sexual response, sexual activity, satisfaction, relationship, masturbation, problems and medical impact	✓	✓		✓

(Continues)

TABLE 3 (Continued)

		Items covered according to the ternary neo-theoretical framework (Cleary and Hegarty, 2011) and cancer specificity			
Measure	Description	Sexual relationship (communication/ intimacy)	Sexual function (including sexual desire)	Sexual self-concept (body image, sexual esteem and sexual self schema)	Cancer specific
SCNS (Chambers)	Supportive Care Needs Survey-sexuality needs subscale, a 34-item Supportive Care Needs Survey Short Form (SCNSS-F34) measures cancer-specific perceived needs in five domains. Items for the sexuality need domain consist of changes in sexual feelings, sexual relationship and provision of information about sexual relationship	✓		✓	✓
SIRA-Q (Wittmann)	The Sexual Information and Recovery Activities Questionnaire, non-validated, 3-item measure designed specifically for the study. Items ask about knowledge about sexual problems in prostate cancer and recovery strategies, couple activities to enhance sexual recovery and frequency of sexual activity	✓	✓		✓
SIS (Baucom)	Self-image scale, an 11-item measure that assesses the effects of cancer on body image			✓	
WSFS (Decker)	Watts Sexual Functioning scale; a 17-item, 5-point Likert-type scale that measures sexual desire, sexual response and sexual satisfaction The total sexual function score ranges from 17 to 85, with high scores being associated with positive sexual function. The measure has been used with a variety of chronically ill populations		✓		
27 measures	Total	18	9	5	6

(✓); main focus of measure is not related to sexuality.

patients with breast or gynaecological cancer or prostate-testicular cancer (Abbott-Anderson & Kwekkeboom, 2012; Carpentier & Fortenberry, 2010; Carroll, Baron, & Carroll, 2016; Chisholm, McCabe, Wootten, & Abbott, 2012; Emilee, Ussher, & Perz, 2010; Gilbert, Ussher, & Perz, 2011; Nelson, Emanu, & Avildsen, 2015). Many of the studies in these reviews did not address the needs of the couple and only provided minimal information on methodological shortcomings adversely affecting the quality of results.

Twelve studies only enrolled patients with prostate and/or breast cancer—of those studies, 10 included patients with prostate cancer and their partners. Prostate cancer most often occurs in older males (Regan et al., 2012). Therefore, the needs and concerns of younger couples may be under-represented. Patients with other types of cancer also experience intrusive problems related to sexuality. Hence, the results of interviews with 657 patients with cancer showed that sexual problems and changed body image also occurred in patients with non-reproductive cancer types, in various age groups, cancer stages and relationships (Ussher et al., 2015). Nevertheless, research studies on couple-based interventions in these other cancer types remained almost absent.

The two studies that included couples classified with “less resources” at baseline both showed significant benefits from receiving the couple-based intervention (Manne et al., 2011; Schover et al., 2012). Unfortunately, most studies omitted data related to the couple’s resources and actual change in their sexual relationship after the cancer diagnosis. Some couples may experience growth—even improvement—in their relationship throughout the illness trajectory (Ussher et al., 2015), but might still benefit from support. For this reason, we advocate using more person-focused outcome measures to capture the gains that even well-functioning couples obtain.

Overall, information on partners was not provided in much detail. The potential characteristics that should be considered in future studies encompass their age, education, health status, for example, cancer, dementia or other diseases that may influence their perception and ability to receive a couple-based intervention.

In two studies, same-sex couples were excluded (Chambers et al., 2015; Schover et al., 2012). Although cancer diagnosis and treatment affect all women and men, regardless of sexual orientation, research on this population is still inadequate (Katz, 2011). A recent research study from Ussher et al. (2016) sheds light on the fact that gay and bisexual men, compared with heterosexual men, may experience an augmented impact of prostate cancer in the domains of psychological distress, ejaculatory problems and lower masculine self-esteem. Nevertheless, only a few interventions have been developed for alleviating the unique concerns of gay and/or bisexual men following prostate cancer (Hartman et al., 2014; Katz, 2015). A qualitative study revealed that lesbian women found less change in sexuality after cancer diagnosis than heterosexual women, presumably due to greater acceptance of physical changes and having an already established sexual repertoire of non-penetrative sexual practices (Ussher et al., 2014). The unique experiences of same-sex couples warrant closer attention because their concerns may offer valuable insights when planning couple-based interventions.

Since outcome measures predominantly focused on sexual relationship and sexual function, future research projects should prioritize developing and validating a more balanced sexuality scale that encompasses items corresponding to the main areas of the neo-theoretical model of sexuality. This corresponds with recommendations from The European Organization for Research and Treatment of Cancer supporting the view that questionnaires on the sexual health of female and male cancer patients should include a comprehensive bio-psycho-social construct of sexuality (Nagele, Den Oudsten, & Greimel, 2015).

It is of interest that the couple-based interventions, in spite of their diversity, shared common threads, as reflected in S3. These can be summarized into four themes: (1) improving communication skills; (2) facing the consequences of cancer treatment on sexuality; (3) relationship adaptation; and (4) identifying/restructuring negative beliefs about sexual activities. Previously, it has been suggested that merging elements of education, mutual coping support and sex therapy tend to produce stronger effects in alleviating sexual concerns after cancer than more narrowly focused sexual interventions (Carroll et al., 2016; Scott & Kayser, 2009). A huge setback that we observed in studies involving a control group was that the authors did not elaborate on how the experimental intervention diverged from usual care.

4.1 | Clinical implications

Although we cannot provide solid recommendations on how to structure couple-based interventions, the results of previous research, in line with our results, indicated that couple-based interventions are more likely to result in positive adaptation if they are tailored to the needs of the couple (Martire, 2013; Regan et al., 2012). In this regard, various modes of delivery have different advantages. For example, therapeutic contact via face-to-face or videoconference/telephone are more useful for adapting the treatment to the needs of the couple than a group or web-based format.

In six studies, only 13%–51% of invited couples participated. The reasons given for not joining were being too distant from the hospital, lack of time, feeling that sexual problems were not relevant, finding it too difficult to discuss sexual issues and feeling too ill (Baucom et al., 2009; Reese et al., 2014). Therefore, we recommend that nurses thoroughly contemplate the strengths and weaknesses of the various modes of delivery, travelling distance from the intervention site and how the intervention is offered to the couple.

The initiative for offering couple-based interventions should come from health professionals because patients may have difficulties expressing the need for interventions. To exemplify, in a study among gynaecologic and breast cancer survivors, over 40% of them had expressed an interest in receiving sexual health care. However, in reality, only 7% had sought help for sexual issues (Hill et al., 2011). Lack of skills among oncology nurses in addressing sexuality may partly explain this problem and improving this situation is a logical clinical aim. A recent educational project has shown that nurses can improve their skills in providing sexual health care but also that ongoing training is required if they are to maintain their qualifications (Jonsdottir et al., 2016).

4.2 | Limitations

Unfortunately, it was not possible to provide an overall recommendation for implementation of couple-based sexuality interventions in clinical care because there are still too many uncertainties at play. Many of the studies were comparatively small and did not offer complete information on several study components, for instance on outcome measures and on whether and how the interventionist(s) had been trained. Logically, the quality of the conclusions that we can draw cannot exceed the quality of reporting in each of the included studies. To improve the description and comparison of interventions in future studies, we recommend that available checklists such as Criteria for Reporting the Development and Evaluation of Complex Interventions in health care (CReDECI 2) or TIDieR should be used routinely (Hoffmann et al., 2014; Möhler, Köpke, & Meyer, 2015).

All the studies were from English-speaking countries and studies from other parts of the world are needed. Based on the applied search strategy, we cannot rule out that publications on couple-based interventions following cancer exist in other languages than English.

5 | CONCLUSION

Findings of the review provide new insight into how the structure, design and reporting of future research studies of couple-based interventions to alleviate sexual concerns, following cancer, can be improved. We found that couple-based interventions are complex to investigate due to the large heterogeneity in the population and the different needs for support that couples have. Therefore, in future research studies, consideration should be given to using methods in which the couples function as their own control group, before moving on to larger randomized controlled study designs. More work is also needed to construct, refine and validate cancer-specific outcome measures that reach into all areas of the neo-theoretical framework of sexuality.

Nurses' skills need to be enhanced in regard to addressing sexual concerns that couples encounter after cancer and they should be more proactive in seeking solutions to counterbalance challenges related to sexual function, sexual relationship and sexual identity.

AUTHOR CONTRIBUTIONS

JIJ, HJ and MEK were responsible for the study conception and design. JIJ performed the initial literature searches; JIJ and HJ performed the initial assessment of risk of bias. MEK was involved in consensus discussions. Data were extracted by JIJ and MEK. JIJ was responsible for drafting the manuscript, and MEK and HJ made critical revisions to the article for important intellectual content.

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [http://www.icmje.org/recommendations/]):

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

How to cite this article: Jonsdottir JI, Jonsdottir H, Klinke M. A systematic review of characteristics of couple-based intervention studies addressing sexuality following cancer. *J Adv Nurs*. 2018;74:760–773. https://doi.org/10.1111/jan.13470

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Paper II

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The Benefit of a Couple-Based Intervention Among Women in Active Cancer Treatment on Sexual Concerns

A Quasi-Experimental Study

KEYWORDS
Advanced practice nursing
Couple therapy
Neoplasms
Psychosocial support systems
Sexual health
Sexuality
Spouses
Women

Background: Sexuality-related problems are common in women with cancer, threatening their sexual well-being and intimate relationships. Evidence-based interventions addressing the full range of sexual concerns among women in active cancer treatment are scarce. **Objective:** The aim of this study was to evaluate the benefits of a novel couple-based intervention focusing on sexual concerns among women undergoing cancer treatment, including a subgroup of women with breast cancer. A secondary aim was to assess changes in illness intrusiveness in daily life. **Methods:** A quasi-experimental single-group pre-post follow-up design was used. The study was initially planned as a randomized controlled trial with waitlist control group receiving delayed intervention. However, substantial differences were observed in clinical and demographic variables between the treatment group and control group, resulting in using a single-group pre-post follow-up design. The intervention consists of 3 advanced nurse-led, face-to-face couple-based sessions supported by access to web-based information. **Results:** Women in active cancer treatment participated in the study (n = 60) together with their partners (n = 60). The main results showed significant differences between time points in the outcome measures for concerns related to the sexual adverse effects of cancer treatment (T1 vs T2, and T2 vs T3), sexual concerns related to the women's partners (T1 vs T2), and for concerns related to communication

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This study was supported by grants from the following institutions: Research Fund of Ingibjorg R. Magnusdottir, the Icelandic Nurses' Association Scientific Fund, the Landspitali University Hospital Scientific Fund, and the Scientific Fund of the Icelandic Cancer Society.

The authors have no conflicts of interest to disclose.

The trial was registered at clinicaltrials.gov (entry NCT03936400), Development of Therapeutic Conversations with Females Diagnosed with Cancer and Their Partners).

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Accepted for publication October 29, 2020.
DOI: 10.1097/NCC.0000000000000949

with healthcare providers about sexuality-related issues (T1 vs T2). No significant changes were found over time with respect to illness interference on the intimacy or instrumental subscales. **Conclusions:** The results demonstrated that the approach of 3 couple-based therapeutic conversations is beneficial in reducing sexual concerns among women in active cancer treatment. **Implications for Practice:** Advanced nurse practitioners can develop and offer brief psychoeducational support that is helpful in reducing sexual concerns among women in active cancer treatment.

Sexuality is an integral aspect of the human experience. For the purpose of this study, a concept of sexuality reflecting an integrative biopsychosocial understanding was prioritized. We drew on the neotheoretical framework that conceptualizes sexuality as an integrative, multidimensional construct that comprised sexual response (desire, arousal, orgasm), sexual self-concept (body image, sexual esteem, sexual self-schema), and sexual or intimate relationship (aspects related to communication and intimacy).[1] Intimacy was further defined in the study as emotional sharing, communication, and physical intimacy that increase the sense of closeness.[2]

Cancer treatment can negatively affect women's sexuality in its emotional, physical, and relational aspects.[3,4] However, intimate relationships—a unique form of social support—may positively affect the sexual lives of women receiving active cancer treatment.[5] For women with intimate partners, the sexual adverse effects of cancer treatment can lead to loss of sexual intimacy, changes in their sense of femininity, and relationship strain.[6] This indicates the importance of acknowledging the intimate partner's key role when devising interventions.

Claims regarding the efficacy of couple-focused therapies tend to be mostly limited to variants of either behavioral or emotion-focused couple therapies.[7] Despite research findings suggesting that couple-based interventions can both accentuate intervention benefits and reduce illness-related distress in one or both partners, couple-based interventions in the context of cancer are markedly few.[8–10] Couple-based interventions specifically designed to address sexual concerns among women suffering from diverse forms of cancer are absent from the published literature. The few couple-based interventions that have been developed for women with cancer have focused on women with breast cancer.[11–13] Overall, the results of these intervention studies showed positive effects on sexual function, body image, and intimate relationships. Baucom and colleagues,[11] in a pilot randomized controlled trial study, implemented a 6-session face-to-face couple-based intervention for 14 women with breast cancer and their partners over 3 months. The results showed a positive direction of effect, albeit most often small to medium effect size, for relationship satisfaction, sexual functioning, and acceptance of bodily changes. In another couple-based intervention study that implemented a quasi-experimental design, women with breast cancer and their partners participated in 3 sessions over a period of 6 to 9 weeks, supported by written materials.[12] The results showed a trend toward improved relationship functioning and intimacy. Finally, in a recent randomized pilot trial, 20 women with breast cancer and their partners participated in 4 weekly sessions using standardized protocol delivered via telephone.[13] Women in the experimental group showed greater improvements in various sexual quality-of-life outcome measures than did women in the control group.

It is essential that such couple-based interventions adequately reflect the full range of women's sexual concerns—that is, not only the physical aspects of sexuality but also the renegotiation of sexual expression and intimacy.[6,14] Despite their diversity in terms of theoretical frameworks and components, couple-based interventions aimed at alleviating sexual concerns following cancer treatment share several common threads, including the improvement of communication skills, acknowledgement of the consequences of cancer treatment for sexuality, relationship adaptation, and the restructuring of negative beliefs about sexual activities.[15] Furthermore, because sexuality and intimacy are inherently sensitive and personal topics, couple-based interventions should employ theoretical frameworks that are likely to build trust between the couple and the healthcare provider. Studies have confirmed that cancer patients prefer a person-oriented approach in coping with changes in sexuality. A "one-size-fits-all" approach is not realistic because individuals and couples manage these changes in different ways.[6,16] Findings from a recent qualitative study among women with breast cancer and their intimate partners support this view.[17] The authors concluded that the couples' abilities to "work as a team" and open communication were the 2 most important elements in coping with sexual changes following cancer.

Although advanced nurse practitioners (ANPs) have unique positions that allow them to address the full range of sexual concerns among women in active cancer treatment and their partners, they have not yet developed or tested such interventions within family nursing. Regrettably, women with cancer often perceive a lack of interest in sexuality-related matters among healthcare providers.[14,18] This can unfortunately impact their preparedness for the sexual adverse effects of cancer diagnosis and treatment, given that studies have repeatedly confirmed that most women with cancer want their sexual concerns to be addressed but rarely ask for help.[19] When women with cancer are encouraged to voice the "unspeakable," they are offered an opportunity to validate any sexual concerns that they might have.[20,21] In a recent online survey, 667 Dutch breast cancer survivors responding to an open-ended question reported perceiving trust as a key requirement for such a conversation.[22] This finding further confirms the importance of trust between the healthcare provider and the couple in couple-based intervention for a sexual concern. In response to this, health providers in cancer survivorship care have issued evidence-based guidelines on interventions that address women's sexual problems and a manifesto to optimize preservation of the capacity for sexual life and sexual function of women affected by cancer.[23,24]

Based on the literature review, a novel couple-based intervention—the Couple Strengths-Oriented Therapeutic Conversation (CO-SOTC) intervention—was developed and tested among 60 women with diverse cancer types in active cancer treatment and their partners.

■ Aim

The primary aim of this study was to assess the benefits of a couple-based intervention on sexual concerns among women in active cancer treatment. A secondary aim was to assess changes in the extent to which illness intrudes on daily life.

■ Study Hypotheses

Based on previous literature, it was hypothesized that (1) women diagnosed with cancer in general and (2) breast cancer in particular who are in active cancer treatment and receive the CO-SOTC intervention will report significantly lower concerns over time in relation to

(a) Sexual adverse effects of cancer treatment
(b) Sexual concerns related to their partners
(c) Concerns related to communication with healthcare providers about sexuality-related issues

■ Research Questions

The following research question was asked:

Do any differences emerge over time in the extent to which illness intrudes in daily life, particularly with respect to the intimacy and sex lives, of women undergoing active cancer treatment and diagnosed with cancer in general and breast cancer in particular?

■ Methods

Study Design

A single-group pre-post study design was used with 1 preintervention and 2 postintervention assessments. Initially, the study was intended as a randomized controlled trial with wait-list control group (receiving delayed intervention). However, substantial differences in clinical and demographic variables were observed between treatment and control groups. Therefore, a repeated single-group pre-post follow-up test setup was used, comparing women with cancer and their partners over the 3 time points. All 60 couples in the data set in the present article provided at least 1 preintervention and 2 postintervention assessments over a 3-month time.

Participants and Setting

The study participants were women who met the following inclusion criteria: 18 years or older, diagnosed with cancer (irrespective of type and stage), in active cancer treatment, in an intimate relationship, and fluency in written and spoken Icelandic language. Sample size assessments indicated that, given repeated-measures tests of mean differences and an average effect size of 0.5 (based on Cohen *D*), an N of 27 would be needed for statistical power of 80% and an N of 36 would be needed for statistical power of 90%.[25] The women were approached by clinical nurses and radiologists at Landspitali University Hospital in hematology/oncology, radiotherapy, gynecology, and surgical hospital departments. Eligible participants were given a letter with information about the study and a consent form. The main researcher, who also administered the intervention, received the written consent forms from the women who agreed to participate and scheduled their first visits. The intervention was delivered in a neutral setting outside the hospital.

Enrollment

During the enrollment period, 149 women were deemed eligible and invited to participate (Figure). If the woman agreed to participate, she then asked her partner if he was willing to participate with her in the intervention. A total of 73 women and their partners agreed to participate, resulting in a 49% acceptance rate. Of those 73 couples, 2 failed to fully meet the inclusion criteria and were excluded (in both instances, the partner did not speak, write, or read Icelandic), and 10 couples withdrew their consent before the intervention, mostly due to deteriorating health, but other known reasons included "stressful cancer treatment," "difficulty in finding time due to partner's work schedule," or "cancer treatment finished." One couple withdrew from the study after allocation. Finally, 4 couples who pilot-tested the intervention were included in the analysis because no changes were made to the intervention following pilot testing. Thus, a total of 60 couples took part in the intervention.

Data Collection

Data were collected from April 15, 2017, to August 20, 2019. The participants completed the assessment instruments prior to the first session at baseline (T1), postintervention (T2), and after the follow-up session (T3). All 60 couples attended all 3 face-to-face sessions, resulting in a 100% completion rate.

Assessment Instruments

This article describes an intervention that was part of a larger research project where a total of 4 main outcome measures were used (Sexual Concern Questionnaire [SCQ],[26] Illness Intrusiveness Rating Scale [IIRS],[27] Ice-Beliefs Questionnaire for couples [ICE-Couple],[28] Partnership Questionnaire [Partnerschaftsfragebogen; PFB][29]). The woman answered all 4 outcome measures, and the intimate partner, 2 of them

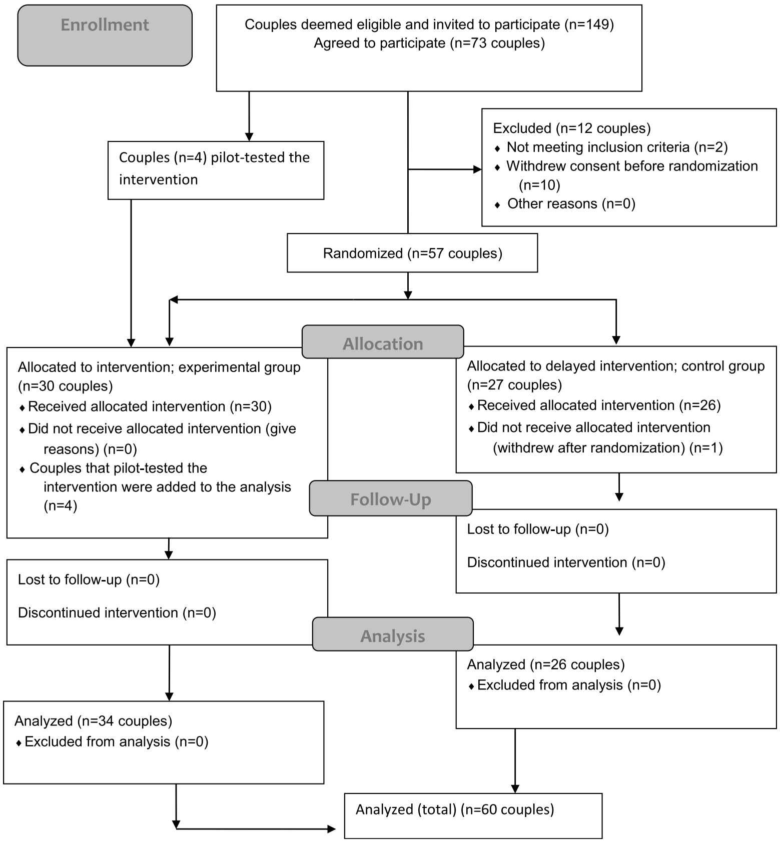

Figure ■ CONSORT flow diagram.

(ICE-Couple and PFB). In the present article, data from the woman's perspective were reported, and therefore the SCQ and IIRS outcome measures were analyzed.

DEMOGRAPHIC QUESTIONNAIRE

The demographic questionnaire included 16 questions covering topics such as age, education, time since cancer diagnosis, stage of cancer, type of cancer treatment, and comorbidities.

THE SEXUAL CONCERN QUESTIONNAIRE

The SCQ, originally SCQ–Gynecological Cancer is a 42 question 5-point Likert scale cancer-specific questionnaire that assesses sexual concerns after gynecological cancer diagnosis.[26] Only a minor adaptation was necessary to ensure its applicability for women diagnosed with any type of cancer. The questionnaire reflects an integrative biopsychosocial approach and was therefore suitable for use in this study.[30] It comprises 4 subscales and 2 open-ended questions about other sexual concerns or anything else the woman might wish to share. The first subscale is a 22-item scale that measures sexual concerns related to sexual adverse effects associated with cancer treatment, such as diminished interest in sexual activity or associated pain. The second subscale is a 10-item scale that measures the women's sexual concerns relating to their partners, such as concerns that their partners do not find them sexually attractive or their experiences of not feeling emotionally close to their partners. The third subscale includes 5 items pertaining to concerns about communication with healthcare providers in relation to sexual concerns, including the healthcare providers' perceived discomfort in discussing sexuality. Because the fourth subscale of the questionnaire is aimed at women currently without partners, it was omitted from this study. An earlier study reported Cronbach's α of .78 for the entire questionnaire and test-retest reliability of 0.89 at 2 weeks and 0.99 at 3 to 4 weeks. Cronbach's α was .89 for the first subscale, .83 for the second, and .93 for the third.[26]

ILLNESS INTRUSIVENESS RATING SCALE

The IIRS is a 13-item self-report questionnaire, with 3 subscales measuring the extent to which illness interferes with meaningful activities or interests in daily life.[27] The first subscale—social relations and personal development—comprises six questions about family relations, other social relations, passive recreation, self-expression, religious expression, and community and civic involvement. The second subscale—intimacy—comprises 2 questions about the respondents' relationship with their intimate partner and their sex life. The third subscale—instrumental—comprises 4 questions about the respondents' health, work, active recreation, and their financial situation. The IIRS has been used among diverse patient groups, including breast cancer patients, and has been found to be valid and reliable.[27] For the Icelandic version of the questionnaire, Cronbach's α was .933 for the entire questionnaire, .901 for the subscale social relations and personal development, .793 for the intimacy subscale, and .842 for the instrumental subscale.[31]

Intervention

The CO-SOTC intervention is a face-to-face couple-based intervention consisting of 3 strengths-oriented therapeutic conversations. After completing the first session, the couple is given access to evidence-based information on a secure website. The information is presented in a 42-page booklet about the most common sexual adverse effects of cancer treatments in women and possible solutions. The information available on the website is an optional part of the intervention.

Development of the Intervention

The overall theoretical framework of the intervention used in this study is the Family Strengths-Oriented Therapeutic Conversation (FAM-SOTC) intervention, a family nursing intervention developed and tested in clinical settings.[32–34] The development of the FAM-SOTC intervention aspires to reflect an advanced nursing practice competency that is based on clinical practice and empirical evidence.[35] The structure and content of most therapeutic conversations are influenced by 2 main theoretical frameworks—dyadic theories that originated in social psychology (eg, relationship- or attachment-oriented theories) and theories focusing on the individual (eg, cognitive-social processing or stress-coping frameworks).[10] The intervention in this study relies predominantly on the Illness Beliefs Model (IBM) of Wright and Bell.[20] The IBM, a component of FAM-SOTC intervention, is an advanced clinical practice model grounded in postmodernism, a world view that is advanced in the biology of cognition theory and grand theories such as systems theory, communication theory, cybernetic theory, and change theory, along with midrange theories from family nursing.[36–38] The systemic and relational (dyadic) emphasis of the IBM is ideally suited as a clinical practice model to frame an intervention offered to women in active cancer treatment and their partners. For example, the couple is considered a "unit" in the sessions, and the questions used in the therapeutic conversations reflect the systemic understanding of their sexual relationship.

For a comprehensive understanding of the multiple factors that shape women's sexuality, the New View Manifesto, a theoretical framework offering a woman-centered understanding of sexual problems, and the neotheoretical framework of sexuality provide the necessary background (Table 1).[1,40]

Implementation of the Intervention

The CO-SOTC intervention was provided in three 45-minute face-to-face sessions on site. The first 2 sessions were scheduled 1 to 2 weeks apart, and the final booster session took place 3 months after the first session. The timing of the sessions in the CO-SOTC intervention was chosen for several reasons. First, the participants were in active treatment at the time of enrollment. Therefore, it was not practical to hold the first 2 sessions too far apart, as many of the women were at risk of experiencing debilitating adverse effects from their cancer treatment. Second, the first 2 sessions were spaced 1 to 2 weeks apart to facilitate better preservation of the therapeutic relationship's bonds and to foster continuation of the therapeutic conversations' momentum. Third, the final booster session was scheduled for 3 months after the first session to allow the couple some time to reflect on their experiences of participation in a brief intervention.

Session components (Table 2) reflected the theoretical frameworks (Table 1) guiding this study. After completing the first session, the couples were handed a sheet directing them toward noninteractive, evidence-based information on a secure website.

Advanced Nurse Practitioner

The ANP provided the intervention throughout this study and wrote the evidence-based information for the secure website.

Intervention Fidelity

The ANP participated in an in-person training course abroad regarding the clinical nursing practice model guiding the therapeutic conversation in the intervention. To further enhance intervention fidelity, diary notes were written after each session, for example, in relation to the facilitating and hindering beliefs of the woman and her partner. The ANP's supervisor regularly attended and observed the sessions.

Statistical Analysis

Descriptive statistics were used to report background variables. Repeated-measures analysis of variance was used to assess outcomes. Mauchly's test generally showed deviation from sphericity on outcomes in both the SCQ and IIRS scales. Therefore, the Greenhouse-Geisser formula was used for correcting deviation from sphericity. The Statistical Package for the Social Sciences[41] version 26.0 was used for descriptive statistics and statistical analyses. The significance value for the difference between means was set at $P < .05$.

Ethical Procedures

The study was granted ethical approval by the Scientific Ethics Board at Landspitali–The National University Hospital of Iceland (No. 23/2016) which also notified the National Bioethics Committee about the study. The study was approved by the chief executives of nursing and medicine and head nurses in participating wards at Landspitali–The National University Hospital of Iceland. The trial was registered at Clinicaltrials.gov (entry NCT03936400; Development of Therapeutic Conversations With Females Diagnosed With Cancer and Their Partners).

■ Results

The sample included 60 women diagnosed with diverse types of cancer who were in active cancer treatment, as well as their partners (all males) (Table 3). However, in this study, only the data from the women were analyzed. The average age of the women was 52 years (range, 30–70 years). The average length of their current relationships was 25.12 years (median, 24 years). Forty-three women (72.9%) had university-level education. Most had been diagnosed with breast cancer (76.7%). The majority of the women had localized cancer (72.7%), and 27.3% had advanced cancer. Among the 15 women reporting advanced

Table 1 • Intervention: Theoretical Frameworks, Rationale, and Utilization of the Couple-based Strengths-Oriented Therapeutic Conversation (CO-SOTC) Intervention in Clinical Practice

Theoretical Frameworks Guiding the Intervention and Rationale	Utilization of CO-SOTC in Clinical Practice
Family Strengths-Oriented Therapeutic Conversation (FAM-SOTC) intervention is the overarching framework.[34] It is a family system nursing intervention, rooted in a clinical nursing practice that is based on 4 models: the Calgary Family Assessment/Intervention models, the Illness Belief Model (IBM), and the Resilience component of the Resiliency Model.[20,34,39] The FAM-SOTC intervention can be implemented on different levels, according to the nurse's professional competence. In the couple-based intervention in this research study, an ANP with training in family systems nursing and specialization in clinical sexology provides the intervention.	In the intervention in this study, all 5 key components guiding the FAM-SOTC intervention are utilized: eliciting the illness narrative; asking therapeutic questions; strengthening helpful beliefs and challenging hindering beliefs; identifying resources, strengths, and flexibility; and offering information based on evidence. Furthermore, a genogram was adapted to outline the couple's internal and external structures, including their unique relationship history.[37]
The intervention in this study relies predominantly on the IBM of FAM-SOTC.[20,21,38] The systemic, relational, and narrative elements of the IBM are well suited to clinical work with couples. The core idea of the IBM is that it is not automatically the clinical problem or illness but rather beliefs about the clinical problem or illness that serves as the main source of suffering for the family and subsystem, such as the couple. Clinically useful illness-related beliefs about 8 major aspects guide the therapeutic conversations: • suffering • diagnosis • etiology • healing, and treatment • mastery/control/influence • prognosis • religion/spirituality • the place of illness in lives and relationships	The clinical illness beliefs of the IBM are applied to the CO-SOTC in order to identify constraining beliefs, challenge them, and support facilitating beliefs using certain conversational processes. The task of the ANP utilizing the IBM model in the intervention in this study centers around 4 main conversational pillars: • Create context for changing beliefs • Distinguish illness beliefs • Challenge constraining beliefs • Strengthen facilitating beliefs The couple is offered 3 therapeutic conversations based on the FAM-SOTC intervention, highlighting the IBM's conversational processes (see session components in Table 2). The couple is invited to reflect through interventive questions—linear or circular—adapted to the subject of sexuality and intimacy. For change to become evident or become reality, it must be distinguished. This is achieved by exploring the effects of change and inviting the couple to observe the change in each other and focus on facilitating beliefs, celebrating, or highlighting the change. Compliments and commendations are another way to witness and thereby strengthen facilitating beliefs.
The neotheoretical framework of sexuality asserts that sexuality should be viewed as a multidimensional construct and must be assessed accordingly.[1] These dimensions are sexual response (desire, arousal, orgasm), sexual self-concept (body image, sexual esteem, sexual self-schema), and sexual relationship (aspects related to communication and intimacy).	To increase the likelihood of the successful adjustment of a sexual life, the advanced nurse practitioner must attend to all 3 domains of the neotheoretical framework of sexuality in the sessions. The advanced nurse practitioner considers these domains to represent the absolute minimal dimensions of sexuality that must be considered and addressed in the sessions. The questions used in the sessions are designed to reflect this understanding.
The New View Manifesto on women's sexual problems is a theoretical framework and classification system for women's sexual problems grounded in sexual rights rather than biology and provides an overarching alternative framework for women's sexuality.[40] It also offers a woman-centered definition of sexual problems as discontent or dissatisfaction with any emotional, physical, or relational aspect of sexual experience that may arise in one or more interrelated aspects of women's sexual lives. These aspects of women's sexual lives are related to (*a*) sociocultural, political, or economic factors; (*b*) partner and relationship factors; (*c*) psychological factors; and (*d*) medical factors.	The New View Manifesto extends beyond the neotheoretical framework of understanding on how women's sexuality can be influenced and what can become "a sexual problem" for women. The manifesto takes into account the complexities of the "lived experience" of women's sexuality. Multiple factors besides cancer diagnosis and treatment can affect women's sexuality. The advance nurse practitioner is aware of this, prepares the therapeutic conversations accordingly, and expects the "unexpected" in terms of potential sexuality-related issues. The implicit views expressed in the manifesto regarding the potential sources and meanings of women's sexual problems align with beliefs about suffering expressed in the IBM: "Illness suffering can be physical, emotional, relational, and/or spiritual."[20(p36)]

Table 2 • Session Components of Couple-based Strengths-Oriented Therapeutic Conversation (CO-SOTC) Intervention

The advanced nurse practitioner (ANP) meets each couple face-to-face on site for a total of 3 sessions. In each session, the couple engages in conversation with the ANP who asks the couple questions that encourage a strengths-oriented therapeutic conversation. In each session, the beliefs and perceptions of both the woman and her partner are elicited during the conversations. The components of each session reflect the theoretical frameworks and utilization described in Table 1.

First session

- Emphasis is on establishing a good therapeutic relationship
- Creation of a couple-based genogram in collaboration with the couple
- Couple invited to share stories about how cancer diagnosis and cancer treatment have affected their daily life, including sexuality and intimacy
- After the first session has concluded, the couples are given a leaflet with information on how they can access evidence-based information concerning the common adverse effects of cancer treatment and possible solutions at home via a secure study website

Second session (1–2 wk after the first session)

- Reflection on the first session
- Effects of illness on sexuality and intimacy
- Beliefs regarding causes of changes in sexuality
- Perceived control over changes
- Possible helpful solutions regarding any sexual concerns
- The couples are asked whether they had any questions about the information to which they were given access via the study website
- Most/least useful aspects of previous professional advice regarding any sexual concerns
- Expectations for future regarding sexuality and intimacy
- Most/least useful aspects of session

Third and final booster session (scheduled 3 mo after the first session)

- Assessment of adjustment in intimate relationships since the first session
- Accentuation of positive changes
- Reflection on previous sessions
- Changes in sexual life/intimacy since the first session
- Cementing/celebrating change

illness, 10 had breast cancer. Previous cancer diagnoses were reported by 11 women (18.6%). Nine of the 11 women reporting previous cancer diagnoses had breast cancer during the study. The average time since diagnosis was 12 months (range, 1–115; median, 6 months).

The main finding from the hypotheses test (Table 4) demonstrated that women with a cancer diagnosis reported significantly reduced sexual concerns associated with the sexual adverse effects of cancer treatment, as measured by the first subscale of SCQ from baseline (T1) to postintervention (T2) (P = .003) as well as the follow-up booster session (T2–T3, P = .012), thereby supporting hypothesis 1a. Among the subgroup of women with breast cancer, these sexual concerns were also significantly reduced from T1 to T2 (P = .010), but no statistical difference was observed from T2 toT3, partly supporting hypothesis 2a. The findings were most consistent when the total number of participants was considered, which can be explained by their greater number, which increased the possibility of significant results.

The women's sexual concerns in relation to their partners were significantly reduced from baseline (T1) to postintervention (T2) in the total group (P = .001) and also in the subgroup of women with breast cancer (P = .005), but not from T2 toT3, thus partially supporting hypotheses 1b and 2b.

Regarding the concerns related to communication with healthcare providers about sexuality-related issues, the participants reported significantly reduced concerns from baseline (T1) to postintervention (T2) in the total group (P = .021), partly supporting hypothesis 1c. Among the subgroup of women with breast cancer, this hypothesis was not supported.

The women perceived no significant differences over time with respect to their illnesses' intrusiveness on the intimacy or instrumental subscale (Table 5). However, they perceived significantly more illness intrusiveness on the social relations and personal development subscale from T1 to T2.

■ Discussion

The overall findings are new and verify the overall success of the CO-SOTC intervention. These findings are encouraging, particularly because this study tested a new couple-based intervention. The results from this study corroborate several earlier studies, in that interventions addressing sexuality-related concern following cancer that also include the patient's partners are more likely than interventions that do not include partners to yield significant effects with respect to sexual adjustment.[8,42]

The adherence rate to the CO-SOTC intervention was exceptional at 100%, showing that the intervention was well received by the women and their partners. This is in contrast with reported dropout rates of up to one-third among couples in similar intervention studies addressing sexuality following cancer.[15]

The overall promising findings indicate that the theoretical framework and contents of the CO-SOTC intervention had several advantages in addressing sexuality-related issues among women with cancer. First, the CO-SOTC intervention underlined the collaborative aspect between the couple and the healthcare provider—for example, in the sessions, the women themselves and their partners raised the topics that they deemed important in relation to

Table 3 • Characteristics of Participants (n = 60)

Characteristic	Mean	%	Median	SD	Range
Age, y					
Total (n = 60)	52.03		53.50	10.737	30–70
Breast (n = 46)	52.57		54.0	10.489	33–70
Other types of cancer (n = 14)	50.29		52.0	11.750	30–67
Marital status					
Married (n = 53)		88.3			
Cohabitation (n = 7)		11.7			
Length of present relationship, y	25.12		24	13.321	2–50
Type of cancer					
Breast (n = 46)		76.7			
Blood (n = 7)		11.7			
Lung (n = 3)		5.0			
Gastrointestinal (n = 3)		5.0			
Brain (n = 1)		1.6			
Time since diagnosis, mo	12.0		6.0	19.1	1–115
Previous cancer diagnosis					
Yes (n = 11)		18.6			
No (n = 48)		81.4			
No answer (n = 1)					
Stage					
Local (n = 40)		72.7			
Advanced (n = 15)		27.3			
No answer (n = 5)					
Treatment					
Surgery (n = 46)		76.7			
Chemotherapy (n = 45)		75.0			
Radiation therapy (n = 45)		75.0			
Endocrine therapy (n = 27)		45.0			
Other treatment (n = 6)		10.0			
Comorbidity (n = 23)					
Arthritis (n = 9)		39.1			
Hypertension (n = 7)		30.4			
Mental illness (n = 4)		17.4			
Lung disease (n = 2)		8.7			
Cardiovascular disease (n = 1)		4.3			
Gastrointestinal disease (n = 1)		4.3			
Diabetes (n = 1)		4.3			
Other (n = 6)		26.1			
Currently on sick leave					
Yes (n = 37)		62.7			
No (n = 22)		37.3			
No answer (n = 1)					
Education completed					
Primary school education (n = 3)		5.0			
Secondary school education (n = 13)		22.1			
University-level education (n = 43)		72.9			
No answer (n = 1)					

sexuality and intimacy. In this manner, the intervention structure and content explicitly avoided a "one-size-fits-all" approach or a standardized protocol in favor of strength-oriented therapeutic conversations to discover the unique "sexual fingerprint" of the woman and her partner. Second, the CO-SOTC intervention strongly emphasized the creation of favorable therapeutic relationships, for example, by opening the first session with the couple-based genogram so that the healthcare provider and the couple could gradually become acquainted and move from more general aspects of their lives to specific aspects of the woman's cancer as it related to their sexual concerns. This process helped to build trust, a vital cornerstone of conversations about sexuality and intimacy in clinical practice. Third, the findings support the idea that the CO-SOTC intervention might have softened the perceived intrusiveness of the illness in daily life, particularly with respect to the women's relationships with their partners and intimacy. The central element of the CO-SOTCT intervention is that beliefs about the effects of cancer on sexuality may be the primary

Table 4 • Difference in Mean of Sexual Concerns Questionnaire (SCQ) Between Time Points using Repeated-Measures Analysis of Variance

Variables (n)	Baseline (T1) Mean (SD)	Postintervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	*F* (*P*)	Time T1 vs T2 *P*	Time T2 vs T3 *P*
Sexual concerns related to the sexual adverse effects of cancer treatment						
All women (n = 59)	35.3 (24.8)	30.8 (25.8)	25.9 (22.9)	2619 (0.000)[a]	.003	.012
Subgroup of women with breast cancer (n = 45)	32.1 (24.8)	27.7 (24.5)	23.8 (22.5)	1579 (0.000)	.010	.064
Sexual concerns with partner						
All women (n = 59)	12.1 (11.6)	8.8 (9.9)	7.9 (9.9)	559 (0.000)[a]	.001	.242
Subgroup of women with breast cancer (n = 45)	11.0 (11.4)	7.7 (8.9)	7.0 (9.8)	416 (0.001)[a]	.005	.481
Concerns related to communication with healthcare provider about sexuality-related issues						
All women (n = 57)	3.9 (4.1)	2.8 (3.4)	2.5 (3.0)	62 (0.009)[a]	.021	.362
Subgroup of women with breast cancer (n = 43)	3.7 (4.1)	3.0 (3.7)	2.5 (3.1)	33 (0.036)	.133	.195

[a]Greenhouse-Geisser correction.

source of concern rather than the cancer itself. One of the 8 major contents of the CO-SOTC intervention concerns illness beliefs—that is, how the woman perceives the illness's influence on her sexuality, including intimacy. Therefore, at the time of the follow-up session, women with cancer diagnoses may have believed that they were more in control of the extent to which their illness influenced their intimate relationships. Nevertheless, women with cancer diagnoses perceived significantly greater illness intrusiveness on the social relations and personal development subscale from T1 to T2. A possible explanation for this is that the CO-SOTC intervention is above all focused on alleviating the sexual concerns of the woman and her partner and not on social activity in general.

The reported benefits among the subgroup of women with breast cancer regarding their sexual concerns in relation to their partners were short-term. This may be attributable to the so-called "ceiling effect"; upon their enrollment in the study, the couples may already have had relationships of above-average quality, which may have prevented the continuous improvement of partner-related sexual concerns.

It was encouraging that women with various types of cancer were open to receiving the CO-SOTC intervention. Studies have repeatedly recommended couple-based interventions that can be offered to women and their partners across different types of cancer.[43,44] Although no women with gynecological cancer participated in the study, the findings are nonetheless promising, because they indicate that the CO-SOTC intervention has the potential to benefit women irrespective of the type of cancer.

The CO-SOTC intervention was a brief psychosexual support offered to 60 women as 2 sessions plus 1 follow-up booster session and showed promising, significant benefits. Although 2 of the 3 studies of couple-based interventions for women with breast cancer provided more than 3 sessions, only the effect size was reported.[11–13] These studies had fewer than 30 women in their samples, therefore reducing the likelihood that absolute change regarding sexual concerns would be detected.

Our findings corroborate a frequent finding in the literature—that women with cancer often experience a lack of communication about sexuality-related issues with their healthcare providers.[22] A likely cause of the apparent concern related to communication

Table 5 • Difference in Mean of Illness Intrusiveness Rating Scale Between Time Points Using Repeated-Measures Analysis of Variance

Variables (n)	Baseline (T1) Mean (SD)	Postintervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	*F* (*P*)	Time T1 vs T2 *P*	Time T2 vs T3 *P*
		Social relations and personal development				
All women (n = 53)	2.4 (1.2)	2.7 (1.3)	2.8 (1.4)	5.80 (0.009)	.035	.375
Subgroup of women with breast cancer (n = 40)	2.3 (1.3)	2.7 (1.4)	2.7 (1.5)	4.14 (0.035)	.057	.669
		Intimacy				
All women (n = 55)	3.5 (1.9)	3.5 (1.9)	3.5 (2.0)	0.20 (0.820)[a]	—	—
Subgroup of women with breast cancer (n = 41)	3.4 (1.9)	3.5 (1.9)	3.3 (2.1)	0.74 (0.545)[a]	—	—
		Instrumental				
All women (n = 55)	4.4 (1.5)	4.4 (1.5)	4.4 (1.6)	0.13 (0.864)[a]	—	—
Subgroup of women with breast cancer (n = 42)	4.3 (1.6)	4.3 (1.6)	4.2 (1.7)	0.11 (0.882)[a]	—	—

[a]Greenhouse-Geisser correction.

with health providers about sexuality-related issues in our study is that the CO-SOTC intervention is primarily focused on sexuality and intimacy of the woman and her partner and not on concerns related to communication with healthcare providers about sexuality issues.

The question as to when in the cancer trajectory it is realistic to offer a couple-based support for sexual concerns frequently arises. In the present study, participants were in active treatment at the time of participation, and some of the sample (n = 11) had previous cancer diagnoses. A recent study on women with breast cancer dismissed the idea of there being a particularly appropriate timing for communication and information about sexuality-related issues.[22] The women expressed different preferences regarding timing: support should be provided at every stage of the disease, but particularly soon after the initiation of cancer treatment. To ensure that a couple-based intervention targeting sexual concerns following cancer such as CO-SOTC can be delivered to women in active cancer treatment, ANPs with specialist training in sexuality should receive specific training in CO-SOTC.

Implications for Clinical Practice

The study's findings help to narrow the gap in interventions addressing sexuality and intimacy specifically designed for women with cancer and their partners. Moreover, this novel advanced nurse-led couple-based intervention provides an example of an intervention developed from a broad empirical evidence resource, originating from advanced family nursing research.

■ Strengths and Limitations

The adherence rate to the CO-SOTC intervention was exceptional at 100%. This couple-based intervention offers promising benefits to women diagnosed with various types of cancer. The same ANP administered the intervention throughout for all participants, thus enhancing intervention fidelity in terms of session contents and consistency in delivery. No woman diagnosed with gynecological cancer participated in the study despite recruitment efforts. This study was open to lesbian couples; however, only heterosexual women agreed to participate.

Future Research

Future studies may benefit from a randomized controlled design and a stratified recruitment of participants to reduce the risk of sample heterogeneity. Considering the absence of women with gynecological cancer in this study, whether the CO-SOTC intervention is beneficial for these women remains to be seen.

■ Conclusion

This study's outcomes suggest that CO-SOTC intervention was beneficial in alleviating sexual concerns among the participants, justifying further development. Our findings should encourage ANPs to intensify their current efforts so that women with cancer can access evidence-based psychosexual support.

ACKNOWLEDGMENT

We owe gratitude to Gudny Bergthora Tryggvadottir for sharing her knowledge and assisting in the analysis of data and its statistical computation.

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Paper III

European Journal of Oncology Nursing 52 (2021) 101975

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Effectiveness of a couple-based intervention on sexuality and intimacy among women in active cancer treatment: A quasi-experimental study[☆]

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A R T I C L E I N F O

Keywords:
Neoplasms
Women
Sexuality
Sexual health
Couples therapy
Spouses
Psychosocial support systems
Advanced practice nursing

Purpose: To evaluate the effectiveness of a strenghts-oriented therapeutic conversation intervention on confidence about how illness beliefs affect sexuality and intimacy and on perceived relationship quality among women in active cancer treatment and their partners.

Methods: A quasi-experimental single-group pre-post-follow-up design was used. Women in active cancer treatment and their intimate partners were randomly assigned to a nurse-managed couple-based intervention (experimental group, n = 30 couples) or wait-list (delayed intervention) control group (n = 27 couples) plus 4 additional couples who pilot tested feasibility of the intervention, prior to the RCT. However, baseline differences in demographic and clinical variables prevented comparisons between groups. Therefore, a repeated-one-group pre-post test setup was used, comparing women with cancer and their partners over three time points. The intervention consisted of three Couple-Strengths-Oriented Therapeutic Conversations (CO-SOTC) sessions. The participants also had access to web-based evidence-based educational information. Data were collected before intervention (T1, baseline), one to two weeks post-intervention (T2), and after a follow-up session at three months (T3). Data from 60 couples (N = 120) were analyzed.

Results: Significant differences were observed, for both women and intimate partners, over time in more confidence about how illness beliefs affected sexuality and intimacy (T1 versus T2, and T1 versus T3), and increased overall quality of the relationship (T1 versus T2, and T1 versus T3). No differences were found between dyad members' scores on illness beliefs or relationship quality at any time point.

Conclusions: The CO-SOTC intervention was effective in supporting sexual adjustment among women in cancer treatment and their intimate partners.

Trial registration number: NCT03936400 at clinicaltrials.gov.

1. Introduction

Cancer treatment can negatively affect the emotional, physical, and relational aspects of sexuality of women and their intimate partners, and sexual difficulties can continue long after cancer treatment is concluded (Perz et al., 2014; Ussher et al., 2012b; Altschuler, 2015; Sears et al., 2018; Parton, 2019). On the other hand, intimate relationships provide a unique form of social support, may reduce cancer-related stress and among women with cancer, good relationship quality can lower the risk of sexual difficulties (Naaman et al., 2009; Gilbert et al., 2010; Diamond and Huebner, 2012; Ussher et al., 2012a; Fang et al., 2015; Schoebi and Randall, 2015; Kowalczyk et al., 2019). However, the importance of sexuality and intimacy in women's well-being after cancer has often been neglected (Enzlin et al., 2017).

1.1. Interconnection of sexuality, intimacy and relationship quality

In the present study, sexuality is viewed as an integral aspect of the human experience, which influences relationship quality. According to the neo-theoretical framework, sexuality comprises sexual response (desire, arousal, and orgasm), sexual self-concept (body image, sexual esteem, and sexual self-schema), and sexual or intimate relationship (aspects related to communication and intimacy) (Cleary and Hegarty, 2011). The typical aspects of intimacy include emotional sharing, communication, and physical intimacy that enhance the sense of closeness. Relationship quality is often described on the basis of how

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[☆] Abstract.

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https://doi.org/10.1016/j.ejon.2021.101975
Received 14 December 2020; Received in revised form 26 April 2021; Accepted 28 April 2021

well the couple gets along and how happy or content the individuals are in their relationship (Reynolds et al., 2014).

1.2. Intimate partners of an individual with cancer

The experience of partners has often been neglected in research on sexuality and intimacy; however, there has been growing recognition of their unmet needs for support (Hawkins et al., 2009; Gilbert et al., 2009, 2010; Ussher et al., 2012b; Enzlin et al., 2017). Intimate partners of an individual with cancer have reported that the onset of cancer may negatively influence their sexual relationship including cessation or decreased frequency of sex and renegotiation of sexual and non-sexual intimacy (Hawkins et al., 2009). In addition, intimate partners have also linked sexual changes following cancer with stress, weariness, revised priorities involving coping and survival, and their role as a caregiver rather than a lover. Consequently, intimate partners may struggle with moral concerns about dissatisfaction with the sexual relationship and feelings of guilt when trying to renegotiate sexuality and intimacy (Canzona et al., 2019).

1.3. Sexual adjustment in the cancer illness

Positive communication, perceived good relationship, and the ability to redefine the meaning of sexual intimacy facilitate sexual adjustment of the individual couple facing cancer (Gilbert et al., 2010; Ussher et al., 2012; Canzona et al., 2019). Increased certainty about sexual changes following cancer can ease sexual adjustment (Milbury and Badr, 2013; Canzona et al., 2019; Gorman et al., 2020). Benoot and colleagues (2019) identified three different pathways of sexual adjustment: as a grieving process, as a cognitive restructuring process, and as a rehabilitation process. They urge health care providers to use a strength-based approach, integrate all three pathways, and concentrate on the aspects that are unique for each couple. Authors of another study agree with this recommendation and specifically suggest that the Illness Belief Model (IBM; Wright and Bell, 2009) is a powerful tool to identify and address constraining sexual health-related beliefs of the couple, thereby encouraging sexual adjustment (Abbott-Anderson et al., 2020). In addition, findings of a recent review of Badr (2017) suggest that therapeutic questions that elicit reflection on couples‘ unique strengths and encourage facilitating beliefs may help enhance the impact of couple-based interventions in cancer.

1.4. Couple-based interventions addressing sexuality and intimacy

The published literature suggests that empirical data about effective interventions for women with cancer and their partners is in an early development phase Baucom et al. (2009); Decker et al. (2012); Reese et al. (2019). Specifically, the review of the literature reveals a lack of intervention studies addressing sexuality and intimacy for women with cancer and their intimate partners (Jonsdottir et al., 2018).

Nurses with appropriate competency in sexual health play a key role in providing education and support among women affected by cancer but the absence of nurses as interventionists in couple-based studies addressing sexuality and intimacy is noticeable (Charalambous et al., 2018). To address the continuing problem of sub-optimal nurse-led provision of sexual health in integrative cancer care Papadopoulou et al. (2019) propose a two-level international sexual health care competency chart for nurses; an entry level and a champion level. Besides having a personal interest in SHC, experience in the provision of SHC and post-graduate training, nurses at the champion level are essentially nurses with expert knowledge, skills and support of patient's sexual concerns based on evidence (Papadopoulou et al., 2019).

Given this background and the literature review, the purpose of this paper is to describe efficacy of a novel nurse-led couple-based intervention among women in active cancer treatment and their intimate partners.

1.5. Study objectives

The present study aimed to assess the effect of the CO-SOTC intervention on illness beliefs related to sexuality and intimacy and relationship quality among women with cancer who are undergoing treatment and their intimate partners. We present the pre-post-follow-up comparisons with the following hypotheses and research question:

1.6. Study hypotheses

On the basis of the literature review and the theoretical frameworks that guided this study, it was hypothesized that.

1. Women diagnosed with cancer who are undergoing active cancer treatment will report increased confidence about how illness beliefs affect sexuality and intimacy and higher relationship quality after the CO-SOTC intervention.
2. Intimate partners will report increased confidence about how illness beliefs affect sexuality and intimacy and higher relationship quality after the CO-SOTC intervention.

1.7. Research question

The following research question was posed:

Is there a significant difference between women's and their partners' illness beliefs (dyadic difference scores) regarding sexuality and intimacy and relationship quality at each time point?

2. Methods

2.1. Study design

Initially, the study was designed and carried out as a randomized controlled trial with waitlist control. Participants were assigned to experimental and control group using a simple randomization procedure. However, substantial differences in demographic and clinical variables were observed between treatment and control groups after completion of all longitudinal assessments. Therefore, a repeated one-group pre- and post-test setup was used, comparing women with cancer and their partners over three time points. The 60 couples included in the study completed at least one pre- and two post-intervention assessments over 3 months. The CONSORT guidelines were followed for reporting (Schulz et al., 2011).

2.2. Participants and study setting

Eligible study participants were women who met the following inclusion criteria: ≥18 years old, diagnosed with cancer (regardless of type and stage), currently in active cancer treatment, in an intimate relationship, and fluent in written and spoken Icelandic language. The women were contacted by clinical nurses and radiologists working in the Hematology/Oncology, Radiotherapy, Gynecology, and Surgical hospital departments at Landspitali University Hospital. The clinical nurses and radiologists explained the study to eligible participants, gave them a letter with information about the study, and obtained written consent. Women who agreed to participate asked their partners whether they were willing to participate in the intervention. The nurse who administered the intervention (and the principal researcher) received the signed consent forms from the women and contacted them to schedule the couples' first visits. The intervention was provided in a neutral setting outside the hospital.

2.3. Enrollment

In total, 149 women were considered eligible during the enrollment period and invited to participate (see Fig. 1. Consort Flow Diagram). A

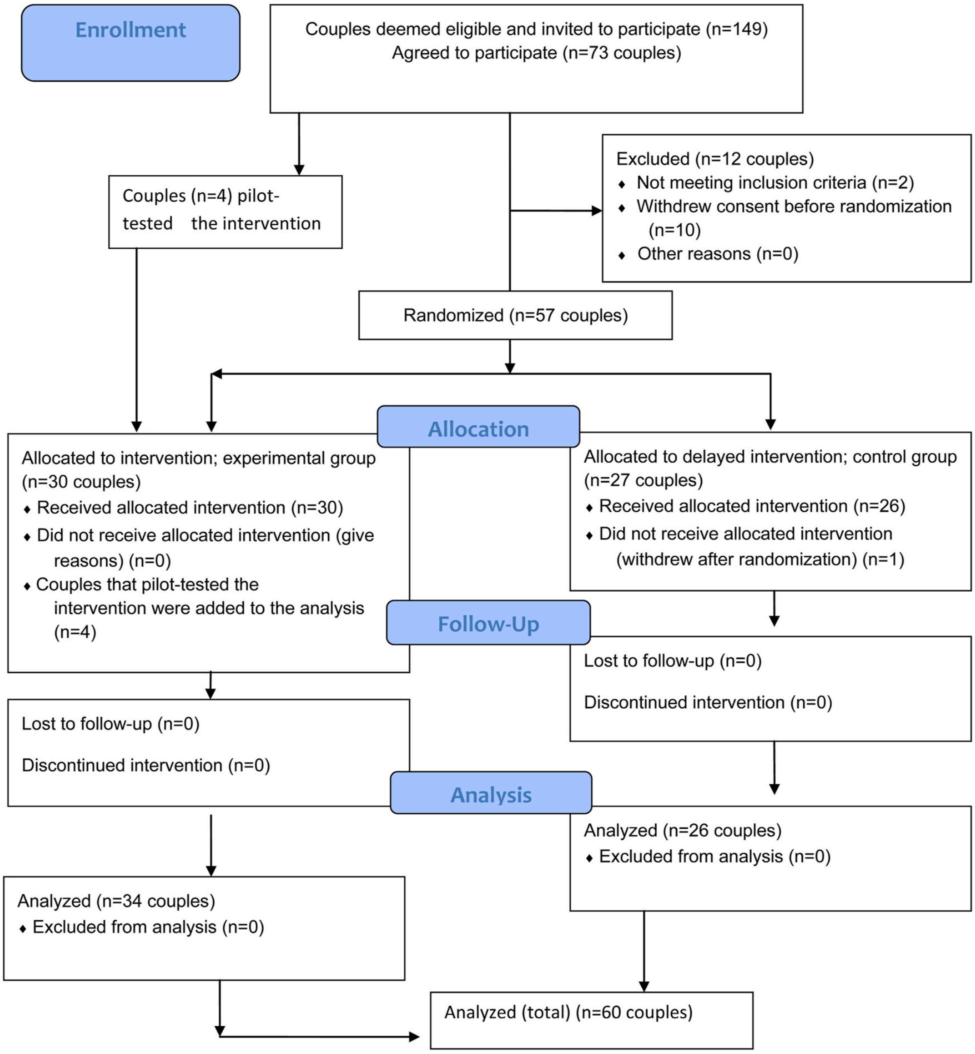

Fig. 1. CONSORT flow diagram.

total of 73 women and their partners provided their consent, resulting in a 49% acceptance rate. Two of these 73 couples were excluded after they had provided informed consent because they failed to fully meet the inclusion criteria. Additional 10 couples withdrew their consent before the intervention, mostly owing to worsening illness. Other known reasons were “stressful cancer treatment”, “trouble in finding time due to partner’s work schedule”, or “cancer treatment finished”. One couple withdrew from the study after allocation to the delayed intervention but before starting their participation in the intervention. Four out of the 73 couples that agreed to participate pilot-tested the intervention. Following the pilot-testing, no changes were needed to be made to the intervention. Therefore, the four couples who pilot-tested the intervention were included in the final analysis. Thus, a total of 60 couples participated in the intervention.

2.4. *Data collection*

Data were collected from April 2017 to August 2019. The participants completed the outcome measures prior to the first session at baseline (T1), at 1–2 weeks post intervention (T2), and at the 3-month follow-up session (T3). Participants in the group receiving delayed intervention completed the intervention 4 months after assignment. As all 60 couples attended all three face-to-face sessions, the completion rate was 100%.

2.5. *Intervention*

The present study, which is a part of a wider research project, describes the couple strength-oriented therapeutic conversations (CO-SOTC) intervention as a novel, couple-based, family system nursing intervention developed for women with cancer and their partners (Jonsdottir et al., 2021, accepted for publication; Svavarsdottir and Gisladottir, 2019). The development and session components of the CO-SOTC intervention have been described in detail in a previous paper (Jonsdottir et al., 2021-accepted for publication).

2.5.1. *Theoretical models guiding the intervention*

The theoretical model that guides the CO-SOTC intervention is the family strength-oriented therapeutic conversation (FAM-SOTC) intervention that is a family system nursing intervention, found to be beneficial and applicable in clinical practice (Gisladottir and Svavarsdottir, 2017; Svavarsdottir and Gisladottir, 2019; Petursdottir and Svavarsdottir, 2019). FAM-SOTC is based on four models: the Calgary Family Assessment/Intervention models (Shajani Z, Snell D, 2019), the Illness Belief Model (IBM; Wright and Bell, 2009), and the resilience component of the Resiliency Model (McCubbin et al., 1996). The intervention in the present study relies mainly on the clinical practice model of IBM of FAM-SOTC. To provide the necessary background and comprehensive understanding of sexuality, the CO-SOTC intervention additionally uses two frameworks: neo-theoretical framework of sexuality and New View Manifesto of women's sexual problems (Cleary and Hegarty, 2011; Kaschak and Tiefer, 2001). Both frameworks assist the nurse to attend, as a minimum, to the three main domains of sexuality (sexual identity, sexual relationship, and sexual function). Additionally, they provide a necessary understanding of the many factors, apart from cancer diagnosis and treatment, that can affect women's sexuality.

2.5.2. *Components and delivery of the intervention*

At its core, the CO-SOTC intervention includes strength-oriented therapeutic conversations that aim to assist couples in managing changes related to sexuality and intimacy after cancer, through active listening; validating the narrative of the individual couple narrative; asking therapeutic questions; addressing constructive illness beliefs; challenging hindering beliefs, strengths, and resources; and providing information based on evidence (Jonsdottir et al., 2021-accepted for publication).

The CO-SOTC intervention was provided in three 45-min face-to-face sessions with the woman with cancer and her intimate partner at Landspitali University Hospital. The first two sessions were scheduled 1–2 weeks apart, and the final session was conducted 3 months after the first session. The first two sessions were spaced 1–2 weeks apart to promote the therapeutic conversations' effect and maintain the therapeutic relationship's bond with the couple while also minimizing disruption due to the potential debilitating side effects of cancer treatment. The third session, which was a booster session, was scheduled at 3 months after the first session to give the couple time to reflect on their experiences of participating in the intervention. After completing the first session, the couple were handed a sheet on how to access non-interactive, evidence-based, educational information on a secure website. The information was about the side effects of cancer treatment affecting relational, physical, and emotional aspects of sexuality and potential solutions, and it was an optional component of the intervention. The educational information on the website covered ten issues about the following topics: changes in body image, sexual intimacy and well-being, vaginal dryness, diminished sexual desire, use of vaginal dilators, vaginal moisturizers, vaginal lubricants, shorter/narrower vagina, fatigue, and partner's experience and concerns. Although the website information was optional the interventionist provided information as needed in the sessions about sexual side effects of cancer treatment and possible solutions.

2.6. *Interventionist and intervention fidelity*

The nurse delivered the intervention throughout the study and authored the evidence-based information for the secure website. The nurse has authorization in clinical sexology, training in systemic therapy, and participated in a week-long in-person training course on the main clinical nursing practice model guiding the therapeutic conversation in the intervention. The course was provided by the author of the IBM. To promote intervention fidelity, diary notes were written after each session. A supervisor, specialized in relational research as well as in chronic illness such as cancer, regularly attended and observed the sessions.

2.7. *Outcome measures*

2.7.1. *Demographic and clinical questionnaire*

Demographic and clinical data of the women participants were collected at baseline (see Table 1), including age; marital status; length of present relationship; type of cancer; time since diagnosis; previous cancer diagnosis; stage; treatment; comorbidity; sick leave; education completed; and partner characteristics including employment, sick leave, and education completed.

This intervention study is a part of a larger research project using questionnaires for four main outcome measures: the Sexual Concern Questionnaire (SCQ; Abbott-Anderson, 2015), the Illness Intrusiveness Rating Scale (IIRS; Devins, 2010), Ice-Beliefs Questionnaire for couples (ICE-Couple; Svavarsdottir and Jonsdottir, 2016), Partnership Questionnaire (Partnerschaftsfragebogen [PFB]; Hahlweg, 1996; Jonsdottir et al., accepted for publication). The women completed the questionnaires for all four main outcome measures, whereas their intimate partners completed two of them (ICE-Couple and PFB). The present study used data from the couple's perspective and therefore are the following two outcome measures.

2.7.2. *Ice-Beliefs Questionnaire for couples*

The ICE-Couple outcome measure (Svavarsdottir and Jonsdottir, 2016) was devised specifically for this study on the basis of the Ice-Beliefs Questionnaire (ICE-Beliefs), originally developed by one of the authors (Svavarsdottir, 2011, 2014). The ICE-Beliefs is a self-report measure of an individual's beliefs about illness and was developed from the Illness Beliefs Model (Wright and Bell, 2009). The ICE-Couple measures a couple's perception of how both individuals deal with changes in sexuality and intimacy following cancer diagnosis and treatment. The questionnaire was used to measure changes in facilitating or constraining beliefs following the CO-SOTC intervention. In the context of sexual changes following cancer, constraining beliefs are beliefs that hinder finding solutions to distress or concerns (e.g. "All affectionate touching is off because sexual intercourse is no longer possible"), whereas facilitating beliefs are beliefs that open a possibility for a variety of solutions (e.g. "We can learn to live with changes in our sex life and still be intimate"). Participants report the degree to which they believe the illness affects sexuality and intimacy with respect to cause, control, effect, suffering, and support on seven items using a 5-point Likert scale (1, *never* to 5, *all of the time*) and eight open-ended questions. Higher scores indicate more confidence about facilitating beliefs versus constraining beliefs regarding sexuality and intimacy. The instrument has been found to be both valid and reliable (Cronbach's $\alpha =$ 0.780–0.789; Gisladottir and Svavarsdottir, 2016). The internal consistency, Cronbach's α for the ICE-Couple measure in the present study was 0.82 for the women and 0.80 for their intimate partners.

2.7.3. *Partnership Questionnaire*

The PFB is a 30-item outcome measure that assesses relationship quality (Hahlweg, 1996). The PFB consists of three scales (conflict, tenderness, and communication) with ten items each. For example, one of the conflict items is "He/she keeps bringing up mistakes that I have made in the past"; a tenderness item is "He/she makes an effort to be attentive to my wishes and fulfills them when the opportunity arises" and a communication item is "He/she shares his/her thoughts and feelings openly with me." All scale items are given a score using a 4-point Likert scale (Never/very rarely [0], rarely [1], often [2], very often [3]). The PFB can be used to assess relationship quality via subscales, which can be combined to generate a PFB total score (Cronbach's $\alpha = 0.95$). The total score can be used to reliably distinguish between distressed and non-distressed couples and monitor changes resulting from couple therapy. A total score of <53 is regarded as a threshold for low marital quality. Good to very good reliability coefficients have been confirmed for the three subscales (conflict behavior: $\alpha = 0.88$; tenderness: $\alpha = 0.91$; communication: $\alpha = 0.85$; total scale: $\alpha = 0.93$; Hinz et al., 2001; Kliem et al., 2012.). In the present study, Cronbach's α for the participating women and their partners was, respectively, 0.85 and 0.89 for conflict behavior, 0.89 and 0.88 for tenderness, 0.89 and 0.84 for communication, and 0.93 and 0.93 for total scale.

2.8. *Statistical methods*

Sample size assessments showed that, considering repeated measures tests of mean differences and an average effect size of 0.5 (based on Cohen's D), the sample size required for 80% and 90% statistical power is 27 and 36, respectively (Kraemer and Thiemann, 1987). The number

Table 1

Characteristics of participants that took part in the CO-SOTC intervention (N = 120) between April 2017 to August 2019; women in active cancer treatment (n = 60) and their intimate partners (n = 60).

Women characteristic	Mean	%	Median	SD	Range
Age (years)					
Total (n = 60)	52.03		53.50	10.737	30–70
Breast (n = 46)	52.57		54.0	10.489	33–70
Other types of cancer (n = 14)	50.29		52.0	11.750	30–67
Marital status		88.3			
Married (n = 53)		11.7			
Cohabitation (n = 7)					
Length of present relationship (years)	25.12		24.0	13.321	2–50
Type of cancer					
Breast (n = 46)		76.7			
Blood (n = 7)		11.7			
Lung (n = 3)		5.0			
Gastrointestinal (n = 3)		5.0			
Brain (n = 1)		1.6			
Time since diagnosis (months)	12.0		6.0	19.1	1–115
Previous cancer diagnosis					
Yes (n = 11)		18.6			
No (n = 48)		81.4			
No answer (n = 1)					
Stage					
Local (n = 40)		72.7			
Advanced (n = 15)		27.3			
No answer (n = 5)					
Treatment					
Surgery (n = 46)		76.7			
Chemotherapy (n = 45)		75.0			
Radiation therapy (n = 45)		75.0			
Endocrine therapy (n = 27)		45.0			
Other treatment (n = 6)		10.0			
Comorbidity (n = 23)					
Arthritis (n = 9)		39.1			
Hypertension (n = 7)		30.4			
Mental illness (n = 4)		17.4			
Lung disease (n = 2)		8.7			
Cardiovascular disease (n = 1)		4.3			
Gastrointestinal disease (n = 1)		4.3			
Diabetes (n = 1)		4.3			
Other (n = 6)		26.1			
Currently on sick leave					
Yes (n = 37)		62.7			
No (n = 22)		37.3			
No answer (n = 1)					
Education completed					
Primary school education (n = 3)		5.0			
Secondary school education (n = 13)		22.1			
University level education (n = 43)		72.9			
Partner characteristics					
Age (years)	54,3			10.783	30–75
Total (n = 60)					
Employment					
Works overtime – two jobs (n = 17)		28.8			
Full time employed (n = 30)		50.8			
Part time employed (n = 4)		6.8			
Disabled (n = 5)		8.5			
Pensioner (n = 53)		5.1			
Currently on sick leave					
Yes (n = 3)		5.4			
No (n = 53)		94.6			
Education completed					
Primary school (n = 5)		9.8			
Secondary school (n = 24)		47.0			
University level (n = 30)		43.2			

of couples in the study was 60 which is well beyond the minimum number of couples required for adequate statistical power.

Participants were required to answer at least 80% of items on the outcome measure for their data to be included in the analysis. Repeated measures ANOVA was used for an overall assessment of outcome differences. A paired *t*-test was used to further compare the outcomes of the CO-SOTC intervention between measurements from T1-T2, T2-T3, and T1-T3.

The assumption of sphericity was tested using Mauchly's test of sphericity, which showed violations of sphericity for the outcomes of both ICE-Couple and PFB. Therefore, the Greenhouse-Geisser formula was used to correct the violations of sphericity. Effect size was assessed with eta squared (where a value above 0.01, 0.06, and 0.14 denotes a small, intermediate, and large effect, respectively; Field, 2009). The Statistical Package for the Social Sciences (SPSS) version 26.0 was used for descriptive statistics and statistical analyses (IBM Corp Released, 2019). The significance value for the difference between means was set at $P < 0.05$. Dyadic difference scores between the participating women and their intimate partners were computed to assess whether the couples differed on the outcome measures, using an F-test with P values set at <0.05.

2.9. Procedures and trial registration

The study was granted ethical approval by the Scientific Ethics Board at Landspitali—the National University Hospital of Iceland (No. 23/2016), which also notified the National Bioethics Committee about the study. The study was approved by the chief executives of nursing and medicine and head nurses in participating wards at Landspitali—the National University Hospital of Iceland.

3. Results

3.1. Participant characteristics

The participants (N = 120) included 60 women diagnosed with diverse types of cancer who were in active cancer treatment and their intimate partners (all males; n = 60). None of the women went completely off treatment during the study period. A few women finished primary treatment such as chemotherapy or radiation therapy during the CO-SOTC intervention but continued to receive adjuvant hormonal therapy to prevent breast cancer recurrence. When the CO-SOTC intervention was initiated, each woman participant was currently receiving one or more cancer treatments (surgery, chemotherapy, radiation therapy, or endocrine therapy). The average age of the women and their partners was 52 years (range 30–70 years) and 54.3 years (range 30–75 years; see Table 1), respectively. The average length of the relationship was 25.12 years (median 24 years). In total, 43 women (72.9%) and 30 partners (43.2%) had university-level education. Most women had been diagnosed with breast cancer (76.7%). The majority had localized cancer (72.7%), and 27.3% had advanced cancer. Among the 15 women reporting advanced illness, 10 had breast cancer. Nine of the 11 women (18.6%) reporting previous cancer diagnoses had breast cancer during the study. The average time since diagnosis was 12 months (range 1–115; median 6 months).

3.2. Outcomes

3.2.1. Illness beliefs about sexuality and intimacy

Women in active cancer treatment reported significantly increased confidence about how illness beliefs affect sexuality and intimacy from T1 to T2 (p = 0.000; see Table 2). Illness beliefs also differed significantly between T1 and T3 (η2 = 0.155, p = 0.000). Similarly, intimate partners reported significantly increased confidence about illness beliefs from T1 to T2 (p = 0.005) and from T1 to T3 (η2 = 0.114, p = 0.000).

3.2.2. Relationship quality

The women reported increased relationship quality from T1 to T2 (p = 0.022; see Table 3). A significant difference was also found between T1 and T3 (η2 = 0.016, p = 0.005). Intimate partners also reported increased relationship quality from T1 to T2 (p = 0.037) and from T1 to T3 (η2 = 0.012, p = 0.047).

3.2.3. Dyadic difference

No statistically significant differences in dyadic scores were found regarding illness beliefs about sexuality and intimacy or overall relationship quality between women and their intimate partners at any time point (T1, T2, or T3; see Table 4).

4. Discussion

The main findings from this study highlight the value of the CO-SOTC intervention in providing brief psychosexual support to couples facing cancer. The results suggest that strength-oriented therapeutic conversations can be offered in clinical nursing practice. In addition, the findings indicate that the CO-SOTC intervention has the potential to address aspects of sexual changes that are unique for each couple. This is an interesting viewpoint supported by the fact that each individual couple has their own unique sexual adjustment pathway following cancer (Benoot et al., 2017).

The findings supported the hypothesis that participation in the CO-SOTC intervention would significantly increase confidence about how illness beliefs affect their sexuality and intimacy both in the short term (T1 to T2) and long term (T1 to T3), both among women with cancer and their intimate partners. This suggests that the positive changes were not only short term but also long term as they persisted over the study period, even though the participating women were undergoing cancer treatment and nearly one-third of them reported advanced illness. Furthermore, because all women were receiving either primary or secondary cancer treatment while participating in the intervention, the CO-SOTC intervention may have a certain protective effect because no worsening was reported either on illness beliefs or relationship quality during the intervention. However, it has been previously observed that in some couples facing cancer, the illness brings the partners closer together, which may have affected the reported outcomes (Dorval et al., 2005).

Table 2

Difference in mean on illness beliefs about sexuality and intimacy for couples using one-way repeated measurement ANOVA.

Variables (n)	Baseline (T1) Mean (SD)	Post-intervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	F (P value)	Time T1 versus T2 P value	T2 versus T3 P value	T1 versus T3 P value	Eta-Squared (η2)
Confidence about facilitating beliefs versus constraining beliefs about sexuality and intimacy Women (n[b] = 52) Intimate partner (n = 56)	24.2 (6.0) 24.1 (5.4)	27.1.8 (5.9) 26.0 (5.7)	28.0 (5.1) 27.4 (4.5)	420.50 (0.000)[a] 307.21 (0.000)[a]	0.000 0.005	0.135 0.042	0.000 0.000	0.155 0.114

[a] Sphericity Assumed.

[b] n varies due to missing data.

Table 3
Difference in mean of relationship quality for couples using one-way repeated measurement ANOVA.

Variables (n)	Baseline (T1) Mean (SD)	Post-intervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	F (P value)	Time			Eta-squared (η2)
					T1 versus T2 P value	T2 versus T3 P value	T1 versus T3 P value	
Overall relationship quality		70.8 (13.5)	71.8 (13.6)	198.61 (0.010)[b]	0.022	0.263	0.005	0.016
Women (n[c] = 58)		65.9 (13.9)	66.5 (15.3)	132.08 (0.058)[b]	0.037	0.587	0.047	0.012
Intimate partner (n = 48)	69.2 (14.4)	3.9 (4.6)	3.7 (4.7)	8.08 (0.220)[a]	0.322	0.424	0.105	–
Subscales	64.2 (13.6)	4.6 (5.6)	5.0 (6.3)	9.88 (0.198)[a]	0.060	0.302	0.471	–
Conflict		22.6 (5.8)	22.9 (5.4)	64.72 (0.007)[b]	0.001	0.487	0.005	0.026
Women (n = 58)		19.2 (5.8)	19.4 (5.6)	21.29 (0.139)[b]	0.071	0.734	0.101	–
Intimate partner (n = 50)	4.2 (4.5)	22.3 (5.8)	22.5 (5.9)	5.0 (0.599)[a]	0.514	0.671	0.363	–
Tenderness	5.2 (5.6)	21.7 (4.6)	22.0 (4.9)	10.04 (0.364)[a]	0.424	0.469	0.212	–
Women (n = 59)								
Intimate partner (n = 53)								
Communication	21.5 (6.4)							
Women (n = 59)	18.5 (5.9)							
Intimate partner (n = 51)								
	22.1 (6.2)							
	21.4 (4.3)							

[a] Sphericity Assumed.

[b] Greenhouse-Geisser correction.

[c] n varies due to missing data.

Table 4
Dyadic difference scores (the difference between women and their partner score) on illness beliefs about sexuality and intimacy and relationship quality using a F-test.

Variables (n)	Baseline (T1) Mean (SD)	Post-intervention (T2) Mean (SD)	Follow-up (T3) Mean (SD)	Dyadic difference scores Timepoint (n) Mean (SD)	Time F (P value)
Confidence about facilitating beliefs versus constraining beliefs about sexuality and intimacy Women (n[a] = 49) Intimate partner (n = 49) **Overall relationship quality** Women (n = 47) Intimate partner (n = 47)	24.5 (6.1) 24.4 (5.1) 68.1 (14.7) 64.0 (13.6)	27.3 (6.0) 26.1 (5.5) 69.9 (13.9) 65.5 (13.7)	28.2 (5.1) 29.0 (13.9) 71.0 (13.4) 66.0 (15.2)	T1 (n = 49) 0.10 (5.72) T2 (n = 49) 1.19 (5.63) T3 (n = 49) −0.82 (15.25) T1 (n = 47) 4.11 (11.52) T2 (n = 47) 4.36 (10.90) T3 (n = 47) 4.97 (11.26)	0.680 (0.444) 0.245 (0.783)

[a] n varies due to missing data.

The intervention had a large effect (η2) on the illness beliefs (see Table 2) and a small effect on relationship quality (see Table 3) among the women and their partners. The magnitude of the effect size demonstrates that the elements of the CO-SOTC intervention influenced the couples in a meaningful way, particularly regarding increased confidence about their illness beliefs.

The significant improvement in confidence of the intimate partners about how illness beliefs affect sexuality and intimacy is especially noteworthy and encouraging because intimate partners who are dissatisfied with the relationship quality are particularly susceptible to the stress resulting from cancer (Cairo Notari et al., 2017). The intimate partners of patients with cancer struggle with mixed emotions, communication difficulties, and conflicting roles regarding sexuality-related issues during the stressful period of illness. The strength-oriented therapeutic conversations of CO-SOTC emphasize the importance of first acknowledging the stressful illness experience, thereby contributing to a more helpful state when developing facilitating beliefs (Wright, 2015). Thus, the therapeutic conversations may help lessen the grip of the stress experienced by the intimate partners, possibly helping them to preserve the bond of the intimate relationship.

The results about the reported positive changes in overall relationship quality by the intimate partners were similar to the results reported by the participating women. These findings are consistent with previous studies that suggest constructive communication on sexuality-related issues can both lessen the impact of uncertainty about the intimate relationship and improve the perceived relational quality during illness (Canzona et al., 2019). Furthermore, the results substantiate other research findings showing that central strategies related to couple-based interventions for sexual support involve creating opportunities for shared understanding of sexual changes after cancer and enhancing couples‘ communication (Milbury and Badr, 2013; Gorman et al., 2020).

No significant differences were found between the women and their partners in the dyadic scores of illness beliefs and overall relationship quality at different time points before and after the intervention, indicating that women with cancer and their intimate partners scored both outcome measures in a similar manner. In addition, the fact that no considerable difference in dyadic scores was found suggests that the women and their partners experienced the CO-SOTC intervention in a similar way.

This nurse-managed intervention study provides an example of the benefit of a brief psychosexual intervention, based on empirical evidence from advanced family nursing. When sexual health is not firmly established as a legitimate concern in cancer care, it results in missed opportunities to engage in discussion with individuals with cancer and their partners (Jonsdottir et al., 2016; Wittmann, 2016; Annerstedt and Glasdam, 2019). Patients report that they value the opportunity to discuss sexuality (Albers et al., 2020). Health care providers are responsible for obtaining the necessary skills and knowledge so they can provide these opportunities. Clinical practice guidelines echo this responsibility (Barbera et al., 2017; Carter et al., 2018) and recommend offering couple-based interventions to women who are partnered. However, in a systematic review, Fennell and Grant (2019) found that numerous prominent nursing organizations did not include sexual health care in their policy statements. This apparent lack of sexual health care policy within nursing is worrisome and reflects the persistent lack of provision of sexual health care in cancer care (Papadopouluet al., 2019). Therefore, it is somewhat reassuring that nurses with higher education and who have undergone further training more often provide sexual counseling than nurses with an undergraduate education (Krouwel et al., 2015). This observation is consistent with the competency levels according to the International Family Nursing Association Position Statement on Advanced Practice Competencies for Family Nursing (IFNA, 2017).

4.1. Limitations

In the present study, the lack of a comparison group poses a threat to the validity of our findings. The observed changes could have occurred naturally over time as patients approached the end of cancer treatment or adjusted to the effects of cancer. Although we intended to make comparisons between treatment and waitlist groups, substantive baseline differences in demographic and clinical variables precluded such analyses. Stratified recruitment in sufficiently large populations may reduce the risk of inequivalence at baseline in future trials. The participants were highly educated and mainly represented the diagnosis of breast cancer. Despite recruiting efforts, no women with gynecological cancer participated in the study; therefore, it remains unknown whether the CO-SOTC intervention is beneficial for such women. Only heterosexual couples participated in the study although it was open to lesbian couples, creating a research bias. Furthermore, this study was implemented among a population in the western part of the world and can not be generalized to populations in other cultures. Finally, only one nurse delivered the intervention, which could result in a therapist effect.

4.2. Future research

The CO-SOTC intervention remains to be replicated in women with gynecological cancer and in lesbian couples. It would also be of value to compare the effects of the intervention among women who are in active cancer treatment with women whose cancer treatment has concluded. In addition, testing the CO-SOTC intervention in women with different stages of cancer, undergoing various types of cancer treatment, and belonging to different age groups would provide important insights. Finally, considering the known gap between couple therapy research efficacy and effectiveness in clinical practice (Halford et al., 2016), an important task of nurses remains, namely to develop and test successful methods to implement this empirically tested, brief psychosexual support into clinical practice.

5. Conclusion

Offering strength-oriented therapeutic conversations to couples provides an opportunity to address the cancer-related stressors affecting their intimate relationship. The components of this brief CO-SOTC intervention—active listening, validation of the unique individual couple narrative, and facilitation of constructive beliefs—are a powerful tool to help couples manage changes related to sexuality and intimacy after cancer.

This intervention study adds new empirical evidence to the extremely limited pool of couple-based interventions, specifically designed to address changes in sexuality and intimacy among women in active cancer treatment and their intimate partners. To the best of our knowledge, this is the first nurse-managed intervention study to report on the outcomes of a brief psychosexual couple-based intervention offered to women with various types of cancer and their intimate partners. As sexual difficulties can persist long after cancer treatment is concluded, issues related to sexuality and intimacy clearly should not be excluded when providing support in cancer. On the contrary, it should be standard practice among nurses who have the necessary knowledge, clinical skills, and training to offer individuals with cancer and their intimate partners brief psychosexual support.

Funding

This study was supported by grants from the following institutions: Research Fund of Ingibjorg R. Magnusdottir, the Icelandic Nurses' Association Scientific Fund, the Landspitali University Hospital Scientific Fund and the Scientific Fund of the Icelandic Cancer Society.

Study registration

The trial was registered at clinicaltrials.gov (entry NCT03936400, *Development of Therapeutic Conversations with Females Diagnosed with Cancer and Their Partners*).

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

I would like to thank Kristine L Kwekkeboom PhD, RN, FAAN, a member of my doctoral committee, for her advice and constructive criticism in the preparation of this manuscript. We owe gratitued to Gudny Bergthora Tryggvadottir for her assistance in the data analysis and its statistical computations.

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Appendix

Appendix I. The CO-SOTC Intervention Protocol

The CO-SOTC intervention protocol describes the components and lists the potential therapeutic questions that may be used in the three sessions with a woman with cancer and her intimate partner when addressing sexual changes after cancer.

First session

Before the first session of therapeutic conversation begins, the nurse greets the couple and offers a warm welcome, shakes their hand (and makes eye contact with a smile), and introduces herself. Then, the nurse offers them a seat and some refreshments and explains what the intervention entails and asks the couple whether they have any questions about the sessions or about their participation in the intervention.

Couple focused genogram

After the introduction, the nurse explains the purpose of the couple-focused genogram: “If it is alright with you, I would like to begin by examining your background and relationships so that I can better comprehend your situation—is that ok?” (if possible, find an opportunity to compliment/commend the woman/her partner/both in the first 10–15 min of the interview).

Potential questions: age; occupation; marital status; length of marriage/cohabitation; previous close relationships/marriages; parents, siblings, or children (age/name); degree of closeness to closest of kin or children; previous and present health status (of both); for women with cancer: time of cancer diagnosis, type of cancer and cancer treatment, other previous/recent stress factors/traumas

Couple-focused questions: what attracted you to her/your partner when you first met? What would best describe her/your partner? What is it about her/your partner that you most appreciate in the cancer experience/since the illness began? What has helped you to keep the relationship going? What characterizes your relationship the most—before/after the illness began? What do you believe is a “good couple relationship”? Where have you seen examples of it? When you ponder the couple-focused genogram that has been drawn (the nurse shows them the sheet with the genogram), what is your overall impression? Would you like to add something that you deem important regarding your couple relationship?

Interventive questions

After drawing the couple-focused genogram, the nurse asks the following interventive questions (linear questions to obtain information and circular questions to reinforce changes):

Former guidance:

1. Have you previously been to couple counseling? If yes, can you tell me for what reasons and was it helpful/unhelpful—in what way? What was the best/worst advice?

2. Through the cancer trajectory, what has been the best/worst health care advice you have received?

Effect of illness on daily life and sexuality/intimacy:

1. How has the illness affected your (woman/her partner) daily life? What has been the biggest change in your daily life since the illness began?

2. What has changed in your close relationship/your sex life/intimacy since the cancer diagnosis and/or cancer treatment?

3. How has the illness affected your (woman/her partner) close relationship? Your (woman/her partner) sex life/intimacy?

4. What questions do you (woman/her partner) ask yourself throughout the day in relation to your close relationship/your sex life/intimacy?

5. What, if anything, has happened in your close relationship that was perhaps part of the reason you chose to participate in the intervention research?

6. If you (woman/her partner) could only get an answer to one question after our session today, what question would that be?

Causes of changes in sexuality/intimacy and control over these changes:

1. What do you (woman/her partner) believe is the cause of your sexual problem or the changes you are experiencing in your sex life/intimacy?

2. Do you believe you know how much control you have as a couple on your sexual problem or the changes that have occurred in your sex life/intimacy?

3. Do you believe you know how much control the sexual problem or the changes in your sex life/intimacy have on your relationship?

4. What changes would you (woman/her partner) like to see happen in your relationship regarding your sex life/intimacy? What would you like to be the same?

5. Do you (woman/her partner) believe you can predict what may happen in

the future in your sex life/intimacy?

Effects on sexuality/intimacy and whether the partners agree on solutions that may be helpful:

1. Do you believe that you would know what effect it could have on your sexual problem or the changes in your sex life/intimacy if you and your partner were in agreement about the solutions that may help?

2. Do you believe that you know who (woman/her partner) suffers the most or has more difficulties with the effects of the cancer diagnosis and cancer treatment on sexuality/intimacy?

3. Do you believe that you know what has helped the most/the least of what health professionals have offered to help you and your partner to cope with the sexual problems or changes in sex life/intimacy following cancer diagnosis and cancer treatment?

Deeper questions/goals/questions about the future:

1. What do you (woman/her partner) believe that the future holds for you as a couple following cancer diagnosis and cancer treatment?

2. What do you (woman/her partner) believe primarily gives your life meaning these days?

At the end of the session:

What stands out after the session? What was most helpful/least helpful? What would you (woman/her partner) have preferred to discuss more/less in this session? Was this first session helpful or not? What did you hope for to have happened (discussed) in this first session but was not realized? Do you (woman/her partner) believe that you have had a chance to express issues that are important to you? Am I, as the nurse, going too fast or too slow? Is there anything you would have liked to discuss more/less? Am I meeting your expectations and/or concerns?

Educational material on a secure website

The nurse addresses the couple and provides information on how to access the educational material on the secure website and explains that this educational material is optional and can be read by both the woman and her partner. The material is evidence-based information about the most common sexual side effects of cancer treatment in women and solutions. The educational material covers ten issues about the following topics: Changes in body image, sexual intimacy and well-being, vaginal dryness, diminished sexual desire, use of vaginal dilators, vaginal moisturizers, vaginal lubricants, shorter/narrower vagina, fatigue, partner's experience and concerns—a few recommendations.

Second session

Potential therapeutic questions:

1. What stood out for you (woman/her partner) after the first session? Do you believe that the session revolved around issues that are important to you (woman/her partner)? According to you, what was the most important thing that happened/was discussed in the first session? What was most helpful/least helpful? What do you (woman/her partner) wish we had discussed more of/less of in the first session? What topics were you hoping would be discussed but were not discussed?

2. How would you want to use this session today so it will be most useful to you (woman/her partner)?

"Taking the temperature" of the therapeutic alliance:

3. On a scale from 1 to 10, how well do you (woman/her partner) believe I understood your situation in the first session? Was the pace of the session too fast/too slow/about right?

Effects of illness on daily life and the role of partner/health professionals during the illness trajectory:

4. What has been most difficult to cope with during the illness? If the cancer illness had a name, what would it be?

5. Everyone has thoughts (in form of questions) daily; what questions do you ask yourself on a good day/bad day? Of the questions you ask yourself, what question is most uplifting/most depressing? What thoughts go through your mind when you ponder/reflect on the fact that you are alive after having been diagnosed with a serious disease/cancer?

6. When you wonder why you got cancer, what goes through your mind? What do you make of the fact that it was you and not someone else who was diagnosed with a serious disease?

7. How has the illness mostly affected the partner? What role do you (woman/her partner) believe that the partner has during the illness? What role do you believe health professionals have during the illness?

8. In what ways have you (the partner) best managed to receive some

emotional support/other support (“charged your batteries”) during the illness? What do you (the partner) believe has helped you most to handle changes because of the illness?

9. Are you (woman/her partner) someone that believes it is best to overcome the illness or live alongside it?

10. Do you agree on what you believe regarding the prognosis or do you have different views about it?

Effects of illness on sexuality and intimacy:

11. When you (woman/her partner) reflect on the sexual problems/effects of the illness on sexuality/intimacy, what thoughts do mostly emerge?

12. What is the main question you (woman/her partner) ask yourself these days about the sexual problem or the changes in sexuality/intimacy during the illness? Do you more agree or disagree about the effects of illness on sexual life and intimacy?

13. Everyone thinks to themselves daily, often in the form of questions. What questions do you mostly ask yourself in relation to sexuality and intimacy? What questions do you ask in your head on a good day/a bad day?

Control of illness on sexuality and intimacy:

14. Do you (woman/her partner) believe or not believe that you have control over how much the illness changes things in relation to sexuality and intimacy? How much control would you (woman/her partner) like to have in this regard?

15. How much control do you (woman/her partner) believe you have on the extent of the effect of the sexual problems/changes in sexuality (in percentage or on a scale from 1 to 10, where 1 = very little control, 10 = full control)

16. When did you (woman/her partner) first notice that you had begun to exert certain control over the effects of illness on sexuality and intimacy?

Coping with changes in sexuality and intimacy:

17. Is it you or the partner that more believes that it can be helpful to openly discuss (during the illness) this sexual problem/changes in sexuality and intimacy?

18. What do you (woman/her partner) believe is the best way to cope with the changes in sexuality and intimacy that have occurred?

The future:

19. Are you (woman/her partner) more optimistic/more pessimistic about the future regarding the effects of the illness on sexuality and intimacy?

20. What do you believe the future holds for you (woman/her partner) concerning sexuality and intimacy?

21. Let us imagine that you (woman/her partner) would see something positive happening in your sex life, including intimacy. What would you consider positive? How would you notice the positive change?

At the end of the session:

22. Is there something I have not asked you (woman/her partner) today or in a previous session that you wish I had?

23. Is there something you would like to ask your partner about (woman/her partner)?

24. How was this session for you? Was it useful? What are your thoughts about this approach in the conversations with you in the sessions? Are the conversations meeting your expectations?

Follow-up session

This third and final follow-up session is a booster session and scheduled 3 months after the first interview. In this final session, emphasis is placed on highlighting change and tying any loose ends.

1. What stands out when you reflect back on previous sessions? What do you mostly think about when you reflect back on previous conversations in the sessions?

2. What is different/what has changed in your relationship since the first session? What is different/what has changed in your sexual life/intimacy since then? What has been most helpful for you out of all the things that have been discussed in the previous sessions?

3. What is on top of your (woman/her partner) mind today? What would be the most important/most useful issue to discuss in this final session today?

4. Do you (woman/her partner) have any questions or comments for your partner? Do you have any questions you would like me to answer?

5. Are there any other questions that you would have wanted me to ask you, but I have not?

Cementing/celebrating change:

6. What have you (woman/her partner) come to appreciate in your partner regarding the changes that happened in your sexual life/intimacy following the illness?

7. What advice could you give other women with cancer and their partners regarding sexuality and intimacy?

8. I would like to take this opportunity to mention what I saw that was unique in the conversations with you and what I believe are your strengths.

Therapeutic alliance—taking the temperature

9. What advice could you give me so I could strengthen my role as a nurse with women with cancer and their partners?

10. What is the most important advice you would give other health professionals that care for women with cancer and their partners in matters relating to sexuality and cancer?

11. What was the single most useful/important thing that stands out after these three sessions (including in the evidence-based information on the secure website)?

What was the single least useful/important thing that stands out after these three sessions (including in the evidence-based information on the secure website)?

12. Do you (woman/her partner) have any final comments or questions before we depart today and say goodbye? Any loose ends?

Appendix II. Evidence-based Educational Information available on the Website

The evidence-based educational information, presented in Appendix II, is about the side effects of cancer treatment on the relational, physical, and emotional aspects of sexuality and the potential solutions. Thus, the content addresses the three main areas of sexuality: sexual response/function, sexual self-image (including body image), and sexual relationship. The content was also consistent with the main sexual concerns identified in one of the main measures in this study—the cancer-specific Sexual Concerns Questionnaire (SCQ). Offering evidence-based educational information may enhance the face-to-face intervention with the individual couple. For instance, one review on web-based intervention suggests that evidence-based information on website may complement face-to-face symptom management (Fridriksdottir et al., 2018). Further, research has time and again identified the benefits of patient educational information in enhancing coping, including information about sexual side effects of cancer treatment among women (Faithfull & White, 2008).

After completing the first session, the couple were handed a sheet on how to access non-interactive, evidence-based educational information on a secure website. The educational information was an optional component of the intervention. The educational material was written by Jona Ingibjorg Jonsdottir, except the section on vaginal dilation, which was, with permission, adapted from a patient education booklet (CANO/ACIO, 2015).

Vaginal dryness

Vaginal dryness is among the most common side effects of cancer treatment and, by far, the most common cause of sexual difficulties reported by women after treatment. Chemotherapy, radiotherapy, and surgery affect the skin and mucous membranes. Dry vaginal mucous membrane can become tender and sensitive and cause burning and itching, which cause discomfort and pain during sex, especially during sexual intercourse. There is a risk of small abrasions occurring in the mucous membrane, which may bleed. The vagina is not as elastic as before, which can also cause discomfort during sex. There may be vulvar and vaginal irritation, involuntary urination, increased urge to urinate, burning sensation, and increased vaginal discharge. When vaginal mucus secretion is normal, the vagina cleanses itself. However, mucus secretion is reduced in case of vaginal dryness. Therefore, women with vaginal dryness are more prone to developing various bacterial and viral vaginal infections that require treatment.

Women who have not reached menopause when cancer treatment begins (chemotherapy, pelvic radiation, or ovary removal) can experience an abrupt menopause as a side effect of treatment, which is either permanent or temporary. Women who have reached menopause before cancer treatment may experience increased vaginal dryness.

Normal blood flow and hormonal function are key to healthy vaginal mucous membrane. When the blood flow to the genitals decreases for some reason, less nutrition and oxygen reach the lining of the vagina, and the risk of dryness increases. Blood flow is closely related to vaginal mucus production because vaginal mucus or moisture comes from blood filtering through the mucous membrane and not from glands. Sexual stimulation increases the vaginal blood flow and thereby mucus production (vaginal lubrication).

The hormone estrogen increases blood flow and maintains the thickness, moisture, and elasticity of the vaginal lining. It is produced in the ovaries and also in small amounts in the adrenal gland and placenta. As estrogen production in the body decreases, vaginal mucus production decreases, resulting in thinning of the mucous membrane and decrease in elasticity. These changes usually happen over a long period during menopause although they manifest differently in different women. However, in the case of ovarian cancer treatment, the vaginal and hormonal changes occur relatively rapidly, causing an early and abrupt menopause.

A few suggestions are provided below:

- Ask health care providers in charge of the cancer treatment whether the treatment has any sexual side effects.
- It is helpful to consider that many things other than cancer treatment may also contribute to vaginal dryness, such as breastfeeding, menopause, and various diseases such as diabetes and/or untreated vaginal infections. Many drugs other than chemotherapy, such as antihistamines or allergens, affect the blood flow to the pelvic area.
- The use of lubricants and/or moisturizers is advisable (see more educational materials: Lubricants, Moisturizers). There are differences between vaginal moisturizers and lubricants. Moisturizing substances are intended to increase vaginal moisture, restore the mucous membrane, and reduce discomfort due to irritation. They are not intended as a lubricant for sexual intercourse; however, increased vaginal moisture facilitates sexual intercourse to some extent. Lubricants are, however, specifically intended to reduce discomfort due to friction during vaginal intercourse. Moisturizing substances are inserted into the vagina, but lubricants are applied on

the vulva and vaginal opening. Moisturizing substances are also of little use if they are used only while having vaginal intercourse. They should be used regularly, usually before bedtime, such that they have the desired effect on the properties of the vaginal mucous membrane. In the case of severe vaginal dryness, the use of lubricants and/or moisturizing substances may not be able to remedy it.

- If severe pain occurs during vaginal intercourse, local anesthetic can reduce the pain according to a recent study. Place 4% lidocaine gel (local anesthetic) on a cloth, and keep the cloth at the vaginal opening for 3 min before intercourse (Goetsch et al., 2016).
- Avoid the use of soap, fragrances, and creams on the genitals and in the vagina (it is enough to rinse these parts with lukewarm water).
- Estrogen administration: In an abrupt menopause, hormones may be administered unless it is inadvisable owing to the presence of hormone receptors on the tumor (Bennet et al., 2016). There are divided opinions about the use of local estrogen therapy in women with hormone-dependent breast cancer (Falk, 2016); therefore, it is advisable to seek advice from the oncologist in charge of the cancer treatment. If there are no contraindications, local estrogen treatment can be used, for example, Ovestin (creams/pessaries), Vagifem (pessaries), or Estring (vaginal ring).
- Vitamin E oil: If hormones for vaginal dryness or mucosal atrophy is not advisable, it is possible to use vitamin E oil (capsules) (Morali et al., 2006; Falk, 2016). To extract the oil, puncture the capsule with a small needle (at both ends), and squeeze the oil out. Insert the oil into the vagina with your fingers or put the punctured capsule with the oil in the vagina, where it melts.
- Keep the vagina healthy by increasing the blood flow to it. Use ample time for caressing/foreplay. An even more effective way to increase the blood flow to the genitals is to use a vibrator for stimulation. Sexual stimulation increases the blood flow to the genitals, and more nutrients and oxygen reach the vaginal mucous membrane. Increased blood flow during sexual stimulation results in enhanced mucus production (vaginal lubrication). Regular vaginal intercourse also maintains vaginal elasticity (Sinha & Ewies, 2013).
- It is possible to enjoy sexual activity without vaginal intercourse (in

the case of discomfort caused by vaginal dryness). Reducing sexual activity may reduce physical intimacy, which in turn may decrease the intimacy in the relationship (Cleary & Hegarty, 2011). Therefore, flexibility in ideas about what physical intimacy requires can contribute to maintaining intimacy.

- Relaxation of the pelvic floor muscles: If one has more than one episode of pain during sexual intercourse due to vaginal dryness, it increases the likelihood of involuntary stiffening of the pelvic floor muscles during sex. By doing regular pelvic floor muscle exercises (Kegel exercises), tense and relax the pelvic floor muscles before—and while—the penis slowly enters the vagina. Another method to learn how to relax the pelvic floor muscles is to use vaginal dilators that come in different sizes (see more educational material: Vaginal dilators).

Fatigue

Fatigue and lack of energy are among the most common side effects of cancer treatment. After vaginal dryness, fatigue is the second most common cause of sexual problems in women following cancer treatment (Ussher et al., 2015).

A few suggestions are given below:

- Explore ways to nourish yourself, both physically and mentally, such as meditation, relaxation, yoga, walking, or dancing. Increased physical energy and improved mental well-being can increase interest in intimacy, whether it is sexual or non-sexual.
- Save your energy for what you deem as most important.
- Your energy levels may be at their best at a certain time of the day; you and your partner could choose to be physically intimate at this time if that feels right.
- Take a few shorter naps (rather than one long nap) and/or regularly take time to rest.
- Distribute tasks throughout the day, assign tasks to others, and ask for help.
- Ask your employer for more flexible hours, for example, approval to come to work later in the morning.

Decreased sexual desire

Approximately 50% of women report decreased sexual desire after cancer treatment, whether it is surgery, radiotherapy, and/or chemotherapy (Falk, 2016). The treatment of cancer contributes to reduced sexual desire, for example by stopping or reducing the production of estrogen hormones, changing the physical appearance or organ functioning, and/or causing changes in mucus secretion. Indirect side effects of cancer treatment also affect sexual well-being owing to fatigue, pain, nausea, hair loss, and changes in body weight. Anxiety and sadness or depression also affect sexual desire. In fact, many factors contribute to changes in sexual desire, including disagreements with partner, excessive stress, breastfeeding, menopause, past trauma, various diseases, and side effect of drugs such as serotonin-enhancing antidepressants.

Few suggestions

- Consider discussing the changes in sexual desire with your partner. Not talking about it can more likely enhance the feelings of insecurity and rejection in your partner. When matters are discussed, the likelihood of mutual understanding increases. It is also more likely that you and your partner can find ways to maintain sexual intimacy.
- Ask healthcare professionals about whether the cancer treatment has sexual side effects that can affect sexual desire.
- When a woman repeatedly experiences pain during sexual intercourse, it can easily reduce her sexual desire, and then it is important to act immediately (see the following education material: Vaginal dryness, Lubricants, Moisturizers).
- Your energy levels may be at their best at a certain time of the day; you and your partner could choose to be physically intimate at that time if that feels right.
- If a woman experienced sexual desire before she was diagnosed with cancer, she is more likely to experience sexual desire over time, after cancer treatment is concluded. If sexual desire does not gradually return, seek professional help.
- Explore ways to nourish yourself, both physically and mentally, such as meditation, relaxation, yoga, walking, or dancing. Increased physical energy and improved mental well-being can increase interest in intimacy, whether it is sexual or non-sexual.

- Some women say that knowledge about different types of sexual desire is helpful. There are different types of sexual desire: “responsive sexual desire” and “spontaneous sexual desire.” Knowing that sexual desire can manifest in different ways has practical implications. One can be sexually neutral, which implies that sexual desire does not have to be noticeable before sexual activity begins (Shifren, 2016; Basson, 2003). If a woman has good relations with her partner and is willing to experience sexual touch, it is after some sexual touching that the sexual desire is elicited. This is what “responsive sexual desire” refers to. In long-term relationships, sexual desire is more frequently activated after sexual caressing starts. However, the process of responsive sexual desire is very sensitive and easy to interrupt in women, also as a result of diagnosis and treatment of cancer. This type of sexual desire differs from (although equally normal) spontaneous sexual desire, which refers to existing sexual desires before the sexual caressing begins. Spontaneous sexual desire is more common at the start of a new intimate relationship, whereas responsive sexual desire becomes more prominent in stable, long-term relationships.
- Reduced sexual desire after cancer treatment does not have to result in excluding all close contact with a partner. If a couple wishes to and circumstances allow it, they may enjoy intimate touching or sexual activity. What suits one couple may not be suitable for another, but here are some ideas: enjoy a weekend out of town together, organize a date with each other, going for walks and holding hands, enjoy facial touching (one partner sits upright with a pillow on their lap, and the other lays their head on the pillow and accepts gentle facial touching or massage with oil), practice synchronized breathing (while lying down together side by side similar to two spoons in a drawer, the person who lies at the back puts one of their hands on the abdomen of the person in the front, and both lie still and notice their own breathing and breathing of the partner), listen to music together, take a bath or shower together and apply lotion or oil on each other’s bodies afterwards, perform mutual massage, rest your head on a pillow and look into each other's eyes and hold hands in silence or enjoy physical intimacy without sexual intercourse (e.g., kissing, caressing, and oral sex).
- Some women like to masturbate. Using sex toys such as vibrators increases the blood flow to the genital mucosa and enhances sexual

arousal and orgasm. Here is a brochure about vibrators; you can copy the following website link:

https://sexualityresources.com/sites/default/files/documents/Vibrators13.pdf

A question that often arises is whether drugs can increase sexual desire in women. The short answer is “no;” however, some drugs that are occasionally mentioned in the context of this question are described below:

- Estrogen: Menopause and early menopause due to cancer treatment are associated with decreased sexual desire, but administration of estrogen has not been proven to be effective in this regard (Falk, 2016, p.8). Moreover, there is insufficient evidence for local administration of estrogen in women diagnosed with breast cancer (Bennet et al., 2016).
- Testosterone: Testosterone is converted into estrogen in the body; therefore, it is not an option for women advised against taking estrogen because of hormone-dependent breast cancer (Falk, 2016).
- Flibanserin: This is a new drug that was developed to help women with extremely low sexual desire (Falk, 2016). This drug was first developed as an antidepressant but was not effective as such. Flibanserin affects neurotransmitters in the brain. This drug is not suitable for women who have reached menopause. Furthermore, this drug is not suitable for women who have decreased sexual desire owing to physical or psychiatric health problems, relationship difficulties, or medication. Therefore, women who are receiving chemotherapy are advised against taking this drug.
- “Erection drugs” for women: Studies have shown that “erection drugs” for women are no better than placebo (Falk, 2016). This finding is not unexpected because insufficient blood flow is not a primary reason for decreased sexual desire in women (Kaschak and Tiefer, 2001), and therefore, a drug that dilates blood vessels is a poor solution for a lack of sexual desire in women.

Changes in body image

Body image is part of one’s identity or sense of self. Identity is, as the word suggests, the image that every woman has of herself and what is typically associated with being a woman. Changes in body image after cancer treatment are most commonly associated with changes in appearance, loss of a body part, or changes in bodily function. These include hair loss, weight gain or loss, lymphoedema, breast removal, stoma insertion, scarring, or decrease in genital sensitivity. Women who undergo early menopause after chemotherapy sometimes feel older than their chronological age. Changes in body image and self-esteem can make women feel less sexually attractive than before. Feeling less attractive is among the most common concerns in the sex life of women diagnosed with cancer (Ussher et al., 2015).

A few suggestions are as follows:

- It can help to accept the changes in body image. It is sometimes considered necessary to be able look ahead in terms of self-esteem/body image. That said, it needs be emphasized that different individuals cope with changes in body image in different ways. You can give yourself both permission and time to grieve for the past. You can ask your partner to listen and discuss the potential effects the changes may have or ask what they now find attractive about you. It can also be helpful to hear about experiences of other women in similar situations. All this can provide one a chance to reflect on one's own experiences.
- Reconnect with your new body. A woman may "distance" herself from her own body during cancer treatment so that she can better deal with the bodily changes. Sometimes, this distancing continues after the treatment is over. This distancing makes it harder for her to enjoy herself in intimate, physical interactions. It is possible to reconnect with your new body and nourish yourself in various ways, both mentally and physically, for example, through a relaxation massage, meditation, or an improvised "pampering package." However, imagination alone determines what the woman chooses to do to better connect with her own body.
- When experiencing illness, it is normal to be preoccupied with what is not right or focus more on what could go wrong regarding physical appearance or functioning of the body. Try to think about what about your body you appreciate and feel positive about. Then make a list in your mind or on a piece of paper of what you value, are grateful for, or feel positive about your own body. You can do this in private, in front of a large mirror, or in the presence of your partner.
- A woman's partner is occasionally insecure about whether or how much touch she wants and withdraws physically from her. You and

your partner could spend some time together where your partner touches you by “mapping your body” to identify what kind of touch you now like.

- If a woman has a stoma, the partner could inspect or touch the stoma. When having sexual intercourse, the woman can choose a position in which there is little pressure on the stoma or put a small cushion on top of it, between the woman and the partner. If the woman is afraid that the stoma may leak, the couple could use the shower as a place to have sex.
- A partner could ask the woman where she would like to be touched, what kind of touch she wants and does not want, and whether they may touch the scar. If the woman does not want to be touched somewhere or looked at, she may want her partner to have an understanding that she wants to cover up or have the room dimly lit.

Lubricants

Lubricants are substances without hormones that are used when there is a risk of pain owing to friction during vaginal intercourse or vaginal dryness causing discomfort. It is advisable to apply a lubricant to the vulvar area, vaginal opening, and penis immediately before vaginal intercourse. It is also especially important to use a lubricant during anal intercourse as the anal opening does not produce natural lubrication during sexual stimulation as the vagina does.

The types of lubricants that are most often recommended are silicone lubricants and water-soluble lubricants (with or without glycerin). Both of these types of lubricants can be used with latex rubber condoms.

Water-soluble lubricants (with or without glycerin)

Water-soluble lubricants dry relatively quickly. Sometimes you can recall the properties of water-soluble lubricants by putting a little bit of water or saliva on them on the mucous membrane. Water-soluble lubricants that contain the preservative glycerin (should be specified in the ingredient list if it is in the lubricant) are less suitable for women who are prone to develop vaginal yeast infections or have diabetes. Instead, they are advised to use lubricants without glycerin.

Silicone-based lubricants

Silicone-based lubricants (with the ingredient dimethicone) last longer than water-soluble lubricants (they remain on the skin longer as they contain no water). There is also the advantage that silicone lubricants can be used when having sex in the bath or shower (the water-soluble lubricants wash away more quickly in the shower). Some examples are ID millennium, Durex play-perfect glide, iLube, System JO, Eros, Wet platinum, and Pink, some of which are available in Iceland. It should be noted that silicone lubricants must not come into contact with silicone sex toys or so-called “cyberskin” because silicone destroys the surface of these sex toys.

Other lubricants

It is usually not recommended to use vegetable oil, baby oil, hand cream or lotion, and fat-soluble ointments such as Vaseline. Vaseline is primarily used to protect the skin by creating a barrier; it is not a lubricant that eases friction. Oils and Vaseline must not be used with latex rubber condoms because these substances destroy the condom by making tiny holes in the rubber. Among vegetable oils, coconut oil may be suitable because the skin absorbs that oil most easily. Vegetable oils and Vaseline are usually difficult to rinse from the mucous membrane and increase the risk of bacterial and yeast infections. However, there are specially produced lubricants made from vegetable oils that are suitable for use, for example, the lubricant Yes (oil-based).

Ingredients to avoid

If the vaginal mucous membrane is sensitive or dry, it is best to avoid all lubricants containing various additives considered to increase sensitivity or be stimulating. These are often substances that cause irritation or a burning sensation, such as capsaicin, menthol mixture, and acacia honey or high levels of glycerin, which increases the risk of yeast infection. Caution should also be exercised for the use of lubricants considered to have a numbing effect because pain is an essential guide for one’s own health. Other substances can also be irritating to the vaginal mucous membrane, such as chlorhexidine, which is an antibacterial agent, and parabens, which are preservatives.

Table 11: Overview of lubricants

Silicone based lubricants		
Advantages	**Disadvantages**	**Name - examples**
Remain on your skin longer	Silicone based lubricants must not come into contact with silicone sex toys or so-called "cyberskin" because the silicone destroys the surface of these sex toys	ID millenium, Durex play-perfect glide, iLube, System JO, Eros, Wet platinum and Pink are some examples of a silicone lubricant
Small amounts go a long way	Usually cost a little more than the water-sore lubricants	
Feels less sticky less than the water-soluble lubricants	Can leave a stain in bed linen (can be washed out)	
Is not absorbed by the skin		
Can be used when having sex in the bath or shower		
Does not change the pH-acidity of the vagina		
Suitable for body massage		
Can be washed off with soap and water		
Water-soluble lubricants		
Advantages	**Disadvantages**	**Name - examples**
Putting a tiny amount of water or saliva on a water-soluble lubricant on the mucous membrane you can recall the properties of the water-soluble lubricant	Dries quickly	Examples of water- based lubricants without glycerin: Durex play - feel, Yes – water based Examples of water-based lubricants with glycerin: Astroglide, Yes, Durex-play Feminine –Intimate Lubricating gel
Can be used with latex rubber (a substance in some condoms and sex toys)	Not advised (washes away easily) to use for sexual activities in shower or bath	
Doesn't leave spots in bedsheets	If the water-soluble lubricant contains glycerin or sorbitol, these substances can turn into sugars in the vagina (and change pH levels in the vagina). These lubricants are less suitable for women who are prone to develop vaginal yeast infections or have diabetes	
Easy to clean off with soap and water	May feel sticky when it dries (especially if the lure contains high levels of glycerin)	
Absorbed by the skin/evaporates		

Vaginal moisturizers

Vaginal moisturizers, with or without hormones, are substances inserted into the vagina to the vaginal moistness, restore the endometrium, and reduce discomfort due to irritation. It is recommended to use moisturizing substances regularly, usually before bedtime, so that they have the desired effect on the vaginal walls. Moisturizing substances are not the same as lubricants although increased vaginal moistness may, to some extent, make it easier to have vaginal intercourse. However, lubricants are intended to reduce discomfort due to friction during vaginal intercourse (see more educational material: Lubricants).

Non-hormonal moisturizers are suitable for women who cannot or do not want to use local estrogen hormone therapy (Krychman & Millheiser, 2013). Non-hormonal moisturizing substances contain hyaluronic acid, which reduces mucous membrane dryness by sealing in the moisture. An example of a non-hormonal moisturizing substance is Pre-meno Duo (pessaries), which can be purchased without a prescription.

Localized treatment with estrogen hormones to reduce vaginal tenderness and thinning of the mucous membrane has, apart from other effects, moisturizing effects in the vagina. Hormonal moisturizers include Ovestin (creams/pessaries), Vagifem (pessaries), and Estring (vaginal ring).

Some women are advised to use both moisturizing substances and lubricants if the vaginal walls are highly sensitive and vaginal dryness is severe. When a woman stops using moisturizing substances and/or lubricants, vaginal dryness can recur unless the ovaries start producing estrogen again.

Couples and sexual well-being

Different couples react differently regarding sex and intimacy following the diagnosis and treatment of cancer. Some couples believe that the cancer experience has brought them closer and has had a positive effect on their relationship. Some believe that their intimate relationship is strengthened and they have adjusted to the changes in sexual activity and perhaps also redefined intimacy (Falk, 2016, Ussher et al., 2015). Other couples feel that they have turned away from each other and experience less intimacy, more communication difficulties, and more stress in the relationship during the cancer experience (Ussher et al., 2015). For many, sexual intimacy allows one to share one’s innermost feelings and experiences with a loved one. However, perceptions about the best way to experience sexual intimacy together differ among individuals.

A few ways to experience sexual intimacy are described below:

- Expectations that sex should be the way it used to be before the woman was diagnosed with cancer should be set aside for a while. Any enjoyable interaction together as a couple is what counts.
- Synchronized breathing: While lying together side by side similar to two spoons in a drawer, the person who lies at the back puts one of their hands on the abdomen of the person in the front, and both lie still and notice their own breathing and the breathing of the partner.

- “Mapping” of the body: Ask your partner to touch your whole body, including the face, and notice how the touch affects your feelings. Let your partner know what you experience.
- Take a bath or shower together and apply lotion or oil on each other’s bodies afterwards, ask for mutual massage, rest your head on a pillow and look into each other's eyes and hold hands in silence or enjoy physical intimacy without sexual intercourse (e.g., kissing, caressing, and oral sex).
- Lie opposite each other with your heads on a pillow, perhaps holding hands, relax (sinking into the mattress), and look into each other's eyes for a few minutes without talking.
- Consider talking to your partner about the sexual changes you are experiencing after cancer. When these changes are openly discussed, the likelihood of mutual understanding increases. It is also more likely that you and your partner can find ways to maintain sexual intimacy.

Partner’s sexual concerns

Following cancer diagnosis and treatment, both the woman and her intimate partner may notice changes related to sex and intimacy. Concerns and distress about sexuality-related issues can be just as important for the partner as for the woman with cancer. Therefore, it is also important to be mindful of the partner’s well-being. Paying attention to the intimate partner’s concerns increases the likelihood of an improved quality of life and better well-being for both the woman and the partner, as time progresses.

Partner support is valuable when confronted with cancer. However, when the partner plays the role of a caregiver, it is sometimes difficult to switch from that role to expressing sexual interest. It is not uncommon that the partners want to express their sexual interest but are worried about possibly causing the woman distress. If the woman expresses sexual interest in her partner, their reaction may be mixed and perhaps ridden with guilt. Not talking about those mixed feelings towards sex can lead to loneliness, rejection, and sadness. As a result, a vicious cycle ensues despite good intentions.

It may take some time for the partner to get used to the changes in the woman’s appearance. It is also not uncommon for emotions such as feelings of loss to emerge in the partner. In addition, the partner may fear that having sex may harm the woman because of the cancer or cancer treatment and is insecure about how to address these sexuality-related concerns. The cancer itself is not contagious. The partner may wonder if radiation or chemotherapy can affect their own health, for example, during kissing or intercourse. Radiation and chemotherapy are not contagious nor are they transmitted between the woman and her partner during kissing or sexual activity. However, it is generally recommended that a couple use a condom during vaginal intercourse if less than 48 h have passed since administration of chemotherapy.

As far as pregnancy is concerned, women are generally advised not to get pregnant during treatment and wait for 1–2 years after cancer treatment is completed. The risk of infertility in the woman depends on both the type of treatment and the type of cancer. Infertility can be both temporary or permanent. Eggs cannot be frozen but embryos (fertilized eggs) can be frozen.

Below are a few suggestions for the partner:

- To be in the role of a caregiver during the illness can be challenging. Therefore, it is important that you also take care of yourself both mentally and physically and regularly take a break from this role. Family and friends can provide help and support. It is also possible to talk to someone outside your regular network of family and friends to reflect on your own experience and well-being.
- The sooner the couple talks about what is going on the better. Talk about the sexuality-related changes you have experienced after the cancer illness entered your life. You can also write down these concerns on a piece of paper before sitting down to talk.
- You can plan some time together as a couple (not as the “caregiver” and the “patient”) for an activity that you both enjoy.
- Find ways to be sexually intimate without necessarily having vaginal intercourse. It can include oral sex, kissing, mutual masturbation, or massage/caressing with or without oil.
- It may sound contradictory, but spontaneous things do happen when planning a specific step.
- Set expectations aside, for short or long term, that sex should be the way it was before the woman was diagnosed with cancer.
- Masturbation is one thing, and sex with the person you love is another. Individuals have different attitudes toward masturbation, but it has been said that masturbation can be a valuable “equalizer” in an intimate relationship.

Vaginal narrowing

In women who undergo internal and external radiotherapy in which the vagina is exposed to radiation, vaginal narrowing and shortening may occur; it is also observed in some cases after genital surgery. Moreover, chemotherapy may add to this side effect. Radiation damages the mucous membrane, blood vessels, and connective tissue. When the mucous membrane is restored after completion of radiotherapy, there is an enlargement of connective tissue and smooth muscle cells, which narrows the vagina. The extent of vaginal narrowing and/or shortening depends on the amount, type, and extent of radiation used in the treatment. In most cases, the woman first notices the narrowing during sexual intercourse or during a pelvic (vaginal) examination. Pelvic examination shows that the lining of the vagina has a visible white hue and lower elasticity.

In women who undergo hematopoietic stem cell transplantation, a graft-versus-host disease can cause scar tissue formation in the vagina with subsequent narrowing. When the vagina is narrowed considerably or the walls of the vagina almost completely stick together, it is sometimes referred to as “vaginal stenosis.”

Few suggestions

- Gradually widen the vagina using specially made dilators of different sizes. Dilators are different from vibrators: dilators are designed to maintain the length and diameter of the vagina, whereas vibrators are primarily used on or around the clitoris to enhance sexual pleasure and promote orgasm. Vaginal dilation can increase the length and diameter of the vagina by 1–2 cm (Falk, 2016; see more educational material: Vaginal dilation after pelvic radiation).
- Use lubricants generously (see more educational materials: Lubricants, Moisturizers).
- Having regular vaginal intercourse may help but special precautions need to be taken. It is better to use sexual positions in which the penis cannot penetrate deep into the vagina or in which you can control the movement, for example, the woman sits on top or the couple lies side by side and the partner lies behind her. The sexual position where the male is on top is not suitable if the vagina is narrower and shorter than usual. It is important that you let your partner know how you feel during sex. If you do that, you are less likely to experience a vicious cycle (pain -> anxiety about the next

intercourse -> more pain). If you experience a painful intercourse, it is best to stop immediately and try other ways to be physically intimate.

- Ensure sufficient sexual stimulation, give yourself enough time for foreplay. It can be helpful to insert your own finger (or your partner's finger) into the vagina as a way to better relax before trying to insert the penis.
- Topical steroid therapy: If vaginal stenosis occurs after hematopoietic stem cell transplantation, it is—in most cases—first treated with topical steroid therapy, in the form of a cream (Falk, 2016).
- Sexual counseling
- Physiotherapy

Vaginal dilation

When do I start dilating?

It is recommended to start 2 weeks after the completion of pelvic radiation. If the vaginal opening feels swollen, raw, and sore to touch, it is advisable to wait for a few days and then try again. If you have not started vaginal dilatation by 8 weeks, it is recommended that you talk to the healthcare professionals in charge of the treatment.

What dilator size do I use?

Start with the smallest dilator. If it is easy to insert into the vagina, try the next size up, and so on. As you insert the dilator, you should feel stretching, pressure, and perhaps a bit of burning or stinging sensation. This discomfort should reduce over time. Discomfort and a little bleeding („spotting") are normal.

How long does the dilator stay in?

The dilator should be inside the vagina for at least 3 min and no longer than 10 min.

When do I switch to a larger dilator?

When there is little difficulty inserting the dilator, it is time to switch to a larger one.

How often should I dilate?

- For the first 6 months, three times a week is usually adequate for most women.

- From 6 months to 1 year, dilate at least once a week.
- After 1 year, dilate once a month (if you find it difficult to insert the dilator, then you should dilate more often). After 1 year, the need for regular dilation is reevaluated.

Do I need to dilate if I am having sexual intercourse (or other types of vaginal penetration ?)

You can reduce or stop vaginal dilation if you are having regular intercourse. If you stop having regular sexual intercourse, it is advisable to begin the vaginal dilation if you require regular pelvic (vaginal) examinations.

What is a vaginal lubricant?

Vaginal lubricant is a gel-like liquid. The lubricant is placed on the dilator so that it is able to enter the vagina more easily. For sexual activity, vaginal lubricants can also be applied at the vaginal opening and on the clitoris, fingers, penis, or sex toys.

What if...

... I bleed after I dilate?

- It is quite common to notice some spotting (small amount of blood) after vaginal dilation. It gradually decreases it in a matter of weeks.
- If the bleeding is more than spotting, for example, if you are bleeding enough that you need to use a pad, you should contact your healthcare provider.
- If the bleeding is so heavy that you need a new pad every hour or so, go to the emergency room.

... I notice other vaginal symptoms?

Contact healthcare providers in case of any of the following symptoms as these may be symptoms of a vaginal infection:

- New vaginal discharge
- New odor
- New vulvar itching
- Menstrual-like cramps

... I have a fever?

There are different reasons for having a fever. If you have been given instructions on what to do by your cancer care team (for instance, because your blood counts are low), follow their instructions.

If you get a fever and also, for instance, begin experiencing new pain, odor, vaginal discharge, bleeding, or cramping, contact your health care providers or go to the emergency department.

... I have new pain?

Contact your healthcare provider or go to the emergency room in case of any of the following symptoms:

- You develop new pain while inserting the dilator or continue to feel pain after its removal
- You experience new severe pain putting your fingers or the dilators into your vagina.

... I choose not to dilate?

Talk to the radiologist or oncologist if you think that you do not want to dilate. Here are some reasons why women choose not to dilate:

- The doctor has told them that they never have to have a pelvic (vaginal) examination again in their life.
- They do not want to keep their vagina open for sexual activity.
- They do not want to undergo vaginal dilation (even though they know that vaginal examinations will likely be uncomfortable).