



UNIVERSITETET I AGDER

# **Gynaecological cancer patients` experience with sexual counselling. A qualitative metasynthesis.**

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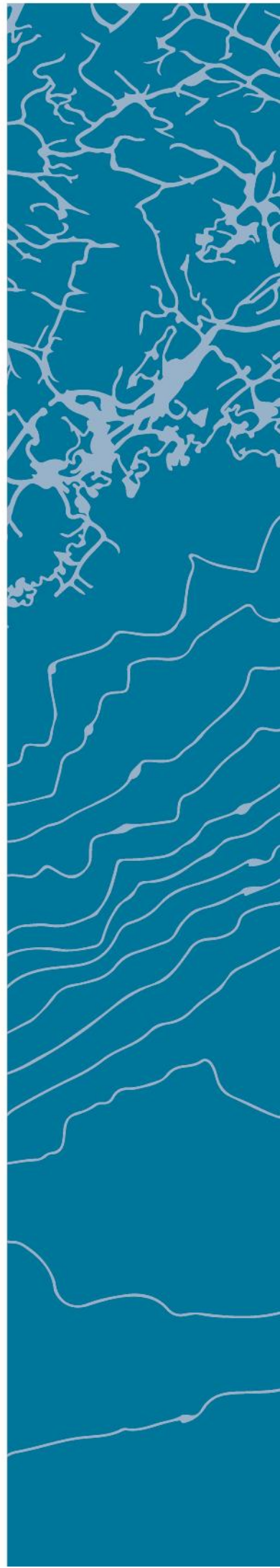
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University of Agder, May 2018

Anita Paulsen

# TABLE OF CONTENTS

## Sammendrag

## Abstract

<b>1.0 INTRODUCTION</b> .....	1
1.1 Background.....	1
1.2 Aim, research question and structure.....	2
<b>2.0 THEORETICAL FRAMEWORK</b> .....	3
2.1 Gynaecological cancer and sexual implications .....	3
2.2 Sexual counselling.....	5
2.3 A positive and holistic view on sexuality .....	6
2.3.1 Sexual function.....	8
2.3.2 Sexual self-concept.....	8
2.3.3 Sexual relationships.....	8
2.4 Despite all the knowledge.....	9
<b>3.0 METHODS</b> .....	10
3.1 Conceiving the synthesis .....	10
3.2 Searching and retrieving literature.....	11
3.3 Appraisal findings.....	14
3.4 Classifying findings .....	15
<b>4.0 DISCUSSION</b> .....	17
4.1 Strengths and limitations .....	17
<b>5.0 CONCLUSION</b> .....	21
<b>6.0 ETICS</b> .....	21
<b>REFRANCES</b> .....	22
<b>SCIENTEFIC ARTICLE</b> .....	26

## LIST OF FIGURES<sup>1</sup>

Figure 1: Neo Theoretical Framework of sexuality based on the work of Woods .....	7
Figure 2: Search strategy inspired by the PICO-model .....	12
Figure 3: Gynaecological cancer patients' experience with sexual counselling .....	17

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<sup>1</sup> The figures and tables in the article will not be listed here. When handing in the manuscript the figures and tables will be attached to the article. For the simplicity and context the figures and tables in the article are inserted where they will be found in the completed article in the journal *Nordisk sygeplejeforskning*.

## **Sammendrag**

**Bakgrunn:** Endringer knyttet til seksualitet kan være et vanskelig aspekt etter behandling for gynekologisk kreft. Det er viktig å imøtekomme gynekologiske kreftoverleveres behov for sexologisk veiledning, men også finne ut mer om hvordan de opplever slik veiledning.

**Hensikt:** Formålet med denne studien er å undersøke hvordan gynekologisk kreftpasienter erfarer sexologisk veiledning.

**Metode:** Inspirert av Sandelowski og Barroso ble det gjennomført en kvalitativ metasyntese, basert på et systematisk litteratursøk i CINAHL (EBSCO Host), MEDLINE (OvidSP) og Psycinfo (Ovid SP) i september 2017. Funnene ble overført til NVivo 11 og ble analysert og syntetisert til meta-oppsummering og metasyntese. Inkluderingskriteriene var a) primærstudier med kvalitative data, b) fokus på kvinnes erfaringer, c) deltagere med en gynekologisk kreftdiagnose som hadde mottatt sexologisk veiledning og e) publisert på nordisk eller engelsk.

**Resultat:** Fem artikler ble inkludert. De var basert på intervjuer med totalt 89 kvinner. De ble samlet i tre kategorier; viktigheten av riktig timing, viktigheten av anerkjennelse og viktigheten av sexologisk veiledning.

**Konklusjon:** Gynekologiske kreftpasienters behov for veiledning og informasjon om seksuelle problemer må anerkjennes av helsepersonell . Seksualitet er kanskje ikke den største bekymringen på diagnosetidspunktet, men kvinner trenger kunnskap om hvordan seksualitet påvirkes av kreftdiagnosen og behandlingen fra diagnose til rehabilitering. Resultatene av denne studien kan bidra til at helsepersonell får en forståelse for kvinnes erfaringer – og dermed kan bidra til å hjelpe disse kvinnene til et nytt liv etter kreftbehandlingen der de kan opprettholde sin seksuelle helse.

**Nøkkelord:** Female genital neoplasm, qualitative study, sex counselling, support, advice

## **Abstract**

**Background:** Changes to sexuality can be one of the most difficult aspects of life following treatment for gynaecologic cancer. It is important to address gynaecological cancer survivors need for counselling on this matter and find out more on how they experience sexual counselling.

**Aim:** The purpose of this study is to explore gynaecological cancer patients` experience with sexual counselling.

**Methods:** Inspired by Sandelowski and Barroso a qualitative metasynthesis was conducted, based on a systematic literature search in CINAHL (EBSCO Host), MEDLINE (OvidSP) and Psycinfo (Ovid SP) during September 2017.

The findings were imported to NVivo 11 and the findings was analyzed and synthesizid into metasummaries and metasynthesis. Inclusion criteria were primary studies a) containing qualitative data, b) focusing on women`s experiences, c) including participants with a gynaecological cancer diagnosis who have experience with sexual counselling, e) and published in English or Nordic language.

**Results:** Five articles based on interviews with 89 women were included. The results were themed into three categories; the importance of timing, the importance of acknowledgement and the importance of receiving sexual counselling.

**Conclusion:** Gynaecological cancer patiens need to be acknowledged by health care providers concerning their needs for counselling and information on sexual issues. Sexuality may not be the main concern at time of diagnose, however the women need to know about sexuality all along the timeline from diagnose to post-treatment. The findings of this study may provide guidance for healthcare professionals in their efforts to help these women adopt to a new life and to empower the women to maintain their sexual health.

**Keywords:** Female genital neoplasm, qualitative study, sex counselling, support, advice

## 1.0 INTRODUCTION

This thesis constitutes the completion of a master's degree in Clinical Health Science. The sexual concerns of gynaecological cancer patients have been well known for decades, but there are still aspects of this that need further exploration.

### 1.1 Background

I have been working as a nurse since 2001. Early in my career, I started to work with patients diagnosed with gynaecological cancer. I administered chemotherapy to them, met them post-treatment when they had to come in for follow-ups or when they had a progression and had to start a new line of treatment or transfer to palliative care.

During the first years as a nurse, I read a lot of literature on gynaecological cancer, also about the sexual aspects. I was surprised to learn that despite the knowledge about the sexual side-effects during and after cancer treatment, health care providers rarely or never addressed the subject matter of sexuality.

To learn more about this aspect I started an education as a sexual counsellor, and in 2008 I got a certification from The Nordic Association for Clinical Sexology (NACS) and a small position as sexual counsellor at the hospital where I work. I have been counselling cancer patients with sexual concerns ever since. At some point I started to wonder how these patients were experiencing the counselling.

There is also an increasing focus on the importance of sexual health. In Norway the government has made a strategy for sexual health for 2017-2022 called *Snakk om det* (Talk about it) (Helse- og omsorgsdepartementet, 2016). When working with this strategy I was so lucky to be invited, along with hundreds of other professionals who works in some area of sexual health, to make an input on this strategy. The strategy is based upon the fact that sexuality is important for our health in all stages of life, and that the individual's ability to ensure good sexual health contributes to good quality of life. The target group for the strategy is the population in general, everyone working in the health care services, in patient interest organisations, in educational institutions and politicians.

## **1.2 Aim, research question and structure**

The number of gynaecological cancer patients are increasing, and this also means that the number of women who will live with side-effects that can have a negative impact on sexuality and sexual function will rise.

The knowledge of gynaecological cancer patients' experience with sexual counselling, advising, guidance or information is poor, and hence this study's aim is to explore gynaecological cancer patients' experience with sexual counselling. The research question is: How does gynecological cancer patients experience sexual counselling?

The master's thesis constitutes this report and a scientific article. The report will elaborate theoretical aspects of the study, the method which will describe the systematic literature search and Sandelowski and Barrosos' steps to a qualitative metasynthesis and a discussion which will emphasise the strengths and limitations of the study.

The findings will be presented in the article. Also, the discussion of the findings will be highlighted there. The article is a draft and it is intended to be published in the journal *Nordisk sygeplejeforskning* (Nordisk sygeplejeforskning, 2014b).



## **2.0 THEORETICAL FRAMEWORK**

More advanced screening, improved diagnostic and more efficient treatment of gynaecological cancer causes an increase in the number of women who become survivors after gynaecological cancer (Bruner & Boyd, 1999; Kreftregisteret, 2016; Rasmusson & Thomé, 2008; Sekse, Råheim, & Gjengedal, 2015). Also, the incidence of ovarian, uterine and cervical cancer is predicted to rise due to an aging population the next years (Bruner & Boyd, 1999; Cook, McIntyre, Lee, & Recoche, 2015; Rasmusson & Thomé, 2008; Sekse et al., 2015)

A gynaecological cancer diagnosis and its associated treatments can have a negative impact on sexuality and sexual function (Alison & L., 2006; Bradford et al., 2015; Gilbert, Perz, & Ussher, 2016; Ratner, Foran, Schwartz, & Minkin, 2010), and therefore, information and counselling on this area are needed.

### **2.1 Gynaecological cancer and sexual implications**

Gynaecological cancer is malignant tumors originated in the female reproductive organs, including cervix, ovaries, uterus, fallopian tubes, vagina, vulva and tumors from the placenta (trophoblast tumors) (Cook, McIntyre, Recoche, & Lee, 2017; "Oncolex," 2017).

1746 women were diagnosed with gynaecological cancer in Norway in 2016 (Kreftregisteret, 2016). Except from cervical cancer, this diagnosis affects mainly women in their 60's (Kreftregisteret, 2016). Women diagnosed with cervical cancer are younger; the median age of being diagnosed with cervical cancer was 45 and the mean age was 52 in Norway in 2016 (Kreftregisteret, 2016; "Oncolex," 2017). However, cervical cancer is the only diagnosis of the gynaecological cancer which has a screening test, namely the pep-test. Also, there is a vaccination for a virus called human papillomavirus (HPV) which can cause this type of cancer. HPV spreads through sexual contact, and most human bodies can fight this infection, but sometimes the virus leads to cancer. Nevertheless, due to low vaccine uptake, we do not know the full effect of the HPV-vaccination in countries where it is available, but the first results are promising (Chaturvedi et al., 2018; Cook et al., 2015; Sanders, Slade, & Patton, 2012).

Ovarian cancer is still the most serious type of the gynaecological cancers because it can only be diagnosed at an advanced stage ("Oncolox," 2017). Ovarian cancer is hard to detect early and many times women with ovarian cancer have no symptoms or just mild symptoms until the disease is in an advanced stage and hard to treat. To date, there is no effective screening regimen for ovarian cancer and more than half of women with ovarian cancer have advanced-stage disease at the time of diagnosis (Cook et al., 2015). Consequently, the five-year survival rate for women with ovarian cancer is much lower than for the other types of gynaecological cancer and the consequences, burdens and side-effects are much higher (Kreftregisteret, 2016; "Oncolox," 2017).

Vulvar cancer is a rare cancer, but women treated for vulvar cancer must struggle with surgery, which can involve the removal of substantial sections of the external genitalia, including the labia majora, the labia minora, the clitoris and removal of the inguinofemoral lymph nodes which can result in lower limb lymphoedema (Barlow, Hacker, Hussain, & Parmenter, 2014; Green et al., 2000). This treatment and the long-term sequelae have a major impact on sexuality (Green et al., 2000).

Being diagnosed with any of the gynaecological cancers can have an impact on all aspects of women's sexuality, both sexual functioning, intimate relationships and sense of self, both during and after treatment (Abbott-Anderson & Kwekkeboom, 2012; Bodurka & Sun, 2006; Juraskova et al., 2003; Liavaag et al., 2008; Ratner et al., 2010).

Sexual functioning can be affected by the disease as well as the treatment (Ratner et al., 2010). Cancer surgery can include loss of the uterus and ovaries, organs that can represent femininity, motherhood and sexuality. And for some, loss of femininity can be a consequence in addition to the physical changes (Cleary & Hegarty, 2011).

Chemotherapy can cause physical limitations such as fatigue, nausea, pain, hairloss and disabilities such as temporary or permanent loss of ovarian function (Oskay, Beji, Bal, & Yilmaz, 2011; Stead, Fallowfield, Selby, & Brown, 2007).

Radiotherapy, administered externally or vaginally, may damage vaginal tissue, nerves and blood vessels (Abbott-Anderson & Kwekkeboom, 2012; Bilodeau & Bouchard, 2011), pelvic pain, bladder, intestinal problems, anxiety and depression (Vistad, Cvancarova, Kristensen, &

Fosså, 2011) and vaginal epithelial atrophy (Hofsjö, Bergmark, Blomgren, Jahren, & Bohm-Starke, 2018). Because of this, the women need to use a vaginal dilatation, a smooth plastic tube, to maintain the vaginas ability to stretch, and this can cause great distress for some (Katz, 2009).

Sexual side-effects can also be seen in a dimensional way; In the physical dimension changes in hormone levels, and loss of sexual organs such as surgical removal of the uterus, fallopian tubes, ovaries, and/or cervix, and resultant damage to pelvic nerves, dyspareunia and decreased sexual activity (Abbott-Anderson & Kwekkeboom, 2012).

In the psychological dimension, common concerns are feelings of pain, anger, anxiety, stress (Ratner et al., 2010), grief , depression, decreased libido, alterations in body image and anxiety related to sexual performance (Abbott-Anderson & Kwekkeboom, 2012)

In the social dimension, common concerns are difficulty maintaining previous sexual roles, emotional distancing from the partner, and perceived change in the partner's level of sexual interest (Abbott-Anderson & Kwekkeboom, 2012).

Women who have completed treatment for gynaecological cancer are normally followed up in hospital outpatient clinics for at least five years to detect and manage cancer recurrence, and to monitor physical and psychosocial late effects of treatment (Vistad et al., 2017). This should give the physician sufficient time to check out the patients' sexual concerns.

## **2.2 Sexual counselling**

Counselling can be a confusing term because it can be defined differently in different counselling theories (Burnard, 2005). It can be synonymous to *supervision, guidance, advice, tutoring* and *mentoring* to mention some (Tveiten, 2008). In this thesis sexual counselling will be defined as “*an interaction with patients that includes information on sexual concerns and safe return to sexual activity*” (Gamel, Davis, & Hengeveld, 1993) as well as “*assessment, support, and specific advice related to psychological and sexual problems*” (Steinke et al., 2013).

This definition underscores the importance of health care providers taking a role in sexual assessment and counselling. Schover (1999) says that brief sexual counselling includes educating the patient (and often the partner) about the ways that cancer treatment can interfere with sexual function; giving suggestions on how to resume sex comfortably; encouraging more open communication about sex between partners; helping patients cope with physical changes that make them feel less attractive to a partner or interfere technically with sex; and helping patients obtain treatment for specific sexual problems.

To many women, sexuality is much more than the ability to have intercourse or the ability to reproduce (Thaler-DeMers, 2001) it is therefore crucial to approach women with gynaecological cancer in a holistic way.

### **2.3 A positive and holistic view on sexuality**

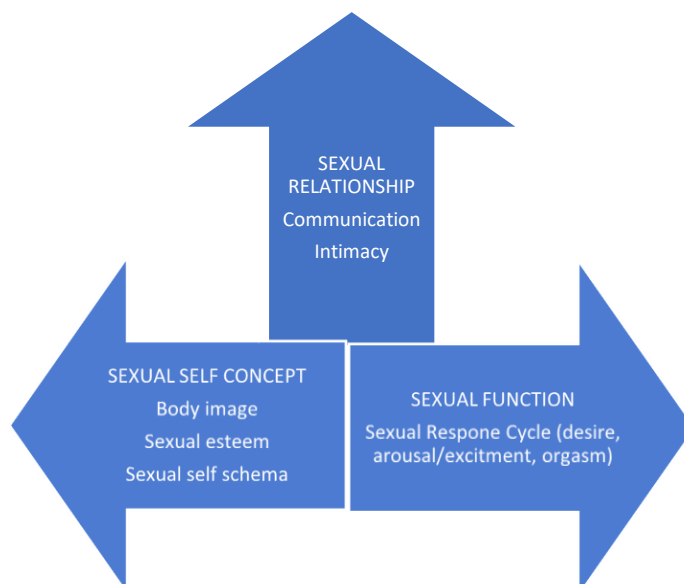
Good sexual health seems to be connected to well-being and quality of life. Greater openness about sexuality and better access to information and offerings to sexual counselling can help prevent sexual and relational problems (Helse- og omsorgsdepartementet, 2016). Many women with gynaecological cancer consider their sexual relationship as a very important part of their lives (Gilbert et al., 2016; M. McCallum, Lefebvre, Jolicoeur, Maheu, & Lebel, 2012; Vermeer, Bakker, Kenter, Stiggelbout, & Ter Kuile, 2016) and it is therefore important for health care providers to recognise this (Gilbert et al., 2016).

This also requires a sex-positive approach where one acknowledges experiences of pleasure, desire, intimacy and agency. This means being open, communicative, and accepting of the individuals' differences related to sexuality and sexual behaviour (Almås & Pirelli Benestad, 2006)

This thesis will lean on the holistic definition on sexuality provided by World Health Organisation (WHO, 1975) which identifies the various physical, psychological and social dimensions of the concept. Also, others suggests that sexuality is a multidimensional phenomena composed of biological/physical, socio(economic), psychological and spiritual components (Bernhard, 2002; Sheerin & McKenna, 2000). This is important when approaching these women because gynaecological cancer survivors experience all dimensions

of sexual concerns (Abbott-Anderson & Kwekkeboom, 2012; Gilbert, Ussher, & Perz, 2011a).

Woods (1987) proposes a holistic view of sexuality which includes three inter-related dimensions; *sexual function*, *sexual self-concept* and *sexual relationships* as showed in Figure 1. *Neo Theoretical Framework of Sexuality based on the work of Wood*. Cleary & Hegarty (2011) have extended Woods' work and calls it the Neo Theoretical Framework of Sexuality. It is also inspired by the work of Kaplan (Kaplan, 1979) the developer of the sexual response cycle.



**Figure 1 Neo Theoretical Framework of Sexuality based on the work of Wood** (Cleary & Hegarty, 2011).

The dimensions are linked and any alteration in one dimension will automatically cause subsequent alterations in the remaining two dimensions, thus affecting an individual's sexual health (Woods, 1987). Although Woods' work was not developed specifically in a cancer care context, her framework of sexuality has been acknowledged by various researchers in gynaecological cancer related studies (Bruner & Boyd, 1999; Cleary & Hegarty, 2011; Gamel, Hengeveld, & Davis, 2000; Lamb & Sheldon, 1994), and it will also be used as a theoretical framework to this thesis.

### **2.3.1 Sexual function**

Sexual function refers to “the ability of an individual to give and receive sexual pleasure” (Woods, 1987). Included in sexual function is a cycle of various physical and psychological stages which a person progresses during sexual activity known as the sexual response cycle which consists of three stages: desire, arousal/excitement and orgasm (Kaplan, 1979).

The desire phase is caused by sexual thoughts and desire. One can become aroused and it can lead to sexual activity. When entering the excitement phase, various responses occur such as increased blood flow to the sexual organs, moistening of the vagina and erection of the nipples. The orgasmic phase, known as the peak of the sexual response, is defined as contractions of the vagina and uterus (Kaplan, 1979).

### **2.3.2 Sexual self-concept**

Sexual self-concept refers to “the image one has of oneself as a man or a woman and the evaluation of one’s adequacy in masculine or feminine roles”. Sexual self-concept also includes body image, reflecting the abstract representation of one’s body and the evaluation of that image against personal and cultural standards. This definition can be interpreted to suggest that sexual self-concept is made up of numerous dimensions, including body image, sexual self-schema and sexual esteem (Cleary & Hegarty, 2011). Sexual esteem is referred to as the evaluative form of self-esteem (Katz, 2005) and sexual self-schemas are cognitive representations (or thoughts) about sexual aspects of the self thus leading the authors to suggest that this is an integral component of sexual self-concept (Cleary & Hegarty, 2011).

### **2.3.3 Sexual relationships**

Sexual relationships are defined as, “the interpersonal relationships in which one’s sexuality is shared with another.” (Woods, 1987) and includes communication and intimacy. Sexual relationships have the potential to be significantly altered by changes in health status such as a gynaecological cancer diagnosis. Communicating feelings within relationships has been revealed by women with gynaecological cancer, as one of the most difficult aspects in learning to deal with the effects of illness and treatment on sexuality. The need for intimacy is not restricted to physical intercourse but can include a desire to be held and kissed rather than engage in sexual intercourse (Cleary & Hegarty, 2011).

Lack of communication and intimacy can lead to strain and dissatisfaction within relationships which serves to add to the overall burden of gynaecological cancer for women and their families (Cleary & Hegarty, 2011) However, it must be acknowledged that a diagnosis of gynaecological cancer may serve to bring couples closer together (Fitch, Gray, & Franssen, 2000).

## **2.4 Despite all the knowledge**

Despite the knowledge of gynaecological cancer patients' need for information and counselling on sexual matters, these needs are often unmet (Cook et al., 2017; Gilbert et al., 2011a; Gilbert, Ussher, & Perz, 2011b; Megan McCallum et al., 2017; Ussher et al., 2013). Also, there is still a lack of a holistic view of sexuality and sexual health in gynaecological cancer patients (Hordern & Street, 2007; Sheerin & McKenna, 2000). Healthcare professionals do not put aside time or privacy provided for discussion of patients' sexuality and a lot of healthcare providers are not comfortable talking about it. Healthcare professionals and patients have mismatched expectations about communicating around these topics (Bouthillette, 2007).

Literature and studies on gynaecological cancer patients' experiences with sexual counselling, advice, guidance or information is scarce. Gilbert et al. (2016) did a study where they examined whether people with (all) cancer and partners have engaged in a discussion with a health professional about sexuality, and how such interactions are constructed and experienced. They found that many people with cancer and partners had engaged in a discussion about sexuality with a health professional, but not the majority. This is confirmed by previous research (Flynn et al., 2012; Stead, Brown, Fallowfield, & Selby, 2003).

Because of this, the purpose of this study is to explore gynaecological cancer patients' experience with sexual counselling.

### **3.0 METHOD**

Sandelowski and Barroso (2007) claims that with an increasing turn in qualitative research there has become an urge to synthesize. This report will be designed as a metasynthesis and following the guidelines of Sandelowski and Barroso (2007) for synthesizing qualitative research. The term *metasynthesis* describes both a group of methods used to integrate the findings of individual qualitative research studies and the end product of a metasynthesis research project (Sandelowski & Barroso, 2007). Sandelowski and Barroso's (2007) six steps are: (a) conceiving the synthesis, (b) searching and retrieving literature, (c) appraising findings, (d) classifying findings, (e) synthesizing findings into metasummaries, and (f) synthesizing findings into a metasynthesis. The last two will be presented in the article.

#### **3.1 Conceiving the synthesis**

The aim of this study was to identify how gynaecological cancer patients` were experiencing sexual counselling. The aim was also, not only to sum up the patients` experience, but to identify patterns and relations between the findings and to interpret existing knowledge concerning their experience with sexual counselling. At this step it is also important to identify why or how this knowledge can make a difference (Malterud, 2017).

This step involves formulating a clearly defined research question (Sandelowski & Barroso, 2007) and at the same time, a wide-ranging one (Malterud, 2017). In this way it is possible to find as many relevant articles as possible. The research question of this study is: How does gynaecological cancer patients experience sexual counselling?

It is also important to formulating inclusion and exclusion criterias at this step. The inclusion criteria were primary studies a) containing qualitative data, b) focusing on women's experiences, c) including participants with a gynaecological cancer diagnosis who have experience with sexual counselling, e) and published in English or Nordic language.

Exclusion criteria were studies a) published in other language than English or Nordic, b) counselling on other issues than sexuality, g) with other study design than qualitative primary studies and h) including other population than gynaecological cancer patients such as nurses or spouses. If the women's voice was represented adequately in addition to for example a partner or healthcare professional, it was ok to include them.



During this step there was a discussion if the studies should only include women which had been counselled by specialized nurses. Because the focus was on the women's experience we decided not to differ in this. And in a sense all health care providers must be able to have basic counsellor skills because they meet people who are distressed and, in a crisis, (Burnard, 2005).

Intervention studies were not included unless there was done an intervention on sexual counselling and the women were interviewed after the intervention on how it was to be a part of the intervention. Patients of all ages were included, because age itself is indifferent when it comes to concerns about sexuality. Year of publication was not an inclusion criteria as we wanted to include as many articles as possible.

### **3.2 Searching and retrieving literature**

This step involves several parameters such as target topic and discussions concerning what kind of search methods that should be used, search terms, how the information is managed, discussion on the relevance of retrieved studies, and the use of analytic devices and displays (Ludvigsen et al., 2016).

A systematic literature search is important for health care providers as it keeps us updated within the field we work - and provide the basis for practical guidelines and procedures. Furthermore, it helps us to obtain all empirical information that matches the criteria to answer a research question (The Cochrane Library, 2014). Through systematic approach, relevant databases were searched to retrieve findings from scientific publications on the topic *gynaecological cancer patients' experience with sexual counselling*.

The process was both timeconsuming and educational. It was remarkable to discover how important the searching process is; it was like the whole study depended on the search. It became the foundation of the study so to speak. The process took a lot longer time than estimated. The search was done in collaboration with experienced librarian during September 2017. It could not have been done without her. Malterud (2017) claims that unexperienced researcher should not do this without guidance. Nowadays it is also common that librarians are included as formal team members of a reaserch team (Flemming, Graham, Heirs, Fox, & Sowden, 2013).

An initial search with the words “Gynaecological cancer” AND “Sexual counselling” AND “Experience” was performed in JBI, PROSPERO, Oria, Google Scholar, CINAHL (EBSCO Host), MEDLINE (EBSCO Host) and Psycinfo (Ovid SP) was done to obtain knowledge about previous research on gynaecological cancer patients’ experience with sexual counselling. Gray literature was searched in Oria and Google Scholar, and master’s theses and doctoral dissertations by searching PROSPERO and JBI. To our knowledge no systematic review or metasynthesis on the topic has been published or is currently underway. The initial search was also done to find the best search words and find MeSH headings.

Based on the first search a new search was done in CINAHL (EBSCO Host), MEDLINE (Ovid SP) and Psycinfo (Ovid SP). These databases were chosen because they contain articles in the field of nursing, medicine and psychology – and sexology is among other fields a part of these.

PICO is recommended as a tool in systematic reviews (Higgins & Green, 2011; The Cochrane Library, 2014) and was used in this report to develop keywords and make the research question precise. See figure 2. It is important to simply use it as a tool and not get attached too strongly to the PICO formula, as a qualitative metasynthesis` purpose is to interpret and synthesize, and not calculate effects (Booth, 2016; Malterud, 2017).

<b>POPULATION</b>		<b>INTEREST</b>		<b>CONTEXT</b>
Gynaecological cancer OR Female genital neoplasm OR Ovarian neoplasm OR Uterine Neoplasms OR Vaginal Neoplasms OR Vulvar Neoplasms	AND	Sexual counselling OR Sex counselling OR Couples counselling OR Counselling OR Advice OR Support OR Information OR Guide	AND	Experience OR Interview OR Qualitative study OR Qualitative research OR Phenomenology

**Figure 2: Search strategy inspired by the PICO-model**

The keywords were searched for in “all fields” and “keyword, title and abstract”. The final search string with some adjustment and modifications in the different databases was: (Genital Neoplasms, Female OR Ovarian Neoplasms OR Vaginal Neoplasms OR Vulvar Neoplasms OR Uterine Neoplasms) OR ((gynecolog\* OR genital\*) (cancer OR neoplasm\* OR tumor)) AND (Sexual Counselling) OR (Couples Counselling) OR (Counselling) OR ((sex\* OR couple\* OR marital\*) (counse\* OR advice\* OR guide OR support\* OR intervention\* OR care OR nurs\* OR therap\*)) AND Experience.

In all the databases the keywords “qualitative study” OR “qualitative research” OR “phenomenology” OR “grounded theory” OR “hermeneutics” was included but the hits than became fewer so we decided to go a step back – and not include this in the search. It would still be an important inclusion criteria in the screening process. This will also be elaborated in the article and the Figure 1 *PRISMA Flow diagram* show the process from identifying to choosing the final articles.

The search resulted in a total of 799 articles (Cinahl (EBSCO host) n = 196, MEDLINE (OvidSP) n = 553, Psycinfo (OvidSP) n = 47 and grey literature n = 3).

The next step was to review and select the studies, another timeconsuming process. This was done in collaboration with experienced supervisor and researcher (LF). The 799 articles were imported to Rayyan (Mourad Ouzzani, 2016), a web application, which was used to help with the screening process. This was very useful because the reviewers can go through the articles blinded – and then change the blinding mode when going over them together. The articles that needed more clarification were labelled as *undecided* and they were discussed and explored together. We were prepared to involve a third person in this process, but it was not needed as we agreed along the way.

145 duplicates were removed before the articles was screened by title and abstract on language, if they were about sexual counselling in any sense, if they were qualitative studies (design) or if they were about gynaecological cancer patients (population). After screening the total number of articles was 12. These 12 primary studies were assessed for eligibility and read by full text. Additional nine articles were excluded because they were not about sexual counselling (n = 7) or had the wrong study design (n = 2).

Our next step was to identify articles through cited by citation searches and go through references. One article (Rasmusson & Thomé, 2008) was identified when going through the references and one article (Sekse et al., 2015) was identified when going through cited by citation searches. The reason that it did not turn up in the structured literature searches can be that standardised keywords was not used and therefore it was not possible to identify it (Ludvigsen et al., 2016). This article was an intervention study, but we decided to include it because it was an intervention on sexual counselling and the women were interviewed after the intervention on how it was to receive information on sexual issues. The citation search was performed for all the articles in Google Scholar Pubmed (MEDLINE) OvidSP (MEDLINE, Psycinfo, EMBASE, AMED) and Scopus. Eventually a total of five articles was included.

### **3.3 Appraisal findings**

After inclusion of the articles the process proceeds with critical appraisal and evaluation of the individual reports followed by a comparative appraisal and evaluation across the articles (Sandelowski & Barroso, 2007).

Each article was read individually several times to get acquainted with the content, find methodological strengths and flaws, locate target findings and to explore whether the studies met the inclusion criteria (Ludvigsen et al., 2016).

There are different ways to make a critical appraisal of studies. In this study the JBI-QARI - Checklist for Qualitative Research checklist - from Joanna Briggs Institute (JBI) (The Joanna Briggs Institute, 2014) was used. JBI is recognized for methodology regarding qualitative systematic studies. This checklist is a standardized tool to systematically review key factors in the articles, and guides structured throughout the study. A strength of this instrument is also that it contained only 10 questions, see table Table 1: *JBS Critical Appraisal Tool – Checklist for Qualitative Research* in the article. Another strength was the question concerning whether participants and their voices were adequately represented (Q8). This criteria were met in all the articles and it was an important one; the women to the study that data presented patient experiences as expressed by themselves and not through others such as partners or health care providers.

We found that all the studies had congruity between the research methodology and the research question (Q2), between the research methodology and the methods used to collect data (Q3) and between the research methodology and the interpretation of results (Q5). We also found that the participants, and their voices, were adequately represented (Q8), that there was evidence of ethical approval by an appropriate body (Q9) and that the conclusions drawn in the research report flow from the analysis, or interpretation, of the data (Q10) in all the five studies. Q8 was especially important because it was also part of the inclusion criteria.

Two of the studies (Rasmusson & Thomé, 2008; Stead et al., 2003) did not present their philosophical perspective, and it was thus not possible to appraise (Q1). One study (Stead et al., 2003) did not describe the analysis method (Q4).

In two of the studies (Stead et al., 2003; Vermeer et al., 2016) we could not find a statement locating the researcher culturally or theoretically (Q6). According to Sandelowski and Barroso (2007) a high quality report will include a statement that clarifies this, but no article should be excluded because of poor quality.

Three of the studies (Sekse et al., 2015; Stead et al., 2003; Vermeer et al., 2016) were unclear about if the influence of the researcher on the research, and vice-versa, were addressed (Q7).

The checklist was done in collaboration with supervisor (LF) and I was surprised to know how useful the process was regarding to getting to know the studies better. The process required reading through all included studies, and examine specific details about the phenomenon being investigated, participants and study methods. When there was uncertainty, we discussed it. It was a time-consuming process, but the appraisal step made it possible to learn and understand more of the articles before proceeding to the steps of comparing and integrating findings.

### **3.4 Classifying findings**

Classifying findings is vital according to Sandelowski and Barroso (2007). The findings in this report is based on the primary researchers' decisions on including, excluding, and interpreting findings, and these decisions might transform the original data to varying degrees (Ludvigsen et al., 2016).

Sandelowski and Barroso refer to the notion of first-, second-, and third-order constructs where participants in the primary study are the first-order interpreters, the authors of the primary study are the second-order interpreters, and the reviewers are the third-order interpreters (Schutz, 1967). In this study, data quotations by participants who took part in the primary studies (first order) and paraphrases or observations offered by the authors of the primary studies (second order) was included. The findings of this study are based on third-order interpreters.

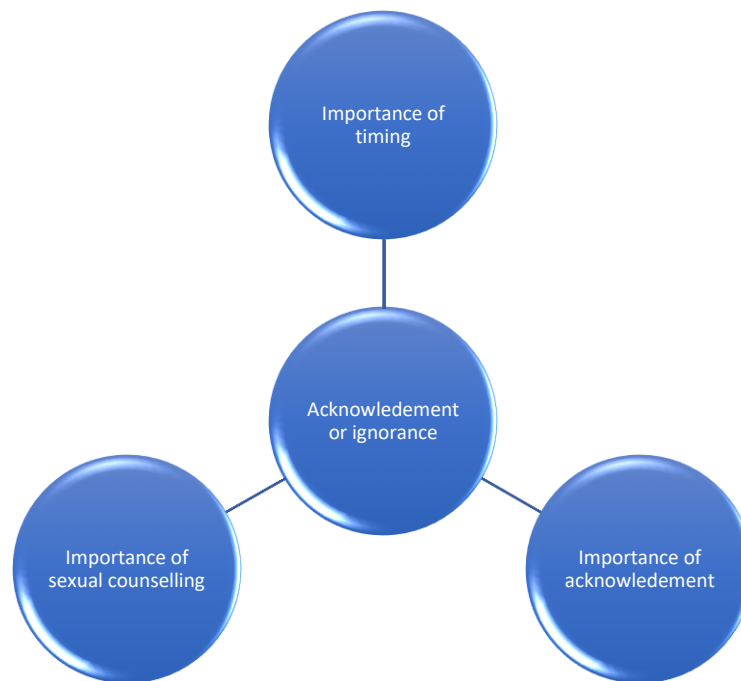
The five studies represent 89 participants, all of them from European countries. All the gynaecological diagnoses were included. The participants were younger than the overall population who is diagnosed with gynaecological cancer. The time of data collection were quite far from when the women were diagnosed in two of the studies (Sekse et al., 2015; Vermeer et al., 2016).

Three of the studies were based on individual interviews, while two of them (Sekse et al., 2014; Sekse et al., 2015) were based on focus-group interviews. The studies were published from 2003 to 2016.

The aim of the differed studies were quite different, but they were all about sexual conselling in some way. The findings of the studies was imported and structured into NVivo 11 (Edhlund & McDougall, 2017) and analyzed and synthesized into metasummaries and metasynthesis. These findings are presented in the article.

## 4.0 DISCUSSION

This metasynthesis based on interpreted findings from five qualitative studies offers an understanding of how gynaecological cancer patients experiences sexual counselling. They were organized into three categories; the importance of timing, the importance of acknowledgement and the importance of receiving sexual counselling. They are all linked to acknowledgement or ignorance as showed in Figure 3: *Gynaecological cancer patients' experience with sexual counselling.*



**Figure 3: Gynaecological cancer patients' experience with sexual counselling**

The dicussion of the findings are presented in the article. In this rapport the main focus is the strengths and the limitations.

### 4.1 Strengths and limitations

A strength is that the included studies largely complemented eachother in the findings and the number of participants (n= 89) should be sufficient to perform a metasynthesis on gynaecological cancer patients experience with sexual counselling. Further, the more it is a strength that all the gynaecological diagnoses were included.

One limitation is that several studies were excluded because they were not data on the women's experience or not about sexual counselling. 57 studies were excluded during the first screening because they were written in French, Spanish, Chinese or other language. One article (Bruner & Boyd, 1999) was excluded because it was about gynaecological cancer and breast cancer, but it was not possible to separate the data from the breast cancer participant and the data from the gynaecological cancer participants.

All the studies were from European countries. This may have conducted to bring in depth knowledge to the study, but at the same time the transferability could be reduced because the findings miss articles from the other continents. Studies from other cultures, minority groups and more patriarchal societies would have given further knowledge and variation. Studies from countries that are considered more conservative regarding sexuality could have contributed with other findings. It is well known from research that there is great variation in knowledge about body, illness and sexuality among ethnical minority groups (Helse- og omsorgsdepartementet, 2016). Also race, religion and ethnic background may influence the willingness of patients to discuss sexual issues (Cleary & Hegarty, 2011).

The included articles differed in aim but still the extracted findings on how the women experience sexual counselling has largely complemented each other. This has increased the depth of integration, while at the same time limiting the width and thereby the abstraction level. Although the studies were few and the studies differed in quality, the findings are still considered useful because the women's voice were heard in all the studies.

A strength is that all the studies with the chosen keywords was identified. Also references and citations was investigated. But although search method were comprehensive, far-reaching and done in collaboration with a librarian, we cannot be sure to have discovered all published articles in this field. There might be articles in small journals that we do not know about.

All the participants had a range differ in age, which gave the study width. On the other hand, the mean age was lower than the overall population for women diagnosed with gynaecological cancer. All though the extracted findings have largely complemented each other we cannot know if the results would have been different if the participants were older. There is still very little knowledge in general about sexuality among people over 70 (Vildalen, 2014) which will be the age for many women diagnosed with gynaecological cancer. This is a



paradox as the population over 70 will rise over the years (Statistisk sentralbyrå, 2016). Therefore it is essential to find out more about elderly and sexuality over the next years. Today it is also more common to distinguish between the group of elderly people living at institutions and the group of elderly who live at home rather than a specific age in relation to health and sexuality (Vildalen, 2014).

In two of the studies (Sekse et al., 2015; Vermeer et al., 2016) the women were asked five-six years after treatment. It is a strength that these women are considered long time survivors and will experience several follow up visits over years. Still, one common long-term consequence of chemotherapy could be memory and concentration problems ("Oncolox," 2017) and we can therefore not be sure that the women in this study remember the content of counselling and information after all this years. The assessment of satisfaction with counselling after such a long time would also be influenced by other aspects of life and symptom burden. Despite this, the findings correlates with the findings in the other studies (Rasmusson & Thomé, 2008; Sekse et al., 2014; Stead et al., 2003) were the participants were asked six-eight weeks after treatment, at a median time of 18 months or within two years after treatment.

Two of the studies were done by focus group interviews. According to Kvale & Brinkmann (2015) a focus group consists of 6-10 people. It is characterized by a more freely and loosely way to address certain topics. Kvale & Brinkmann (2015) claims that this can be especially good when it comes to a topic that is sensitive or taboo such as sexuality. If the dynamics of the group is good it can make sensitive issues easier to address (Kvale & Brinkmann, 2015). The aim of the traditional qualitative interview is to obtain knowledge on the interview topic. The quality of the data is depending on the interviewer's skills and knowledge (Kvale & Brinkmann, 2015). It is a strength that this study has data from both interview forms because of their different contribution.

All but one of the studies (Stead et al., 2003) described how the data were analyzed (Q4). In two of the studies (Stead et al., 2003; Vermeer et al., 2016) we could not find a statement locating the researcher culturally or theoretically (Q6). According to JBI Critical Appraisal Tool – Checklist for Qualitative Research a high quality report will include a statement that clarifies this (The Joanna Briggs Institute, 2014), but according to Sandelowski & Barosso (2007) it is important not to exclude any type of finding presentation because they might contain valuable data. This was the case regarding the studies that were included.

Another limitation was that it was difficult to extract what was information, advice, guidance and counselling as none of the studies had definitions on sexual counselling. The definition in this thesis did not differ from this, so by reading them throughly and see if they could fit the inclusion criteria and definition used in the thesis we were still able to find the right articles.

Finally, the findings of the study seem to support prevoius research that shows that healthcare providers tend to address sexuality in narrow biomedical terms. Providing information related to the act of physical intercourse is important for gynaecological cancer patients and the findings support that they want this kind of information. However, addressing this aspect of sexuality in isolation is not sufficient. Healthcare professionals must also provide information related to how the cancer and its treatment has the potential to affect the sexual self-concept of patients, including issues such as body image and sexual esteem, in conjunction with how the cancer and its treatment has the potential to affect relationships with partners. Addressing these three; sexual functioning, sexual self-concept and sexual relationships in unison is necessary to ensure a holistic approach is taken to the sexuality of this important patient population (Cleary & Hegarty, 2011; Woods, 1987)

## **5.0 CONCLUSION**

The research on gynaecological cancer patients' experience with sexological counselling is scarce and is therefore important to sum up and synthesize. The findings of this study indicates that women with gynaecological cancer experience that it should be done at the right time, by the right person and under the right conditions.

The findings of this metasynthesis indicates that women with gynaecological cancer need to be acknowledged by healthcare providers concerning their needs for counselling and information on sexual issues. It is time for health care providers to recognise sexuality is a multidimensional construct. The neo theoretical framework of sexuality is a relevant and suitable framework for healthcare professionals to use when addressing the concept of sexuality in patients with gynaecological cancer. Healthcare professionals must endeavour to provide information to women on how cancer and its treatment have the potential to affect their sexual self-concept, sexual relationships and sexual functioning. In addition, the neo theoretical framework of sexuality proposed in this study is a useful framework to ensure a holistic approach is taken when conducting future research in this area (Cleary & Hegarty, 2011).

In further reaserch it would be interesting to explore gynaecological cancer patients who have received systematic sexual counselling from sexual counsellors or specialised trained nurses. It is also needed to address further what kind of needs they have in different phases of their treatment – and who can/should provide it. It would also be interesting to explore what health personnel require to give the women diagnosed with gynaecological cancer the counselling and guidance they need. Further down the road it would be interesting to see if providing what the patients need would make them feel acknowledged and not ignored.

## **6.0 ETHICS**

The project is approved by the Faculty Ethics Committee at University of Agder. As the study is based on a systematic literature study, no approval has been required from the regional ethics committee (REK). The study is systematic, thorough and transparent. Transparency criteria means that the methodological procedures should be explicitly presented so that the reader can see what has happened. Only when the procedures are explicitly described, does it give meaning and opportunity to repeat it, evaluate its reliability and discuss among professionals (Polit & Beck, 2010).

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**SCIENTIFIC ARTICLE**

**GYNAECOLOGICAL CANCER PATIENS` EXPERIENCE  
WITH SEXUAL COUNSELLING.  
A QUALITATIVE METASYNTHESIS.**

Short title: Gynaecological cancer and sexual counselling

Words: 5087

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## **ABSTRACT**

**Background:** Changes to sexuality can be one of the most difficult aspects of life following treatment for gynaecologic cancer. It is important to address gynaecological cancer survivors need for counselling on this matter and find out more on how they experience sexual counselling.

**Aim:** The purpose of this study is to explore gynaecological cancer patients` experience with sexual counselling.

**Methods:** Inspired by Sandelowski and Barroso a qualitative metasynthesis was conducted, based on a systematic literature search in CINAHL (EBSCO Host), MEDLINE (OvidSP) and Psycinfo (Ovid SP) during September 2017. The findings were imported to NVivo 11 and the findings was analysed and synthesized into metasummaries and metasynthesis. Inclusion criteria were primary studies a) containing qualitative data, b) focusing on women`s experiences, c) including participants with a gynecological cancer diagnosis who have experience with sexual counselling, e) and published in English or Nordic language.

**Results:** Five articles based on interviews with 89 women were included. The results were themed into three categories; the importance of timing, the importance of acknowledgement and the importance of receiving sexual counselling.

**Conclusion:** Gynaecological cancer patients need to be acknowledged by health care providers concerning their needs for counselling and information on sexual issues. Sexuality may not be the main concern at time of diagnose, however the women need to know about sexuality all along the timeline from diagnose to post-treatment. The findings of this study may provide guidance for healthcare professionals in their efforts to help these women adopt to a new life and to empower the women to maintain their sexual health.

**Keywords:** Female genital neoplasm, qualitative study, sex counselling, support, advice.

## **BACKGROUND**

Changes to sexuality can be one of the most difficult aspects of life following cancer (1) and sexual dysfunction is one of the most common long-term consequences of treatment for gynaecologic cancer (2-4). An aging population gives a higher cancer risk and more efficient and better treatment causes the number of women who become survivors after gynaecological cancer to increase (5).

Gynaecological cancer is malignant tumours originating in the female reproductive organs, including cervix uteri, ovaries, uterus (corpus uteri), fallopian tubes, vagina and vulva. Tumours from the placenta (trophoblast tumours) are also part of this group (6, 7). In Norway, 1746 women was diagnosed with gynaecological cancer in 2016 and ovarian cancer is the 6th most common cancer form among women (5, 8). Worldwide gynaecological cancers account for approximately 17 per cent of all cancers where the significant burden is on women diagnosed with cervical cancer in developing countries because of their lack of screening programs (7). The median age at diagnose in Norway for cancer cervix is 45 years, while it is 65 years for ovarian cancer and 68 years for corpus cancer (5). Treatment differ for each of the gynaecological cancers, but a woman will typically have surgery followed by chemotherapy and/or radiotherapy (7).

The treatment is the main reason that the gynaecological cancer survivors experience a broad range of sexual concerns (5). In the psychological dimension, common concerns are decreased libido, alterations in body image, and anxiety related to sexual performance. In the social dimension, common concerns are difficulty maintaining previous sexual roles, emotional distancing from the partner, and perceived change in the partner's level of sexual

interest and in the physical dimension is dyspareunia, changes in the vagina, and decreased sexual activity (9-11).

Sexuality can be defined as:

“...a central aspect of being human throughout life 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, behaviours, practices, roles and relationships. While sexuality can include all these dimensions, they are not always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.” (p. 5) (12).

This definition is wide and holistic and embraces all the aspects of sexuality which is important to consider when approaching these women because of the many dimensions the cancer diagnose and treatment have (9, 10).

Another holistic approach is presented by Wood (13) and the Neo Theoretical Framework of Sexuality (14), which also will be used as a framework in this article. She suggests that sexuality consist of three inter-related dimensions; 1) sexual function which include desire, arousal/excitement and orgasm 2) sexual self-concept which include body image, sexual self-schema and sexual esteem and 3) sexual relationships which include communication in the relationship and the need for intimacy (14). The dimensions are linked to each other and impact in one dimension will automatically cause impact in the remaining two dimensions (13).

Counselling appear to be one of the best ways to address sexual concerns for women diagnosed with gynaecological cancer (15, 16). Counselling is not unique and clearly defined and different counselling theories emphasis different aspects (17). It can be synonym to supervision, guidance, tutoring and mentoring to mention some (18). In this article sexual counselling will be defined as “an interaction with patients that includes information on sexual concerns and safe return to sexual activity (19) as well as assessment, support, and specific advice related to psychological and sexual problems” (20).

Researchers emphasize that gynaecological cancer patients need information and counselling on sexual matters (1, 7, 21-25), however these needs are often unmet (7, 10, 21, 24, 26). The reason they are not attended to is that most healthcare professionals feel embarrassed, they lack the skills or knowledge or are unable to discuss such issues with patients (25, 27, 28). Some also think that it is not their responsibility, the time is to limited, there are a lack of resources to provide support if a problem is identified, it is taboo (29) or they are relying on the patients to raise sexual concerns (30). Absence of communication and information can leave people with cancer and partners feeling that they are sexually ‘abnormal’, unprepared for the sexual side effects of cancer and treatments, lacking in knowledge about the cause and duration of their sexual problems and depressed, or disappointed with health professionals (1).

The aim of this study was thus to summarize and synthesize gynaecological cancer patients` experience with sexual counselling, to identify patterns and relations between the findings and to interpret existing knowledge concerning these women`s experience with sexual counselling.

## **METHODS**

The qualitative metasynthesis was inspired by Sandelowski and Barroso (31) - and the review follows their guidelines for synthesizing qualitative research. The term metasynthesis describes both a group of methods used to integrate the findings of individual qualitative research studies and the product of a metasynthesis research project. Sandelowski and Barroso's six steps are: (a) conceiving the synthesis, (b) searching and retrieving literature, (c) appraising findings, (d) classifying findings, (e) synthesizing findings into metasummaries, and (f) synthesizing findings into a metasynthesis (31).

### **Conceiving the synthesis**

This step involves formulating a clearly defined research question and define the inclusion criterias (31)The research question was; How does gynecological cancer patients experience sexual counseling? Inclusion criteria were primary studies a) containing qualitative data, b) focusing on women's experiences, c) including participants with a gynecological cancer diagnosis who have experience with sexual counselling, e) and published in English or Nordic language.

### **Searching and retrieving literature**

This process was done in collaboration with experienced librarian. An initial search with the words "Gynaecological cancer" AND "Sexual counselling" AND "Experience" was performed in JBI, PROSPERO, Oria, Google Scholar, CINAHL (EBSCO Host), MEDLINE (EBSCO Host) and Psycinfo (Ovid SP) to exclude that there already was a metasynthesis on how gynaecological cancer patients experience sexual counselling and to identify relevant keywords. To clarify the research question and find the right keywords the PICO-model was applied (32).

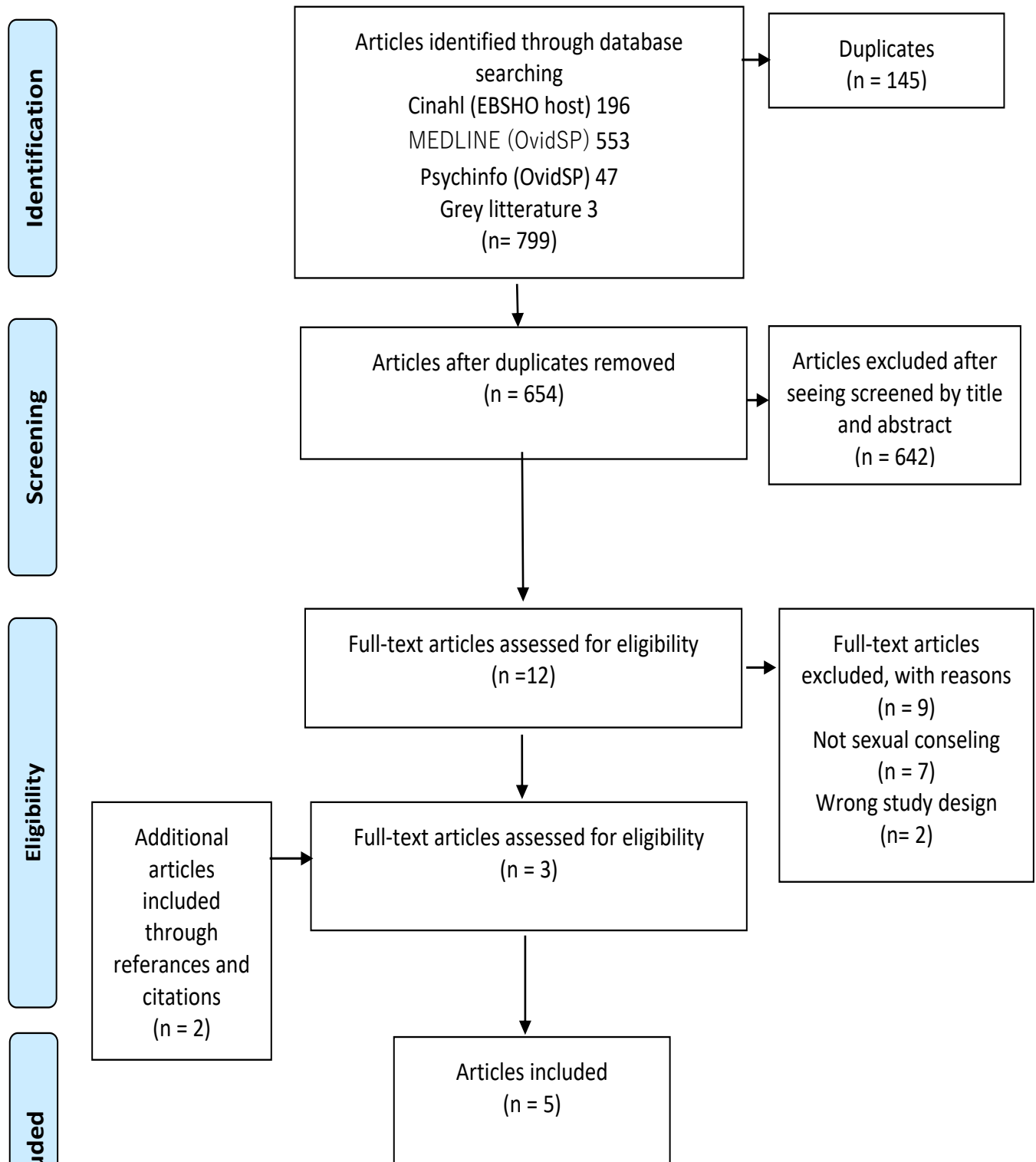
Based on the first search a new search in CINAHL (EBSCO Host), MEDLINE (Ovid SP) and Psycinfo (Ovid SP) was performed. It was done in collaboration with experienced librarian during September 2017. MeSH headings were used when available. These databases were chosen because they contain articles in the field of nursing, medicine and psychology – and sexology is among other fields a part of these.

The final search string with adjustment to the different databases was: (Genital Neoplasms, Female OR Ovarian Neoplasms OR Vaginal Neoplasms OR Vulvar Neoplasms OR Uterine Neoplasms) OR ((gynaecology\* OR genital\*) (cancer OR neoplasm\* OR tumour)) AND (Sexual Counselling) OR (Couples Counselling) OR (Counselling) OR ((sex\* OR couple\* OR marital\*) (counse\* OR advice\* OR guide OR support\* OR intervention\* OR care OR nurs\* OR therap\*)) AND (Experience).

The search was done in “all fields” and “keyword, title and abstract” and the search terms for “Gynaecological” and “Cancer” was made to appear in any order within four words from each other to retrieve the studies we wanted. The words “counselling” and “sexual” appeared within six words from each other. Grey literature was searched for in Oria, Google Scholar and PROSPERO. According to Sandelowski and Barroso it is relevant to retrieve reports by means other than structured, systematized literature searches (31).



# PRISMA 2009 Flow Diagram



Review and selection of studies was done in collaboration with experienced supervisor and researcher (LF). As Figure 1: PRISMA Flow diagram show 799 articles from three databases was imported to Rayyan (33), duplicants were removed, the articles were screened by title and abstract, they were screened by full text and new articles was indetefied when going throug refernces and cited by citation. We were left with a total of five articles.

### **Appraising findings**

The articles were read several times individually. Critical appraisal of the five included studies was conducted using the JBI-QARI -Checklist for Qualitative Research checklist - from Joanna Briggs Institute (JBI) (34). A strength of this instrument is that it contained only 10 questions, se table Table 1: JBS Critical Appraisal Tool – Checklist for Qualitative Research

We found that all the studies had congruity between the research methodology and the research question (Q2), between the research methodology and the methods used to collect data (Q3) and between the research methodology and the interpretation of results (Q5). We also found that the participants, and their voices, were adequately represented (Q8). This was important an a strength of the study.

In two of the studies (23, 27) we could not find a statement locating the researcher culturally or theoretically (Q6). According to Sandelowski and Barroso (31) a high quality report will include a statement that clarifies this, but no article should be excluded because of poor quality.



**Table 1: JBS Critical Appraisal Tool – Checklist for Qualitative Research**

	<b>Rasmusson 2008</b>	<b>Sekse 2014</b>	<b>Sekse 2015</b>	<b>Stead 2003</b>	<b>Vermeer 2016</b>
<b>Q1: Congruity between the stated philosophical perspective and the research methodology?</b>	U	Y	Y	U	Y
<b>Q2: Congruity between the research methodology and the research question or objectives?</b>	Y	Y	Y	Y	Y
<b>Q3: Congruity between the research methodology and the methods used to collect data?</b>	Y	Y	Y	Y	Y
<b>Q4: Congruity between the research methodology and the representation and analysis of data?</b>	Y	Y	Y	N	Y
<b>Q5: Congruity between the research methodology and the interpretation of results?</b>	Y	Y	Y	Y	Y
<b>Q6: Is there a statement locating the researcher culturally or theoretically?</b>	Y	Y	Y	N	N
<b>Q7: Is the influence of the researcher on the research, and vice- versa, addressed?</b>	Y	Y	U	U	U
<b>Q8: Are participants, and their voices, adequately represented?</b>	Y	Y	Y	Y	Y

## **RESULTS**

### **Classifying findings**

The characteristics of the five included articles were summarized in Table 2. The studies represent 89 participants from European countries and all the gynaecological diagnoses were represented. The mean age of women was less than what is normally seen in this group. Also, the time of data collection was quite far from when the women were diagnosed in two of the studies (4, 23).

**Table 2 Characteristics of the included studies**

<b>First author, year and journal</b>	<b>Country</b>	<b>Aim</b>	<b>Diagnosis</b>	<b>Sample</b>	<b>Age</b>	<b>Time of data collection</b>	<b>Data-collection</b>	<b>Analyses</b>	<b>Findings</b>
<b>Rasmusson, 2008</b> Sexuality & Disability	Sweden	Wishes and need for knowlede concerning sexuality	Cervix, corpus or ovarian cancer	11	36-60 Mean age: 48	6-8 weeks after treatment	Qualitative interviews	Content analyses	Wished to be given more in-depth knowledge
<b>Sekse, 2014</b> Scandinavian Journal of Caring Sciences	Norway	Lived experiences (eg. sexualty) of participating in an education and counseling group.	Gynecologi cal cancer	17	20s to almost 80	Completed treatment within the last 2 yrs.	Focus group interwies	Phenomen ological	Living between shyness and openness related to sexuality and intimacy
<b>Sekse, 2015</b> Health Care for Women International	Norway	Handling of sexual changes and intimacy, and dialogue with health care providers	Gynecologi cal cancer	16	30-70 Average: 56	Long-term surviving women (>5 years since treatment)	Focus group interwies	Phenomen ological– Hermeneu tic	Wished that health personnel would initiate dialogue
<b>Stead, 2003</b> British Journal of Cancer	UK	Experiences of communication with doctors and nurses on sexual issues	Ovarian cancer	15	42-71 Median age: 56	8-120 months since diagnosed (Median time 18 months)	Semi structured interwies	Not described.	Healthcare professionals appear to be providing little or no support regarding sexuality
<b>Vermeer, 2016</b> Supportive Care in Cancer	The Netherl ands	Assess experiences with sexual dysfunctions, psychosexual support, and psychosexual healthcare needs.	Cervical cancer	30	36-68 Mean age: 47	Treated the past 1 to 12 years (average 6 years)	Semi structured interwies	The framework method	Most women were asked, but it was often medically oriented.

All the studies were published from 2008 to 2016 and two of them were focus-group interviews. The aim of the different studies was different, but all about sexual counselling in some way. The findings were quite homogenous.

The findings was imported into NVivo 11 (35) and analysed and synthesized into metasummaries and metasynthesis.

### Synthesizing findings into Metasummaries

Metasummaries of characteristics of the included studies is shown in table 3. The results are quantitative aggregations describing the frequency of each finding.

**Table 3 Metasummary showing the intensity of every study used and the frequency of every category.**

	Category	The importance of timing	The importance of acknowledgement	The importance of receiving sexual counseling	Individual studies` contribution to subcategories
<b>Author</b>					
Rasmusson, 2008		X	X	X	3 out of 3 (100 %)
Sekse, 2014			X	X	2 out of 3 (67 %)
Sekse, 2015		X	X	X	3 out of 3 (100 %)
Stead, 2003		X	X	X	3 out of 3 (100 %)
Vermeer, 2016		X	X	X	3 out of 3 (100 %)
	Representation of categories	4 out of 5 (80%)	5 out 5 (100 %)	5 out of 5 (100 %)	

The metasummary show that the categories had an effect size of 80-100 % meaning that 4-5 of the five articles were represented in in the category. As the table also show almost all the individual studies contribution to the categories; all but one study (36) contributed 100 % to

the categories. This means that all the studies will have almost equal influence on the findings.

### **Synthesizing findings into metasynthesis.**

The metasynthesis of gynaecological cancer patients experience with sexual counselling revealed that they could feel acknowledged or ignored concerning sexual issues and how they were assessed. Their experiences were synthesized into three categories: the importance of timing, the importance of acknowledgement and the importance of receiving sexual counselling. The three categories will be elaborated in the following.

#### **The importance of timing**

This category refers to what the participants described as the right moment for health care providers to discuss or give counselling on sexual issues. The women in almost all the studies described this as important (4, 23, 27, 37).

In the beginning, when the participants were diagnosed, they seemed not to be occupied by sexual issues, but rather focused on treatment and recovery (23, 37). "Well, you are sitting at a table with a doctor who is telling you about the surgery and its consequences. And of course, it is being told, that it can have an impact on sexuality, that it can all become less sensitive or that sort of things. And you hear that, but at that moment you are absorbed with the operation and with the cancer. About sexuality, you think, we'll see about that later» (23). The women acknowledged that health care providers had said something about it, but it was not on their mind at the time of diagnose, because of all the other things they were occupied with.

Some suggested that the ideal timing for discussing sexual issues would be between six and 12 months after treatment (23). At this period, they were moving on to follow-ups and their lives were supposed to go back to normal. The participants seemed surprised by the fact that the treatment had such a great impact on their sexuality. It also seemed like some of the women had pushed the idea of sex ahead of them and suddenly it hits them.

However, most women experienced that thoughts about sexuality appeared at different times from diagnosis, through treatment and during follow ups (4, 23, 27, 37). Because of this they expressed that they would have appreciated to receive information about sexuality from the very beginning. "If sex is discussed at the beginning, it's one less thing to be a burden along with everything else"(27). Also, in retrospect some of the women acknowledged that they had a need for dialogue concerning sexuality and that they had wanted health personnel to initiate this from the start. They expressed difficulties initiating such a dialogue (4). In all the studies (4, 23, 27, 37) where the time concept was an issue, the women expressed that it would have been better if the dialog were not something they had to initiate.

They did not necessarily need long dialogues, but information on aspects like how sexual function could be affected and that things could improve over time. They suggested that this could be given written or verbally, for example when they were given information on side effects of the treatment. When more complex issues were accruing regarding sexual problems, face-to-face contact or a consultation with a psychologist or sexologist was

desired (23). The findings also indicate that if information and counselling is offered all along the time of the illness the women could decide whether to take it or not.

### **The importance of acknowledgement**

This category contains aspects of how the women experience acknowledgment from health care providers when receiving sexual counselling - but also how they feel ignored when the counselling is insufficient.

We found that several participants reported that their healthcare provider was accessible if they had sexual concerns. They had asked the health care provider about sexual concerns and some indicated not experiencing any barriers to seek help or to consider these barriers as less important than the benefits of seeking help.

“I began quite early to wonder if I could and how it would feel. Before surgery I asked the doctor and he explained that I could have sex, but we must be careful. He also explained to me what should be removed, during surgery. This was good” (37).

There were also reported ambivalence concerning the topic; on one hand, it was out of the question to initiate dialogue about sexual issues with health personnel. On the other hand, the women acknowledged in retrospect that they had a strong, but unspoken, need for dialogue about intimate issues and that they wished health personnel had initiated such dialogues.

Some reported that the condition to seek help was inadequate. One such condition was lack of time. Others said that it was difficult to express their personal experiences regarding sexuality because of shyness and the interaction between health personnel and the women took place. (4, 27).

Some women had to initiate the dialogue, although they would have wanted the health care provider to do so.

“It’s because you don’t get any information before you go home... and sex is not really what you’re thinking about when you leave the hospital after an operation like that, but of course... when you do come home, and normal life begins, for most of us [sex] is also a part of life and... gosh... what have they done in there... Am I allowed to... Can we do it? And I remember I had to call [health care provider] and ask. “ (36).

One women who had tried to raise the subject because she needed professional help regarding changes in her sexual life finally gave up because health care providers did not respond to her initiatives and thus there was no dialogue concerning her intimate life challenges during the entire follow-up. Finally, she asked for advice at a sex shop (4).

“I felt that there was such a distance between us, the doctor and me. ... He didn’t really say anything, and then I lost courage and didn’t say anything either... or ... if I did say something... he gave me the shortest possible answer. I just couldn’t find the confidence. ... The distance was too great” (4).

We also found that the information they had received could have given them more in-depth

knowledge. They reported that the advice that was given were either limited, a brief question with focus on physical aspects or non-exciting during their follow ups (4, 23, 37).

“Well in my case, they asked “Well how is it with your sexuality?” I said: “I am not sexually active, because I don’t have a partner”, and then that was it. So yes, there was an answer and that was written down, and that’s it. “I don’t have intercourse”. “OK”. But well, at that moment you don’t say: “But I would like to have sex, but I experience problems having it” or you know. So, there is perhaps a task, even it has been a while, to inquire more profoundly. Not only: «Do you have intercourse? » (23).

There were varying opinions of who the best person to give sexual counselling would be, but it seemed that the main thing was that the information was given by a competent person. A lot of participants had experienced that the physician had raised the issue and considered that they were the best to consult for sexual issues (23, 27, 37). Others thought that gynaecologists were not sufficiently skilled to provide support in the case of complex and psychological sexual dysfunctions (23). Some participants reported being referred to or had initiated a consultation with a psychologist or sexologist (23).

### **The importance of receiving sexual counselling**

This category contains aspects of why the women express that sexual counselling is important. They sought genuine involvement and openness from health care providers and more time for conversation.



The women expressed that one reason to why sexual counselling was important to them was because it could have prepared them for the future and the sexual concerns that they could meet (4, 27, 37).

“Isn’t it more important to be prepared for the many years ahead?” (4). Thus, also were connected to another reason why they considered sexual counselling as important; being advised what was normal.

“Understanding that problems were normal – it would make you think that because other women have gone through it, what you’re going through is nothing different, otherwise you feel that you are different. It gives you confidence if you know others are experiencing the same problems” (27). They suggested that this could be done by health care providers by giving examples of the types of problem which may occur and give the women the opportunity to ask questions.

Another experience was that sexual counselling could prevent cancer treatment to have a negative effect on their sexual relationship. The women considered talking to their partner about sexuality as important – and they expressed that it had been easier if the health care professionals had given the information to both partners at the same time (23, 27, 37). In relationships with good communication, the couple could usually handle the changed situation regarding sexuality in a constructive way. On the other hand, feeling close to partner made it more difficult to some to talk about sexuality. Some also expressed that it was to talk to their partner about sexual issues: “it’s a bit quiet between us these days.”

Some were also skeptical of healthcare providers should involve the partner. A few had also experienced that the healthcare provider had insufficiently involved their partner in the information and care provision and that it was not a good experience (23, 27).

Sexual counselling could also contribute to prevent the women to feel ignored regarding sexual issues. Some participants described how lack of counselling could have consequences for their quality of life and sexuality and made them feel lonely. They did not seek help because they felt that they ought to solve sexual concerns on their own or considered it a taboo to talk about sexual dysfunctions (4). "Sometimes I have thought about... when I go to the pharmacy, there's a poster that says you can call the cancer phone. ... But what do you ask about?" (4).

## **DISCUSSION**

This metasynthesis based on interpreted findings from five qualitative studies offers an understanding of how gynaecological cancer patients experience sexual counselling. Their experiences were organized into three categories: the importance of timing, the importance of acknowledgement and the importance of receiving sexual counselling. And in a sense, they are all about feeling acknowledgement or ignorance.

### **Discussion of findings**

The participants seemed to agree that sexual counselling must emerge at the right time. It could differ on when this was, but most participants emphasized that the best timing was post-treatment. It is not surprising that they did not reflect on sexual issues in the beginning.

The diagnostic period is one of great distress and the need for information in general is crucial (38). The fact that they, in retrospect, would have wanted it in the beginning is evidence that it is important to give some information or even offer counselling also in the beginning. Our findings are supported by the study of Gamel and colleagues (39) suggesting that information was needed three times in the illness trajectory; at diagnose and treatment, at recovery and when the sexuality is rebuilt.

The timing-factor will also depend on the extend of the sexual complications. The findings indicate that the treatment influenced the sexual functioning of these women in several ways (4, 23). This is supported by studies which have shown that cervical and ovarian cancer patients experience a reduction in sexual functioning following treatment in comparison to that of control groups (40-42). It is manly when the treatment is over – and life is expected to go back to normal - that the women will be aware of the changes in desire, arousal and orgasm, or what is known as the sexual response cycle (43). These are factors that Woods (13) include in the *sexual function* dimension in her framework and it is referred to as “the ability of an individual to give and receive sexual pleasure.”

To experience acknowledgment the women appreciated that health care providers offered sexual counselling on sexual issues (4, 27, 37). They would have wanted health care personnel to initiate it - and they also had suggestions for how it could be; not necessarily long dialogues but written or verbally information on aspects like how sexual function could be affected and that things could improve over time (23). This findings are supported by Schovers (44) who suggests that brief sexual counselling can include educating by giving

information about the ways that cancer treatment can interfere with sexual function, giving suggestions on how to resume sex comfortably, encouraging more open communication about sex between partners, help to cope with physical changes that make them feel less attractive to a partner or interfere technically with sex and helping patients obtain treatment for specific sexual problems (44). Therapy is usually conducted by experienced therapists for patients and partners who have particularly complex issues (45).

The findings also indicate that there were varying opinions of who the best person to give sexual counselling would be, but it seemed that the main thing was that the information was given by a competent person. Most participants had received information and counselling from a physician. This might be because participants considered them specialized, familiar and hence the obvious professionals to consult for sexual concern. The physician was also the primary care provider during treatment and follow-ups. Women who have completed treatment for gynecological cancer are normally followed up in hospital outpatient clinics for at least five years (46), they therefore have the opportunity to ask the physicians about sexual issues. At the same time this might also be the reason why some participants found the counselling too limited or too focused on physical aspects (4, 23, 37). The follow ups are due to detect and manage cancer recurrence, and to monitor physical and psychosocial late effects of treatment (46) and as a result the physical aspects will be the physicians main concern. Some are suggesting that all health personnel should be able to give information on sexual issues (45). Others that there should be someone on the oncological team who are specialized in sexology (44) and trained to do so (20). Ratner (3) says that to comprehensively understand the nature of sexuality in this unique medical population,

sexual health must be understood via both biological and psychological factors. Considered what is expected to, it could be discussed if the physicians are the best to provide all the information and counselling.

Today it is rare that sexual health is emphasized in health care providers' professional education (47). This contributes to lack of communication. There are several certifications or additional education health care providers can attend to better assess' sexual concerns, such as American Association of Sex Counsellors, Educators & Therapists (AASECT) (48) or Nordic Association of Clinical Sexology (NACS) (49).

Some women wanted information or counselling on sexual concerns because it could prepare them for the future, make them feel normal, prevent them from feeling alone and ignored regarding sexual issues. These findings are in accordance with Woods (13) study describing how body image, sexual self-schema and sexual esteem are affected after going through treatment for gynecological cancer (14). These dimensions are what she call the sexual self-concept (13). Women experience a disruption in their body image following diagnosis and treatment for gynaecological cancer(50, 51). Body image is a complex phenomenon which in its simplest definition is described as the picture of our body which we have in our mind (52) and the many physical changes which occur as a result of cancer and its treatment including weight loss, hair loss and scarring, are factors that can negatively affect a woman's body image (14). Also, feelings of femininity and attractiveness can be part of body image. Loss of femininity has been reported by gynaecological cancer patients in other qualitative studies (53).

They also reported that sexual counselling and information could prevent their sexual relationships to be distressed. Involving the partner seemed important, while others found it more difficult to discuss sexual concerns in the presence of the partner (23, 27, 36, 37). According to Woods (13) sexual relationships have the potential to be altered when a gynaecological cancer diagnosis appear. Communication within sexual relationships has been highlighted as important in various studies (14, 53, 54). Hesitancy from the partner due to fear of pain may lead to misunderstandings and can be interpreted as disinterest or rejection (53). This can also lead to decreased levels of physical contact. Unfortunately, when sexual activity decreases and the couple are not able to talk about it also intimacy within the relationship decreases (55). However, being diagnosed of gynecological cancer may also serve to bring the couples closer together and strengthen the relationship (37, 56, 57).

### **Strengths and limitations**

It is a strength that the studies represent a homogenous group of 89 participants from European countries. This may conduct to bring in depth knowledge to the study. However, this could have reduced the transferability of the findings due to the lack of articles from other continents. It may also be discussed whether the number of final articles has been useful, since only five relevant articles were found. Nevertheless, this was the total number of articles found when conducting the systematic search.

Further the more, all the studies were from European countries. This may have conducted to bring in depth knowledge to the study, but at the same time the transferability could be reduced because the findings miss articles from the other continents.

It was a big range in the woman's age, which gave the study width. On the other hand, the mean age was younger than the overall population for women diagnosed with gynecological cancer. All though the extracted findings have largely complemented each other we cannot know if the results would have been different if the participants were older.

In two of the studies (4, 23) the women were asked five-six years after treatment. It is a strength that these women are considered long time survivors and will have experience with follow-ups. Still, one long term consequences of chemotherapy could be memory and concentration problems (8) we can there for not be sure that the women in this studies remember the content of counselling and information after all this years

Another limitation is that several studies were excluded because they were not data on the women's experience, not about sexual counselling or that they were not written in English or Nordic language.

## **CONCLUSION**

The purpose of this study was to explore gynaecological cancer patients` experience with sexual counselling. The findings of this metasynthesis support previous research indicating that women with gynaecological cancer need to be acknowledged by health care providers concerning their needs for counselling and information on sexual issues. Sexuality may not be the main concern at time of diagnose, however the findings show that women need to know about sexuality all along the timeline from diagnose to post-treatment. Further it is essential to choose the appropriate information and counselling to increase patient satisfaction and promote best sexual health outcomes.

The content of information at the beginning could be brief information in an early consultation – and after treatment the women could be asked if they needed counselling. Because healthcare providers give information it is also important to agree on who will provide what information at each time.

It must be recognised that sexuality is an important component of the well-being of women living with gynaecological cancer and they deserve attention from health care providers in a more holistic way. The findings may provide guidance for healthcare professionals in their efforts to help these women adopt to a new life after cancer treatment but also to empower the women to maintain their sexual health.

In further studies, it would be interesting to explore gynaecological cancer patients who have received systematic sexual counselling from sexual counsellors or specialised trained nurses. It is also needed to address further what kind of needs they have in different phases of their treatment – and who can/should provide it. It would also be interesting to explore what health personnel require to give the women diagnosed with gynaecological cancer the counselling and guidance they need. Further down the road it would be interesting to see if providing what the patients need would make them feel acknowledged and not ignored.

## **ETHICS**

This project is approved by the Faculty Ethics Committee at University of Agder. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.



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