- 1 Male partners' experiences of caregiving for women with cervical cancer a
- 2 qualitative study
- 3 Key words: male partner, cervical cancer, masculinities, sexuality, qualitative
- 4
- 5 What does this paper contribute to the wider global clinical community?
- Male partners describe an interdependence to their partners living with cervical
- 7 cancer.
- Male partners describe the sexual relationship as being harmed.
- Masculinity and care should be reflected on in teaching and supervising in clinical
   practice.

- 12 Abstract
- 13 Aims and objectives: This study aims to develop knowledge on the experiences of male
- 14 partners of women with cervical cancer during and after the illness. We explore men's
- 15 experiences of becoming caregivers as well as how the illness trajectory affects or has affected
- 16 the relationship.
- 17 Background: Receiving a cancer diagnosis has a significant impact on the lives of both the
- 18 cancer patient and their family members. However, studies of male partners' experiences with
- 19 cancer patients are scarce. Additionally, cervical cancer and its impact on male caregivers is less
- 20 explored than how other cancer diagnoses impact male caregivers. The theoretical concept of
- 21 caring masculinities is helpful to interpret men's experiences as caregivers and partners.
- 22 **Design:** The study employs a qualitative design with semi-structured interviews with six
- 23 men/partners recruited through the gynaecological section at a hospital. COREO reporting
- 24 guidelines have been applied.
- 25 Findings: Based on our analyses, we find that men's experiences of being caregivers and

1 partners of women treated for cervical cancer are multifaceted, comprising emotional and
2 practical aspects. However, three main findings stand out as particularly significant for men in
3 the context of cervical cancer: loneliness, an altered sexual relationship and shared feelings of
4 vulnerability.

5 Conclusions: The men describe an interdependence in the relationship with the women but also6 how the relationships have been seriously altered, particularly when it comes to sexuality. These7 findings resonate with hegemonic as well as caring masculinities.

**Relevance to practice:** Complex issues of intimacy and sexuality should be a pivotal element in 9 educating future healthcare professionals. We strongly suggest that issues such as dealing with 10 masculinity and caregiving roles should be on the agenda and reflected upon in teaching and 11 supervising in clinical practice. A broader approach to sexual health and relationships is needed 12 in the patient—clinician relationships, including information about HPV.

14 Introduction

Being diagnosed and treated for cancer has a significant impact on the lives of both patients and their partners. Being the partner of a person diagnosed with cancer means facing new challenges and responsibilities – emotional, social and practical (Lambert, Levesque, & Girgis, 2016; Stenberg, Ruland, & Miaskowski, 2010). However, the experiences and demands of informal caregiving regarding a partner with cancer are not well understood, and more research is needed (Kent et al., 2016; Lambert et al., 2016). The role of caregiving for a family member may be experienced differently by men and women, and in this study, we particularly look into caregiving from male partners' perspectives. Ussher et al. conclude that norms of masculinity and femininity influence partners' ways of participating in their caregiving roles, stating that "cancer caring is not a gender-neutral experience" (Ussher, Sandoval, Perz, Wong, & Butow, 2013, p. 900). For instance, male caregivers tend to seek

1 more external help and support than women (Río-Lozano, García-Calvente, Marcos-Marcos,

2 Entrena-Durán, & Maroto-Navarro, 2013). Men also, more than women, tend to feel closer to

3 the person with cancer (Ussher et al., 2013). There are, however, several knowledge gaps

4 when it comes to such gender differences (Li, Mak, & Loke, 2013). Additionally, in studying

family caregivers' experiences with cancer patients, extensive focus has been given to

6 prostate, breast, gastric-intestinal and lung cancers (Stenberg et al., 2010), while cervical

cancer and its impact on male caregivers is less explored. Male partners' caregiving role for

women with cervical cancer is an understudied subject.

9 Background

Globally, cervical cancer is the fourth most common cancer in women, and in 2012, cervical cancer accounted for 7,5 % of all female cancer deaths worldwide (Globocan, 2012). The incidence of cervical cancer in Norway is around 300/year, making it the most common cancer for women younger than 35 years. Infection with human papillomavirus (HPV), which is transferred by sexual contact, causes cervical cancer. Around 100 different HPV types are known, and of these, types 16 and 18 cause 70% of cervical cancer (World Health Organization, 2016). To prevent cervical cancer in Norway, a national screening programme encourages women between 25 and 69 years to regularly get screened, and free vaccination applies to all young women born in 1991 or later. Starting in 2018, boys will be included in the vaccination scheme.

Cervical cancer treatment depends on the stage of cancer and size of cancer tumour and may consist of surgery, chemotherapy and radiotherapy (Norwegian Cancer Society, 2017). Women may also receive supportive care in the aftermath of treatment, for example by using a vaginal dilator to prevent or treat vaginal stenosis, something which may occur as a side effect of radiotherapy or genital surgery. Improved medical treatment means that today,

the five-year relative survival rate for women diagnosed with cervical cancer is 80.6%

(Cancer Registry of Norway, 2017).

Recent studies indicate that women diagnosed with and treated for gynaecological cancer experience immense changes in their lives (Sekse, Raaheim, Blaaka, & Gjengedal, 2010; Solbraekke & Lorem, 2016). These include tensions around personal growth and fear of recurrence, problems connected to sexuality and especially intercourse because of vaginal stenosis, and difficulties associated with early menopause and infertility. We have found few studies addressing how the changes and challenges women experience upon diagnosis and during/after treatment affect their partners and their relationships.

A systematic review (Teskereci & Kulakaç, 2016) of the life experiences of family caregivers of women with gynaecological cancer, of which 59% of the included caregivers were men, found that caregivers experience a disruption of daily routines and transformation of lifestyle, roles, physical intimacy and plans for the future. The review shows that many caregivers "dreamed of a future when they would turn back to normal" (p. 14). Moreover, acknowledging the need for more gender-sensitive knowledge on caregiving, Lopez et al. (2012) explored male partners' experiences of caring for their wives/partners with breast and gynaecological cancer. The findings show that men tend to minimise disruptions, focus on tasks and keep stress to themselves; this way of being a caregiver is interpreted as being congruent with masculinity, meaning being the stronger person. In characterising a similar caregiving role of husbands of breast cancer patients, Wagner et al. (2011) argue that husbands conceal the burden inherent in their caregiving role to minimise their wives'/partners concerns. Caregivers of women with ovarian cancer describe negative health changes such as anxiety and depression as well as sex life problems (Beesley, Price, & Webb, 2011; Butow et al., 2014; Price et al., 2010).

#### **Caring Masculinities**

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One problematic aspect in the literature on caring for a partner with cancer is that men and masculinity, on one hand, and the care work that comes with the partnership, on the other, are explored as opposites, even as a contradiction in terms (Hanlon, 2012). In light of traditional gendered divisions of labor, this contradiction might hold true. According to Elliot (2016), the effects of traditional forms of masculinity include high-risk behaviours, a lack of safeguarding oneself, poor health and unhealthy relationships, all of which seem to conflict with what may be understood as care work. The problematic side effects of men's traditional gender roles are taken up by Connell (1995) with the concept of hegemonic masculinity. This concept refers to a social structure of norms where some men, because of the privilege of their positions, are enabled to dominate and subordinate women and men with less power. The concept has been influential and debated, and one critical argument against this way of approaching men in general is that "...the understanding of men's lives only in terms of power makes it difficult to theorise men's experiences of powerlessness and vulnerability..." (Hanlon 2012, p. 66, cited in (Elliott, 2016). However, as claimed by Elliot (2016), such issues can be reduced through new forms of masculinity with values that can have positive consequences for men. These positive consequences might be, among others, improved mental and psychosocial health, leading to longer life expectancy, a better social life and better family relationships (Elliott, 2016). Considerations like this have led to the concept of caring masculinities. This term is used to open up and challenge old ideas regarding ways to be a man and discuss "the concept of care in men's lives" (Elliott, 2016, p. 241). In the context of severe illness, we argue that the concept of caring masculinities can help in analysing and interpreting the experiences of men whose partners have had a serious illness, such as cervical cancer, as well as the emotional experiences and intimate relationships that unfold during and after treatment.

To provide healthcare professionals with insights and deeper understanding into male caregivers' experiences when their partner is diagnosed with cervical cancer, and what kind of support is needed during and after treatment, we aim to explore the accounts of male partners' experiences of women with cervical cancer during and after the treatment. This includes men's experiences becoming and being caregivers, as well as how the illness trajectory affects or has affected their relationships with their (formerly) ill partners.

7 Method

### Design

A qualitative design with semi-structured in-depth interviews was considered the most appropriate way to learn how male partners describe their experiences of being caregivers.

The Consolidated criteria for reporting qualitative studies (COREQ) have been applied.

### **Recruiting Participants**

The inclusion criteria for participants in this study were 1) men being partners of women who had been treated for cervical cancer and 2) that the cancer treatment was finished. We recruited potential participants through a contact in the gynaecological department of a Norwegian hospital. Information sheets about the study, including the contact information of the interviewer (i.e. the first author), was given to the women and their partners upon their (return) visit to the department for control after ending cancer treatment. If the male caregivers wanted to participate, they were asked to contact the interviewer by text message. Information about the study together with an invitation to participate in the study was also published on the Gynaecologic Cancer Society's webpage and in the feed of the society's Facebook page. The recruitment period lasted for five months, and during the period, in total six men responded and consented to participate in the study. The average age among the men was 44 years, where Tom and Thomas were in their 30s; Ole, Per and Martin were in their 40s and Morten (all names are pseudonyms) was in his early 50s. All

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1 participants were either cohabiting or married. For most of the men, it had been one to two

2 years since their wives/partners completed cancer treatment, which means that cancer struck

most of the couples in their 30s. Most of the men worked and had one or more children. The

men were not offered compensation for taking part in the interviews.

#### **Procedure**

The first author conducted all interviews, each of which lasted from 30 to 65 minutes. The participants decided where the interview should take place – at their workplace or at the workplace of the interviewer. A semi-structured interview guide ensured that the following issues were discussed in the interviews: the participants' experiences of their partners being diagnosed and their experiences of the illness trajectory, everyday life, communication, intimacy and the future. The interviews were digitally recorded and transcribed verbatim. Upon transcription, the interviews were anonymised, and the names of both the interviewee and those mentioned in the interviews were replaced with pseudonyms. After each interview, first author wrote a note about her experiences during the encounter with the informant, reflections and analytical ideas. The interviewer, being a young woman and an experienced nurse, had an impact on the interview situation. Exactly how aspects such as professional background, gender and age impact is difficult to know, but awareness of the fact that the researcher affects the research process is fundamental to qualitative studies (Doyle, 2013), and was discussed between the authors. The interviewees' quotes used in this article have

# **Analysis**

Data analysis began as soon as the first interview had been transcribed, as right from the start the first interview contained long and detailed statements on the participant's experiences. Even though there were differences between the participants, the overall impression was that the men easily shared their thoughts and experiences, even on rather

been translated from Norwegian to English by the first author.

intimate subjects. In parts of the qualitative research tradition, data saturation is described as 1 2 the gold standard, centring on the question of how many interviews/participants are "needed until nothing new is apparent" (Saunders et al., 2018). However, as our study is embedded in 3 a tradition in which *power information* is acknowledged as the measure for saturation 4 (Malterud, 2016), we find the numbers of participants in our study to be satisfactory. 5 Information power means that the study's data contain information which is adequate for 6 analysis, and that the knowledge derived from the study is relevant to the research question. 7 Further, results from the present study contribute substantially to the knowledge on men as 8 caregivers and as partners, empirically as well as theoretically. 9 10 In analysing the dataset, we looked at how participants answered our research question, which is theoretically influenced by gender theory. We wanted to explore the men's 11 experiences in detail and found thematic analysis, as described by Braun and Clarke (2006), 12 13 to be useful. Thus, the analysis approach is both deductive and inductive. To become familiar with the dataset, the first and last authors read all the transcribed interviews twice and took 14 notes on possible analytical ideas and themes. This process is described as the first phase of 15 thematic analysis (Braun & Clarke, 2006). 16 In the second phase, the first author coded the entire dataset into semantic codes. 17 18 These are codes that refer to verbal statements and nothing else. Then, in the next phase, we developed themes based on the codes. We understand that a theme "captures something 19 important about the data in relation to the research question" (Braun & Clarke, 2006) and that 20 themes represent meanings. In the fourth phase, the four authors discussed the suggested 21 22 themes in relation to the dataset and the research question, and in the fifth phase, we agreed on and named three main themes. Within each main theme, three or four subthemes were 23 identified (see Table 1). Lastly, the authors considered the main themes' validity and 24

reliability by assessing whether enough data supported them and whether some should be

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- removed or replaced. Hence, a constant challenge in analysing the data has been constructing
- themes that are internally coherent and consistent and at the same time distinctive (Braun &
- 3 Clarke, 2006), pp. 90–91). The participants were not offered to provide feedback on the
- 4 findings.

#### **Trustworthiness**

The issue of trustworthiness in interview research is often discussed in relation to objectivity, reliability, validity and generalisation (Kvale & Brinkmann, 2015). In this study, we have carried out what is called *reflexive objectivity*, which means that we are aware of, and have tried to take into account, our contribution as researchers to the result and conclusions. However, as the four authors come from three different disciplines (nursing, philosophy and sociology), we came to a *dialogical intersubjective* agreement when interpreting the data (Kvale & Brinkmann, 2009, p. 279). Further, in regard to reliability, we have particularly addressed the challenges connected to the interview transcriptions as well as translating quotes from Norwegian to English. The transcripts have been thoroughly read by the first and last author and translated quotes checked against the Norwegian versions. According to Kvale and Brinkmann (2015) validation should permeate the entire research process. We have tried to carry out the study in a systematic, reflexive, ethically sound and transparent way throughout the research period.

#### TABLE 1 HERE

#### 21 Ethics

The study was performed according to the Helsinki Declaration of 1975, as revised in 2008 (8), and has been approved by the Norwegian Centre for Research Data (NSD, case number 44848). The NSD required that the male participants inform their partners that they wanted to participate in the study and obtain verbal consent from the women. Before the

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1 interviews were conducted, informed written consent was obtained from the participants.

2 Herein, interviewees were made aware of the fact that participation was voluntary and that

they could withdraw from the study at any given time, including after the interview has taken

place. Sharing experiences about being a partner and caregiver of a woman diagnosed and

treated for cervical cancer can be demanding because it touches upon private and intimate

6 matters. In conducting the interviews, we tried to remain aware of this and were careful when

it came to anonymising the participants. All identifying details, including names, have been

removed. The participants were informed about the helpline at The Norwegian Cancer

9 Association if they became emotionally distressed taking part in the interviews.

10 Findings

Based on the analysis, we find that male partners of women treated for cervical cancer are a varied group and that their experiences during and after their partners' cervical cancer are multifaceted, comprising emotional and practical aspects. However, we identified three analytical themes that particularly highlighted our research question: loneliness, an altered sexual relationship and shared feelings of vulnerability.

### Loneliness

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Different aspects of being on one's own and loneliness were identified in all the men's stories. This came to the fore in different situations, such as being alone in taking care of everyday tasks at home and being neglected as a relative at the hospital as well as a kind of solitude in their relationships with the women.

"It's like being a single father". An overall pattern in the men's accounts was the number of practical challenges they had to face when their partners became seriously ill. This was especially the case for the men who had children. Treatment for cervical cancer is particularly tough on the body, and, according to some of the men, their partners' loss of energy lasted after the treatment period. Hence, responsibility for everyday tasks fell to the

- male partner. During the interviews, several men expressed a sense of overwhelming responsibility. Thomas described "a chaotic everyday life". Tom compared his situation to being a single father:

  As a partner, you should be supportive and take care of the children, who are quite
  - As a partner, you should be supportive and take care of the children, who are quite difficult in themselves, alone. It is like being a single father, and at the same time, you should try to take care of yourself. You should do housework and prepare food. There is much to do, really.
  - "No one talks to you". Nearly all the men said they felt like an outsider when accompanying their partners to the hospital. They had no problems understanding that the focal attention from healthcare professionals was on the patients, their partners. Nevertheless, Martin described how he was "feeling alone in the situation", and Ole said: "during the period when she was in the hospital, I felt very lonely in the setting because the focus was fully on her, and I understand that, have no problem with it. But you are very lonely when that happens".
  - Tom had a conversation with a psychologist just after his wife was diagnosed. "This was the only time I felt like I was in the focus, which was good... because as a relative, no one talks to you; (they) only talk alongside you". Thomas described it as a very hard and challenging time when his partner became ill and said he felt overlooked by the hospital staff. He said, "If I had shared my thoughts with someone at the hospital at that time, they would have realised that I needed help and that I was going downwards".
  - "Inside, I worry". Many participants described a close relationship with their partners during and after treatment. At the same time, as they wanted to be considerate of their partners, some of the men kept their thoughts and worries to themselves. For example, Per asked his wife not to worry about the cancer spreading, but "inside, I worry that things can come back". All the men were concerned, and Tom described how he was overwhelmed by

the situation when his wife was diagnosed and how he was not able to share his worries with 1 2 his wife. "I didn't want to scare her... and I haven't told her how I worried that she should die". 3 4 Ole described how he and his wife both went through difficult emotions but at different times. This led to little understanding towards one another, which added to the 5 already prominent feelings of loneliness for this participant. He also found it difficult to be 6 7 honest with his wife about what he needed and missed in their relationship because it could make her feel guilty about how life had turned out. 8 "Friends that can stand that kind of talk". The men had different situations when it 9 came to friends and family to lean on. If the men had family nearby, they got practical help 10 and emotional support. If that was not the case, or if they did not have many friends, the men 11 experienced more feelings of being by themselves in a difficult situation. At the same time, 12 13 the men also told about being backed up by people they hardly knew, such as other parents from the local football team and colleagues. Sharing experiences about the illness with others 14 was important, as Morten described: 15 It's good to talk to other men, and I have at least a few good friends that can stand that 16 kind of talk. Quite a few men are a bit superficial when it comes to intimate topics. So, 17 I'm lucky. 18 However, unlike Morten, other men strongly missed having relationships that were 19 close enough to talk about such experiences. Some friends even disappeared after the illness 20 entered their lives, as Ole described. "I had a friend, a very good friend who I still talk to. But 21 22 many others disappeared. We actually lost many friends". None of the participants expressed problems with talking to others about the diagnosis. 23

None of the participants expressed problems with talking to others about the diagnosis However, two men thought it was difficult for persons who had no experience with cancer to understand what they were going through, and Tom said: "I don't know how much benefit

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serve as an example of how cervical cancer impacts sexuality:

- 1 you really have from talking to someone who does not have a perception of what cancer is. It
- 2 is something special; if you have not experienced cancer, you know nothing about it and
- 3 would not understand the situation".

# An Altered Sexual Relationship

- "Sex: a non-issue". The men described sex as an intimate and private matter and difficult to talk about. The participants described sex as "a difficult issue", "nothing to think about" and a "non-issue" throughout the treatment period. This was particularly connected to intercourse. The men experienced episodes of their wives/partners bleeding during penetration, which Per described as "a real turn-off on both our parts". Ole's experiences can
  - We have a relationship but do not have the intimate contact many people have; this, of course, is a deprivation for both of us. We are deprived of the opportunity to be intimate since her vagina has grown together. We have not been informed of how we can solve it in other ways. In the beginning, when we had sex, she began to bleed because of the wounds and abrasions after radiation treatment. The vagina also becomes rigid. So many aspects make sex difficult for us.
  - Besides discussing the physical changes in the female genitalia, participants described how hormone treatments affected their partners' libido and resulted in a lack of energy.
- "The magic is lost". The location of the cancer had an impact on the relationship andchanged it. Thomas sums up the change:
  - I have come to know her body well and everything around the cancer, but getting that close, knowing all the bodily details, does something to the love relationship, and in our case, it has lost some of its magic, something of its carelessness, and it (sex) has become more of an issue.

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Two factors added to sexuality being an issue: the vaginal dilator and the HPV. Three of the men referred to the vaginal dilator when talking about how their intimate life and sex had changed. This device is to be used by the woman to prevent the vagina from narrowing or losing its elasticity, something which made intercourse difficult. According to Per, his wife found the dilator "nasty" because "it reminded her of the treatment. She wouldn't even touch it and threw it away". One of the other women also had a bad experience with a dilator and had not used it, resulting in the vagina becoming narrower. Because of this, Ole shared: "We lost the opportunity to be intimate, and we have not received information on how it could be different". When it came to HPV, all the participants were aware of the connection between HPV, sexual activity and cervical cancer. While this was not a difficult or taboo issue for most, two men described that it impacted how they thought about sexual activity with their partners. Thomas discussed how information about the disease and treatments affected his libido, and HPV scared him, considering the serious consequences it has for women. He said: "It works as a block. HPV is such an unseemly thing. Thinking of it as contagious, (it) is unpleasant". "Something is missing". Taking into account the challenges connected to sex, some of the men described how they and their partners had been able to take up sexual activity again, albeit less frequently compared to before cancer struck. Others described how this part of the relationship had changed entirely and continued to be a difficult topic between the two partners. Per experienced it like this: It is not as it was (before), but we are working on it, so it gets better and better. It was, of course, uncomfortable for her when she started bleeding. It was a real turn-off for both, so to speak. I have actually said that it did not bother me, but she closed herself up and did not want to be touched. However, we have managed to get through that. It was after treatment and a while after that, we thought something was missing. We

tried again but there was no success, so we have really worked hard to get things working again. It is now in the past; it has worked well, and we are very happy with it.

Having intercourse was not the only challenge or aspect missing after cancer treatment. Losing the possibility of having biological children also became an issue or even the "biggest obstacle". This was the case for both Ole and Per, as described by Per: "We cannot have children. She is now sterile, and we do not have kids from before, either. We see friends around us becoming parents. That reminds you: who will take over after us when we are gone?"

## **Shared Feelings of Vulnerability**

While the men described loneliness in different situations, they also pointed to feelings they shared with their wives/partners which linked them to each other. The cancer had an impact on them, in constructive as well as harmful ways, as Ole said: "The cancer has had both positive and negative consequences because you have to reflect on certain things... things that we luckily have learned from". By taking part in the cancer trajectory of their partners, the men found that they and their partners learned more about each other than they would have without the cancer experience, as illustrated in Per's words:

We have learned to know each other for better or worse. I have perhaps become more a person that she can rely on if something difficult in life happens. I guess she knows better now that I am there. On the other hand, I also know that if there is something that worries me, I know that I can talk openly with her about it. Therefore, I think we are very good support for each other through life.

"A new perspective on life". Tom felt humbled towards illnesses and being ill as part of life: "Today we talk about illness; we never did that before". When reflecting on how cancer had affected their lives and their partnerships, a common experience among the men

was the feeling as though their partner's cancer had given them "a new perspective on life", as 1 Morten described it. He continued: "We do not care so much about such trivial little things 2 that might annoy us in everyday life, for example. We have learned to let some things go". 3 "We appreciate every day". Thoughts of death varied among the partners. Tom said 4 he did not have any thoughts of death when his partner was diagnosed with cancer, though he 5 seemed surprised that the thought had not occurred to him. Per, however, told how both he 6 and his partner continued to worry that the cancer would come back. For Ole and Thomas, 7 thoughts of death and a constant fear of losing their partner followed them from the time their 8 partners became ill to this very day. Thomas described how the cancer impacted their 9 everyday life: 10 Before the disease, we were both carefree. We never thought of the consequences on 11 our own health or death. We were happy, ignorant, but not any longer. Now, we have 12 13 seen that we are very vulnerable. It has somehow sneaked upon us, especially with me, a big concern for life. It sounds like such a cliché, but we appreciate every day and 14 15 spending time with the kids and stuff like that. "The relationship has been harmed". The findings show experiences of positive 16 outcomes of the disease. However, at the same time, the relationships became more 17 complicated, even harmed. Although the women were the ones to undergo the cancer 18 treatment itself, their partners and relationships can be harmed as well. The participants 19 emphasised that cancer is an experience they preferably wanted to live without, as Thomas 20 illuminated: 21 We have gotten to know each other's strengths and weaknesses in an entirely different 22 way than we would have otherwise. I have really seen that she is my next of kin and I 23

way than we would have otherwise. I have really seen that she is my next of kin and I am hers, which I have really realised now. I am her closest supporter through everything, and she is mine. That is something we probably did not realise or

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appreciate before. If we get through this, we will get through it as better people, and I think we have. We see each other more and appreciate each other more in everyday life. Nevertheless, at the same time, the relationship has been harmed.

4 Discussion

In our study we found that the men described loneliness, an altered sexual relationship and a shared sense of vulnerability as the dominating experiences of being a caregiver. These findings resonate with general descriptions of what characterises caregivers' roles in cancer care (Lambert et al., 2016) and the complexity of the related problems (Stenberg et al., 2010). Being a close relative of and caregiver for someone with cancer is challenging in and of itself, but as we know from the literature, young to middle-aged caregivers tend to be more anxious than older ones, and spousal caregivers experience more anxiety than other caregivers (Lambert et al., 2016). These two groups are the subject of our study. In the following, we will pay closer attention to what we see as the study's main findings and contributions to the research field of informal gendered caregiving, drawing on existing knowledge about caregiving in relation to the concept of caring masculinities.

### **Broadened Understanding of Sexuality**

In an overview on caregivers' roles in cancer care, challenges connected to sexuality are described by Lambert et al. (2016) as a significant problem, and cervical cancer is known to negatively influence a couple's sexual relationship (Sekse, Hufthammer, & Vika, 2017). When the men described the reasons for their changed sexual relationships, they talked about pain, bleeding, the vagina becoming hard and sore, reduced libido and fatigue but also about the women feeling less attractive. It is well known that changes in body image may affect women's experiences of sexuality (Sekse et al., 2017). One of the men confirmed that this was the case for him and his partner. Through getting to know all kinds of details about the genitalia and the treatment consequences, the magic and attraction allegedly needed for a

- 1 "good" sexual relationship had disappeared. In the ways the men talked about sexual
- 2 relationships, sexuality seemed to be reduced to the physical aspects, mainly to penetration
- and intercourse. This way of addressing sexuality may feed into a traditional and hegemonic
- 4 masculine gender role.

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To us it is highly relevant to contest such a narrow and masculinised representation of sexuality and sexual needs and take into account a more human-oriented and relational understanding of the phenomena. Interestingly, the literature highlights sexual function and dysfunction, but a broader approach to sexuality is lacking (Cleary & Hegarty, 2011; Sekse et al., 2017). According to the men in our study, the couples received little information from healthcare professionals about "post-cancer sexuality" except for learning about the use of the vaginal dilator. Cleary and Hegarty (2011) claim that information about sexuality tends to be approached from a biomedical perspective. They argue that a multidimensional approach is needed to understand sexuality better and help people with their sexual relationships. In this regard, we argue that healthcare professionals should encourage the notion of caring masculinity, by and through which women's needs and wishes in sexual relationships might be foregrounded more. After all, our study clearly indicates that men are practising a caregiving role that is sensitive to and inclusive of their female partners' needs and wishes. If such a role is encouraged in sexual relationships after cervical cancer as well, then female sexuality might be foregrounded in couples' relationships. Such encouragement may prove to be challenging in practice. Even though cervical cancer was not perceived as taboo by most of the participants in our study, gynaecological matters are still described in the literature as a taboo and silenced matter (Solbraekke & Lorem, 2016; Wray, Markovic, & Manderson, 2007). We might even speculate whether this is the cultural premise to which our findings concerning sexuality also relate.

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**Interdependent caregiving relationships.** The men talked about how they wanted to protect and spare their partners, something which left them with feelings of being on their own and lonely in the situation. Being the protective counterpart in the relationship resonates with aspects of hegemonic/traditional masculinity, where being the stronger person is the ideal (Elliott, 2016). However, men as caregivers tend to seek support from family (Butow et al., 2014), which also proved true in our study. The participants clearly described their needs and worries and how involving others could help them in different ways. In theorising "caring masculinities", Elliott (2016) presents a practice-based framework for the concept. By "practice-based", the author refers to men's actual practices of care, such as Hanlon's (2012) study of men's caregiving work in the home in Ireland. Our empirical study may also serve as an example of caring masculinities, realised in the context of having a partner with cervical cancer. Referring to Ungerson (2006), Elliot separates between caring for, which entails the practical tasks of care, and caring about, which describes the affective relations of care. As the findings section shows, the men in our study cared for as well as about their partners. Besides taking care of all kinds of practicalities, which is a well-known characteristic of family caregivers (Lambert et al., 2016), they expressed their worries and deep affection towards their partners. The men's descriptions leave us with the perception that the women depended on the care of their husbands/partners – that they needed help and support in many ways. However, what is also significant in our study is how the men described an interdependence in the relationship with the women as well as with other people. The men expressed a need to be acknowledged, talked to, valued and cared for. This is in line with Elliot (2016), who also draws on feminist theory in theorising caring masculinities, especially the concepts of dependency and interdependency. Elliot describes how care is not something given from one person to another; care is always relational. This perspective is also strongly proposed by several scholars critically

Male partners' experiences of caregiving for women with cervical cancer

- investigating care in the context of partners' experiences of severe illness (Aasbo, Solbraekke,
- 2 Kristvik, & Werner, 2016). We find that theorising caring masculinities in a way that
- 3 associates with values such as emotion, interdependence and relationality resonate well with
- 4 the experiences described by our six participants.

#### 5 Strengths and Limitations of the Study

- 6 To make planning the present research project, recruiting participants and the analytic process
- 7 trustworthy, we aimed to describe these different parts in detail to ensure transparency
- 8 (Bazeley, 2013). Moreover, the number of interviews were found to be sufficient for
- 9 obtaining valuable impressions about the men's experiences. However, we do acknowledge
- that the findings in our study may not reflect how the wider male caregiver population in
- Norway might experience these phenomena as this has yet to be studied more thoroughly,
- potentially supported by a quantitative design. Additionally, throughout the research process,
- we have discussed how researchers influence different parts of the study (Denzin & Lincoln,
- 14 2013) and how theoretical perspectives are helpful in understanding and discussing analytical
- 15 findings.

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### **Conclusion and the Way Forward**

The findings of this study shed light on men's experiences when their partners are going through the cervical cancer trajectory and on the field of informal cancer care in general, a field of study that has been underexplored. Men experience going through the cervical cancer trajectory with their partner as something that brings enormous changes to their lives. This includes a reorientation of themselves and the changing of life plans, intense care for and support of their partners and also extended responsibilities for practical matters. The men describe a form of interdependence in the relationship with the women but also how the relationships have been seriously altered, particularly when it comes to sexuality. These findings resonate with hegemonic as well as caring masculinities.

Taking into account what on a more general level has been described as men's caring values in terms of positive emotions, interdependence and relationships (Elliott, 2016), the lack of knowledge in research studies about how men carry out these values when caring for a severely ill partner is thought-provoking. Without such knowledge, there is a risk that we will continue to reproduce stereotypical depictions of how men and women act and react in the context of severe illness. On this point, we agree with Hanlon (2012), who points out that we cannot deconstruct traditional male values without reconstructing men's emotional lives. That is, we should move beyond the idea that norms of being a man and values of care and emotion contrast with each other. Rather, as we, based on our empirical study of men's experiences of being partners of women treated for cervical cancer, have pointed out, in the context of severe illness and care, they might be intertwined already.

#### **Relevance to Clinical Practice**

Based on the findings in our study on the experiences of male partners with women treated for cervical cancer, challenges connected to physical intimacy and sexuality stand out as particularly important, and future research should explore this topic further. Healthcare professionals should be more aware of the complexity of this issue and refer couples to psychologists and/or mental health therapists who are specialised in sex therapy in order to help them to restore their sexual intimacy. Considering the issue of intimacy and sexuality as a pivotal element in educating future healthcare professionals is crucial in this. We also strongly suggest that issues such as dealing with masculinity and care roles should be on the agenda and reflected on in future research as well as in teaching and supervising in clinical practice. Moreover, a broader approach to sexual health and relationships is needed in the patient–clinician relationships. This should include more elaborate information about HPV, as our study shows that this continues to worry some men.

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**Table 1** Main themes and subthemes

Subthemes
It's like being a single father
No one talks to you
Inside, I worry
Friends can't stand that kind of talk
Sex – a non-issue
The magic is lost
Something is missing
A new perspective on life
We appreciate every day
The relationship has been harmed