

ORIGINAL ARTICLE

“But this is a good cancer:” Patient perceptions of endometrial cancer in Denmark

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Abstract

Aims and objectives:: To explore endometrial cancer patients' perceptions of the disease and the influence of favourable prognoses on their experiences.

Background: Endometrial cancer is associated with favourable prognoses, which may imply that patients experience distress to a lesser extent than other cancer patients with less positive treatment outcomes. However, most people with cancer report reduced quality of life and, despite endometrial cancer being prevalent worldwide, experiences of the disease have been little explored.

Design: Ethnographic fieldwork with participant observations and interviews.

Methods: Observations during clinical consultations at two Danish hospitals and interviews with women with endometrial cancer ($n = 18$) over a period of 6 months. The article adheres to the COREQ guidelines for reporting qualitative research.

Results: We identify how patients consider cancer in general very likely to be fatal, while clinicians in contrast characterise endometrial cancer specifically as “good” because of favourable prognoses. We employ the concept of bricolage to illustrate how bits and pieces of biomedical knowledge and statistical evidence become intertwined with patients' past experiences and subjective ways of knowing, suggesting that patients' perceptions of endometrial cancer as a disease are somewhat dynamic.

Conclusions: Public stories and everyday life experiences of cancer provide a central framework for illness perceptions. As a result, patients retain the idea of a close connection between cancer and death, while also adopting the notion of endometrial cancer as “good”. This influenced how women responded to treatment and care. Framing endometrial cancer as “good” is not always helpful, as the impact of a cancer diagnosis per se is rarely favourable.

Relevance to clinical practice: In providing women with endometrial cancer with optimal support through diagnosis and treatment, clinicians should attend to the complexity of patients' illness understandings and be aware that assuring patients of a good prognosis not always has the expected impact.

KEYWORDS

cancer, death and dying, discourse, emotional distress, ethnography, interpersonal communication, interpretative research, knowledge, lived experience, qualitative study

1 | INTRODUCTION

Improved cancer survival emphasises the need to pay greater attention to personal experiences to provide supportive care of people surviving cancer. Endometrial cancer survival is relatively high, because symptoms—particularly abnormal vaginal bleeding—typically present at an early stage. Five-year survival at stage IA is approximately 88%. It is the most common gynaecological cancer in Western societies and the fourth most common cancer among women (Engholm et al., 2016; Siegel, Miller, & Jemal, 2015). Main risk factors are excess oestrogen and obesity (Kehoe, 2016 [2008]; National Cancer Institute 2017). Thus, while the risk of endometrial cancer is age-dependent (around 90% of the cases affect women above 45 years), the global rise in obesity increases the incidence in women under the age of 40 (Cook, Brunton, Pukepuke, & Tan, 2018; Reeves et al., 2007).

Most people with cancer experience significant social, physical and mental health concerns (e.g., Ferrandina et al., 2014; Quinn, Gonçalves, Sehovic, Bowman, & Reed, 2015; Tax, Steenbergen, Zusterzeel, Bekkers, & Rovers, 2017; Walton, Reeve, Brown, & Farquhar, 2010). However, we lack evidence to conclude whether this applies to women with endometrial cancer (Hoeck, Hansen, & Lederer, 2014; Roberts & Clarke, 2009; Shisler et al., 2018). The positive prognoses of endometrial cancer may imply that women diagnosed with this relatively easily treatable cancer experience fewer psychosocial challenges than cancer patients with less positive forecasts. Few studies have investigated this, but a recent study on rare cancers (Ridgway et al., 2016) shows that, despite reassurances of a positive outcome, participants' reactions to the cancer diagnosis were similar to those with less favourable cancers. Such findings suggest that there is no immediate correlation between prognosis and patients' perceptions of cancer and that patients do not distinguish between cancers.

The qualitative literature on endometrial cancer concentrates on outcomes and long-term complications and addresses certain themes such as treatment modality (Bowes et al., 2014; Herling, Palle, Moeller, & Thomsen, 2016; Hughes, Knibb, & Allan, 2010); quality of life (Bowes et al., 2014; Rowlands et al., 2015); follow-up care (Jones et al., 2012); and sexuality (Becker et al., 2011; Onujiogu et al., 2011). Furthermore, endometrial cancer tends to be grouped with other gynaecological cancers, thereby concealing disease-related factors specific to endometrial cancer with questionable transferability to other cancer types and sites (Manderson, 2015, p. 243; Bell, 2014, pp. 56–57; Bowes et al., 2014).

The lack of visibility of endometrial cancer in research seems to be replicated in public spheres. Studying gynaecological cancers in Australia, Manderson, Markovic, and Quinn (2005) note the low public profile of endometrial cancer. While ovarian and cervical cancers have a relatively high public profile due to high mortality and campaigns on vaccination and screening, stories about endometrial cancer achieve little public attention despite its higher incidence (Wray, Markovic, & Manderson, 2007). This is partly related to the lack of an exact known cause, but may also be linked with favourable survival rates and the fact that endometrial cancer is commonly a

What does this study contribute to the wider global clinical community?

- Cancer is associated with death regardless of favorable prognoses, as knowledge of disease is compiled from different sources and experiences.
- Patients have very little knowledge of endometrial cancer and do not differentiate among cancers.
- The results illustrate the significance of paying attention to patients' multiple and at times contradictory understandings of cancer in order to avoid devaluing patients' experiences and to offer them appropriate support.

disease of older women, who tend to attract less media attention (Crosbie & Morrison, 2014). No public suggestions on preventative behaviour are communicated, which again limits exposure and familiarity to this cancer. Many women are unaware that abnormal vaginal bleeding can be indicative of cancer (Kumarakulasingam et al., 2018; Salani, Husain, Oldach, & Katz, 2014), and this may result in diagnostic delay and so more advanced disease. Such contextual factors and lack of awareness affect how women respond to their diagnosis and position their illness experience within a larger frame of understanding cancer (Wray et al., 2007, p. 2262).

The objective of this article is to examine how women's perceptions of endometrial cancer in a Danish context are shaped over time by two dominant representations: cancer in general as potentially fatal and endometrial cancer in particular as “good”. The article provides insight into the complexity and diversity of patients' illness perceptions, adding to our current understanding of the needs and expectations of patients with endometrial cancer and informing approaches by clinicians to offer more satisfactory psychosocial support during diagnosis, treatment and afterwards.

2 | METHODS

The results derive from an ethnographic study of the experiences of Danish women with endometrial cancer. The data set consists of field notes and interview transcripts from fieldwork conducted by Sidenius from September 2013–October 2014 at two Danish hospitals specialised in gynaecological cancers. The study complied with the Helsinki Declaration and was approved by the Danish Data Protection Agency (12-000179). The article adheres to COREQ standards for reporting qualitative research (O'Brien, Harris, Beckman, Reed, & Cook, 2014).

Participants were recruited at the two hospitals, where staff assisted by identifying women suspected of having endometrial cancer. Sidenius then contacted the women, provided information about the study, clarified any questions and invited them to participate; if willing to participate, the women gave written consent. All women were assured of anonymity and informed that they could withdraw

from the study at any time. Given the sensitive subject, consent was continuously affirmed during interviews and participant observation. Women were included only if diagnosed with stage I endometrioid adenocarcinoma, where disease has not spread to cervix or ovaries, and the woman can be treated surgically. This applies to approximately 75% of all cases of endometrial cancer. Women who underwent adjuvant treatment were excluded, as treatment type also influences patient experiences (e.g., Shisler et al., 2018; Westin et al., 2016). A sample of 18 women, aged 48–81 years, was recruited.

To the extent possible, Sidenius followed each woman's trajectory and observed consultations during which she was examined; informed about diagnosis, upcoming surgery or results of pathology samples; or checked for recurrence after completed treatment. Only keywords were noted during the consultations to avoid disrupting the clinical encounter, while detailed field notes were written later in private. In addition, Sidenius conducted ethnographic interviews with each woman during her trajectory: in average (a) 1–3 days before surgery, (b) 2–3 weeks after surgery and (c) 5–6 months after surgery. Semistructured guidelines with a set of topics were used, with flexibility for participants to unfold what they perceived as essential. Conversations about cancer may be sensitive, wherefore, Sidenius included a visual exercise to open the conversation and allow the woman to process the experience in tangible ways. Further, unless the woman wished otherwise, interviews were conducted in participants' homes. Interviews were audio-recorded and transcribed verbatim. All names are pseudonyms.

2.1 | Analysis and theoretical framework

The process of analysis began during fieldwork (Hammersley & Atkinson, 1996 [1983]), as anthropological research is iterative (Emerson, Fretz, & Shaw, 1995). Ideas for analysis emerged through taking and reading field notes, and interview guidelines were continuously adjusted to take account of generated knowledge. Interactions and relationalities between participants and researcher are a critical component of anthropological research in developing an understanding of the social processes and of theorising the significance of individual accounts. In interviews, as women provided narratives of their experiences of diagnosis, treatment and care, they introduced their own theories of experience. The process is iterative, so that each interview is informed by the proceeding interviews. Transcriptions and notes were subjected to several readings by Sidenius in the search for predominant themes. This search was guided by research questions such as “What thoughts and expectations do women with endometrial cancer have for survival and cure?” and “How are these conditions influenced by clinical encounters?” The empirical data were coded into themes and further subgrouped to identify repeated patterns of meaning across participants. Ideas were continuously discussed with the last author. Through the process, it became clear that encounters between patients with endometrial cancer and clinicians represented a meeting of differing worlds: contextual, experience-based understandings of laypeople, in which cancer in general represents a monstrous

creature that threatens to disrupt and ruin people's lives, vs. biomedical, statistically based explanations of endometrial cancer, in which this specific disease is portrayed as “good” and providing high chances of survival. However, there was an interface between these different ways of knowing, as the women's understanding of endometrial cancer became influenced and entwined with objectified knowledge from the clinic.

To understand this process, we turned to anthropologist Hastrup (2004), who argues that knowledge is “organised information” (Hastrup, 2004, p. 456). This implies that knowledge is partial, situated, positioned and always a question of perspective, as there can be no knowledge without someone knowing something in a particular way, making knowledge “a social phenomenon rather than simply a substance” (Hastrup, 2004, p. 456). Hastrup calls this *relational* knowledge, as it is linked to the relations between people or people and objects and thereby emerges “within a dialogical field” (Hastrup, 2004, p. 456). Thus, focus is shifted from the individual woman to the association with others in the construction of knowledge. This approach allowed us to take into account the emotional and social aspects of having endometrial cancer and thereby to become attentive to the dynamics of knowing and the significance of context.

Hastrup further argues that the world and concepts of the world are interrelated. By constructing new concepts, we affect the world. In the long run, all concepts are essentialised (Hastrup, 2004, p. 456), making them objectified in social practice and to appear as tangible, neutral matter of facts. This is the case with statistics. Such abstract calculations are based on group levels, but are seen to indicate something about an individual despite not having a direct connection to the individual's *actual* state of risk or chance (Boholm, 2015; Lock & Nguyen, 2010; Panter-Brick & Fuentes, 2010; Widmark, Lagerlund, Maina Ahlberg, & Tishelman, 2008). That is, generalisable probabilistic numbers are taken as individual prognoses. In contrast to relational knowledge, Hastrup highlights *objectified* knowledge as something that can be “possessed and recycled,” thereby presenting itself in an objective, nonrelational manner. However, as we illustrate, actions are not merely guided by objective biomedical knowledge. Women's responses to endometrial cancer are not only a matter of possessing knowledge about the low risk of mortality, for everyday life understandings and uncertainties of cancer flourish in the midst of scientific certainties.

To understand further how women gain knowledge through social relations—in the healthcare institution as well as other public and private spheres—we employ the concept of *bricolage*, a term popularised by anthropologist Lévi-Strauss (1966) [1962]. Bricolage is an epistemological, analytical term to describe a way of knowing the world, in which a person draws upon existing ways of classifying objects and practices, connects scattered at-hand knowledge and redeploys this knowledge in new ways (1966 [1962], pp. 16–22). In this reconstruction, the “bricoleur” uses different analytical techniques with which she is familiar—she possesses a “toolbox” of representations, discourses, social practices and conceptions, rooted in own experiences (Johnson, 2012; Lévi-Strauss, 1966 [1962]; Rogers, 2012). According to Lévi-Strauss (1966 [1962], pp. 16–19), the

choice of technique is situationally determined, as bricoleurs—in our case, women with endometrial cancer—do not approach knowledge-generating activities with concrete plans or methods. Rather, this is a fluid, open-ended meaning-making process.

3 | RESULTS

The results presented below are organised in relation to temporal changes in women's perceptions of disease at the time of diagnosis, the time of scanning results and treatment plan, and the time after surgery and through to follow-up examinations up until 8 months after surgery.

3.1 | Diagnosis: “Am I going to die now?”

Cancer is often considered a “death sentence” (see for example Jain, 2013; Manderson, 2011; Moser et al., 2014; Reb, 2007; Sontag, 1978). To some extent, this was the case in our study. Most women immediately associated their cancer diagnosis with death; several women reacted very strongly. Lisa, for example, instantly asked if she was going to die and during the rest of the consultation stared blankly at the table as if in shock; she asked no further questions. Recalling the experience, she elaborated:

I went home and planned my own funeral! It all turned completely black. It was like getting a bomb in the head; I was SO scared! I was certain that I would die... Thank God my husband was there 'cause I was in shock; nothing functioned in my head! I couldn't find my way home; I came out of that room and had no idea where I was! It all went black immediately as he said the word: cancer. When you hear the word ‘cancer’ you instantly think that now you'll die!

After the diagnosis, women underwent chest X-rays and MRI scans to establish whether the cancer was invasive, that is, whether it had spread into surrounding tissue or organs. Disease spread was associated with fatal outcomes, confirmed by the women's knowledge of others who had had cancer:

The worst was when the doctor said that it might have spread—at that point I literally died 'cause I know how dangerous that can be! Woosh... my brain couldn't handle it! [...] Everybody I know with cancer, once it has spread to the lymphs [sic] they all die! I don't know anyone who survived that... so I was dead! There was no hope for me; I was dead, literally dead... it was terrible! (Rose)

I've been like a zombie since yesterday! [...] My head's spinning with concerns... has it already spread? [The doctor] said that usually endometrial cancer is

encapsulated [within the uterus], but that's easy for him to say; if it's in the lymphs [sic] then it has spread! (Julia, field note)

Emphasising the connection between cancer and death even further, Susanne described how the doctor “looked like an undertaker” when he and the nurses received her in the consultation room, as if part of a “funeral procession.” Other women did not specifically articulate reflections about death, but their actions showed its presence in terms of the practical matters they felt they had to attend to urgently: Lisa mowed the lawn late at night in the pouring rain, Elsa updated her life insurance policies, Miriam immersed herself in work, Eva immediately started writing a will, Mary spent her nights cleaning up the attic, and Ann met with her bank advisor to “clean up things.” Several women were unable to work due to distress, and a few reported how the diagnosis had led to bodily disturbances such as tics, restlessness, clumsiness and apathy: an embodiment of their anxieties. Hence, the association of cancer with death was powerful in shaping the women's individual experiences in response to the diagnosis and in preparing for the possibility of dying.

3.2 | Scanning results: “Well, it's a good cancer”

After the diagnosis, on the basis of a pathology examination of tissue samples, a gynaecological examination and scanning images, appropriate treatment was planned. If cancer had spread <50% into the uterine wall, surgery was considered to be curative, as disease was encapsulated in the uterus. A spread into *more* than 50% of the wall indicated possible spread to lymph nodes or other organs and, hence, the need for chemotherapy and/or radiation. This cut-off point of percentages became the centre of attention for both women and clinicians; for the women, it was a turning point in their trajectory; and for gynaecologists, it was a determinant in choice of treatment. The results were ready a week after the diagnostic consultation, and the woman was then scheduled for another consultation concerning a treatment plan, that is, whether surgery would be sufficient or whether chemo- and/or radiotherapy was also required.

Most women were extremely anxious about this meeting. They described waiting for the results as “the worst period of time” of the entire trajectory, characterised by immense uncertainty and a lack of control. However, the women were soon placed in a framing of cancer that directly contrasted with the one denoting death. At the time of diagnosis, clinicians had tried to comfort patients, but were also cautious about the possibilities of treatment—as soon as scans showed no spread of cancer, they were unconditionally positive. For several reasons, they now designated endometrial cancer “a good cancer”. First, endometrial cancer is symptomatic, which typically implies detection at an early stage before spread:

Well, Lisa, your scans are fine; the cancer is confined to the uterus with less than 50% invasion, so no need to remove lymphs [sic] or other treatment... we

strongly expect you to be cured after the operation. (Doctor, field note)

Second, endometrial cancer is slow to develop, suggesting that it is not as acute and aggressive as many other cancers, and so there is less urgency in surgical intervention:

It's relatively harmless, a peaceful form of cancer. It grows very slowly; so slowly, in fact, that if we [examine] a woman with signs of cell changes in the uterus, but we are not sure, we might send her home without doing anything and then look at it again four months later. (Doctor, field note)

Third, for the reasons above, endometrial cancer is relatively easily cured through surgery although, as in the quote above, doctors at times perhaps overstated its “peaceful” character in attempts to reassure patients. In addition, most women had laparoscopic surgery, with relatively few complications and a few small stitches, providing far less of an embodied reminder of cancer than traditional open surgery. Thus, most women came to understand surgery as a minor procedure.

Together, such factors constituted a portrayal of endometrial cancer as “a good type.” Sometimes, it was framed as almost fortunate, as it was described as a “lesser evil” than other types of cancer:

Remember, this is a good cancer! After surgery you'll be fine. We usually say that if you're gonna get a gynecological cancer it should definitely be this one [...] You're lucky it's this one! It's not really a true cancer (Doctor, field note)

Clinicians often reinforced this notion by positioning themselves in the patient's situation:

We actually say that if you had the choice, you should definitely choose endometrial cancer. I know I would! Endometrial cancer is nothing serious... well, of course cancer is always serious, but it's not aggressive. You shouldn't worry... not about this at least! Endometrial cancer is discovered in time. (Doctor, field note)

Several aspects of these quotes are important. First, clinicians tended to speak about endometrial cancer as “nothing to worry about,” so downplaying the disease. Second, the discursive processes through which a distinct corporeal diagnosis is transformed into a normative condition of being “good” were related to an understanding of endometrial cancer as not comparable to other cancers. This strong framing, finally, led to an implicit hierarchy of cancers, which implied that endometrial cancer was not a “real cancer” and that patients with endometrial cancer were not “real cancer patients:”

[Patients] say ‘So now I'm a cancer patient’, and I think to myself: ‘What? You don't feel as a cancer patient because of this, right?’—I mean; it's only superficial... and only minor surgery. (Doctor, field note)

Well, it's not really cancer, right? Patients are back to life after a few weeks and barely feel ill... once it's out, they move on. (Nurse, field note)

3.2.1 | Internalising biomedical knowledge

The way clinicians framed endometrial cancer was, as shown, qualitatively different to the conceptualisation of cancer as linked to death, which until then had dominated patients' understandings of the disease. Previously, women had distinguished neither across different cancer types nor between established cancer and cell changes. At the time of diagnosis too, many believed they had been diagnosed with cervical cancer. Perhaps the very similar names in Danish of endometrial (*livmoderkraft*) and cervical (*livmoderhalskraft*) cancer added to this misperception. Even when such confusion was clarified, women still equated all cancers, differentiated only by location in the body. Later into their trajectory, as they came into closer contact with biomedically based knowledge on endometrial cancer, their conception of cancer changed. The way they spoke about their cancer altered as they began to pick up, incorporate and accept the interpretation of endometrial cancer as essentially “good.” The majority of women started repeating, almost verbatim, their doctors' messages during interviews. Instead of talking about cancer in overarching terms, they now explained endometrial cancer as a distinct biological process:

As I told my husband ‘This is the best location if it has to be... the uterus is the best place’. Had it been the other two places [i.e. cervix or ovaries], it would've been much worse. That's what I heard... and then the doctor said that it hadn't grown more than 50% and that's important! (Eva)

Women started integrating specific medical concepts, such as statistics of outgrowth, into their narratives. They stressed that the messages received at the hospital were encouraging, and the more often they heard these messages, the more they took them in. In this manner, representations of endometrial cancer as good were incorporated into their disease understanding:

The doctor said ‘Remember, this is stage I.’ And when we met the nurse afterwards, she grabbed me and said: ‘Remember! Remember what he said; it's stage I – this is absolutely the mildest form of cancer you can get!’... and I've kept that in mind! Hoping that the probability of further treatment is small. They also

said that they expected I was cured after surgery, so... (Sandra)

What we've heard is that uterus and that kind of cancer is the best to get! And every time; the more often we hear it, the more it sticks – the more we believe that's how it is! [...] So now the Grim Reaper appears only sometimes! (Annett)

For some women, the transformation was immense. They went from describing endometrial cancer as fatal to describing it as rather insignificant and explained that they “felt lucky.” Furthermore, many women had never *felt* sick and some began to speak in ways that indicated that they considered their own situation as less serious than other patients with cancer and that they were in less need of support; they started to view themselves as “not *really* ill.”

Equipped with new nuances, women started to imagine outcomes other than death. Lisa, who at first was convinced that she would die, described her second consultation as “being brought back to life.” When asked what the consultation had meant to them, women usually explained how they had adjusted their expectations on the chances of surviving:

Well, now I think it's realistic to [assume I will] survive! There's so many people having surgery for all kinds of stuff and that ends well. And I'm so lucky that it hasn't spread over 50%... well, then it'll be all right for me as well! It's not like I still think I have... perhaps 50% chance of survival; I think I have much greater chances! (Alice)

Thus, the strong correlation between cancer and death seemed moderated in the clinical meeting. Endometrial cancer was no longer synonymous with death; rather, it was placed on a continuum of life and death, with continuous movement between disease representing chaos threatening life and a hope to survive.

3.2.2 | Maintaining reservations

Although women sustained these new understandings, their confidence in a positive prognosis was not without reluctance. Thoughts of death persisted for many women, and these acted as counters to doctors' promises of survival. Prior to surgery, many women still spoke in ways that emphasised death:

You know that cancer's really not good at all, and when it suddenly sneaks up on you, you find out what cancer *really* is—then you become fucking nervous! I haven't slept in eight days! I feel really bad [Ann is very emotional, sighing deeply and in tears]... fuck! Cancer is fatal... No, it has changed a lot in the

last five years. It has become much better... but still, just the word ‘cancer’! (Ann, field note)

I can calm myself again, but when I lie in bed at night... well, the thoughts turn up again! Subconsciously, it just says ‘cancer’ and that's dangerous! I just find it so difficult to convince myself that, damnit, there are 90% who survive! (Karen)

The excerpts illustrate how women typically employed a broader cancer narrative in which the unit of significance was “cancer” in general, not a specific type. References to other people's experiences provided them with stories for comparison; these typically confirmed the link between cancer and death. This demonstrates well how uncertainty can arise from both personal accounts and from other people's experiences of cancer. Like Ann above, most women tried to incorporate medical advances and progress when assessing their situation, but found it difficult to focus on this, as the very word “cancer” invoked emotions of fear and tragedy. Thus, not all women accepted the extremely positive framing of endometrial cancer by clinicians. All eight of Hannah's siblings had died of cancer, and this led her to question epidemiological knowledge and clinical experience by emphasising genes as the general cause. Her doctor, however, refuted this:

Even if doctors say it's not the same type, I still ask ‘Then why are there so many cases in one family?’ [...] They say this is the best form of cancer, but when you hear the word ‘cancer’ you think the worst! And especially with the cases in our family... fatal! Right now my aunt is pretty sick... so cancer is not a positive word for me! [...] It's like getting a bucket of cold water in the face!

Hannah felt that the positive framing diminished her anxieties and made a serious illness seem quite banal. In other cases, women found it difficult to relate to the statistically calculated assessment of 50% invasion, with less than 50% denoting a positive prognosis, more than 50% a cause for concern. The use of visual instruments—in this case scanning images—in a way chronicles a specific point on a natural line of development from healthy to seriously ill, despite the fact that statistical risk has no predetermined development. Whereas the 50% cut-off is based on calculations on a group level, some women challenged this understanding of risk. For example, Sandra's sister was first declared cured of breast cancer, but at her penultimate follow-up examination, doctors discovered that it had spread after all. Sandra's experience of cancer as insidious did not correspond to the statistically low risk of endometrial cancer spread of which she was informed, and although outgrowth of her disease was well below 50%, she insisted on having her lymph nodes removed. This raises questions about the relationship between a technical, scientific understanding, communicated to patients by abstract means, and the socially experienced and lived dimensions of risk. In interpreting probability, doctors focus on the shape and changes of cells in the organism, whereas Sandra linked

the disease to personal understandings, including family history, leading her to question the “facts” and the certainty of diagnostic scans. For her, this was not an all-or-nothing perspective of risk; rather, it was a sense of “the lower the better.” The line between the possible and the probable was blurred.

At last, the feeling of having been given a death sentence sometimes obstructed the transfer of specialist knowledge on endometrial cancer from the clinician to the patient, as some women were unable to internalise biomedical information and incorporate it into their own understandings of the disease. Although her scans indicated limited development of cancerous cells, Lisa remained anxious about disease spread. According to the nurse, Lisa was concerned to such extent that she was unable to take in information about her upcoming surgery:

It was very difficult for her to grasp. I had to write a list of the things she needs to do to make sure that she got it – I also had to repeat things several times [...] She saw everything from a negative perspective; ‘What if it has grown more than 50% down? What if it has spread? What if I need to have lymphs [sic] removed after all—and what if there's something in them? Will I then get chemo... and then what?’ It was quite difficult to work with! (Nurse, field note)

Sometimes, clinicians perceived such concerns as interference. This was, for instance, the case if the woman was anxious and asked “too many questions,” which clinicians experienced as interrupting their capacity to transfer practical information to their patients. While clinicians recognised the common perception of cancer as a death sentence, they wished for more self-restraint from their patients. Women who stayed calm and positive, awaited results and “took one step at a time” were considered “luxury patients” with a “wise” response to the diagnosis; women who “took trouble halfway” and had a so-called negative attitude were seen as difficult to deal with.

3.3 | After surgery: “I've moved on”

Surgery is scheduled within a week from imaging results, and patients are usually discharged the following day. Before discharge, the surgeon visits the woman at bedside, briefly explaining the outcome of the procedure. Typically, surgeons would tell the women that they considered them cured and that they expected pathological examinations of the uterus to confirm this. The woman would be requested to return for a final consultation two weeks later, when the pathological results were ready; both women and clinicians referred to this as “the final answer” to whether or not they were cured.

All women found great relief in the doctor's assessments, but the timing of relief during their trajectory varied. In some cases, the woman's mood lightened immediately after the doctor's visit, as illustrated by field notes on Susanne's conversation with her doctor:

As I leave the room, I think to myself that it's a completely different person I've seen today. Every time I've met her, Susanne has been anxious and discouraged, having lost all faith, but now she's smiling and laughing—she even joked with the nurses! She was much more present in the conversation; less tense, although I could see she was tired. At one point, I even considered discontinuing her participation, as I worried she would collapse mentally... and now she's so happy and welcoming! Now she's chatting away; I didn't even need to ask her questions. It's such a remarkable transition; it's as if it's a whole new world she has woken up to! (Sidenius, field note)

Up until now, the fear of dying had affected Susanne to the extent that she was only able to lie on the sofa; now, her spirits had changed dramatically. Relying upon doctors' preliminary judgements, most women believed they were cured. Some women quickly moved on, as other things started taking focus. This became particularly apparent in the subsequent interviews, where conversations repeatedly shifted to completely different topics and events taking place in the women's lives: Karen's everyday life was impeded by a heel bone fracture that would not heal properly; Ann was busy planning her son's wedding; Alice's granddaughter's confirmation was imminent; Miriam and Rose were both soon expecting their first grandchild; and Susanne was organising her school class trip with departure only a month after surgery. Hence, many women felt they had neither time nor reason to dwell much more on their experiences. When we met six days after surgery, Sandra referred to it as “storing the doomsday stories away” and elaborated:

I've shut the whole experience down! I don't think of it anymore... and [the doctor] told me it was the best kind of cancer; I've certainly taken that with me and trusted that. I think I would've heard if they had some idea that I should have 5–10 radiations or 5 chemotherapies or what the hell, and I have not heard the word [i.e. talk of further treatment]! I put my trust in that. Now I'm rid of it! Of course, I'll get the final answer on the 2nd, but I focus on that it's gone and I'm cured! [...] The way he looked at it—he could not promise me 100%, of course—but I was cured.

3.3.1 | Waiting for reassurance

For some women, however, relief did not transpire before the “final answer” confirmed that their disease had not spread. Although encouraged by the surgeon's positive assessments, they prepared themselves for the worst results:

Hannah

But still... the idea [of death] sits at the back of my head - it does! [...] When [the doctor] said that it's only in the uterus; I want to see that! For the reassurances might as well be taken from you

again! [...] You hear it all the time in the news; people who're told that they're well and then die months later. I dare not [believe]... I'm not sure that it's only in the uterus...

Sidenius The doctor said you are finished now. Does that reassure you?

Hannah No... no... not until tomorrow... when I get the final message. After the tests... the idea [of death] is still there somewhere...

Like Hannah, all women reflected constantly on other cancer cases. Public stories in the media and past experiences of relatives and friends, whose cancers had fatal outcomes, constituted a foundation of reservations and limited trust in surgery:

Now that it's finished, what happens then? There's so much uncertainty with this disease! It might all of the sudden change character; mutate so it's superfast or something like that [...] I don't think there're any questions I could ask, because as I said: [doctors] can't guarantee me anything! (Miriam)

Although Miriam was cured, she still perceived cancer as uncontrollable. Other people's stories were seen as providing evidence of cancer as both unpredictable, striking randomly and pervasive, giving women a sense that "everybody will get it." Throughout the entire period—from diagnosis to postsurgery consultation—the women positioned themselves and their individual illness stories within a nonspecific cancer narrative, where different types of cancer were considered a single uniform disease simply located in different bodily areas: Cancer was perceived as coincidental in both its occurrence (*who*) and physical location (*where*). By mirroring their own situation in others' experiences, most women came to believe that the risk of cancer was always present, making it pointless to consider future chances of staying disease-free. As Miriam argued, science cannot predict the nature of cancer. Not even positive pathology results reassured some women completely.

Physical changes and side effects such as fatigue, pain, incontinence and soreness following surgery also led some women to be concerned about whether they were actually cured. Despite being informed that postsurgery bleeding was normal, many women were surprised by its extent and they panicked:

Ann I was completely run up to a point! I went more and more crazy! I was so, so scared!

Husband Yeah... one begins to doubt a little bit, right?

Sidenius What do you mean?

Husband Well, I still get that thought: 'Have they taken everything? Has it spread?' – 'cause it came so quickly! I sometimes think: 'Have [the doctors] looked closely enough?'

Also Ingrid and Susanne experienced significant problems with abdominal swelling and pain, leading both to consider the possibility

of disease recurrence. Susanne had experienced a number of tragic cancer incidences the previous year, and the death of a friend had especially left its mark—the friend had died very suddenly, only 6 weeks after her diagnosis. However, it was not so much the tragic ending that concerned Susanne as the fact that her friend had had a distended stomach, which Susanne herself experienced after surgery. Unaware that abdominal swelling is typically a symptom of ovarian and not endometrial cancer, the slightest cough led Susanne to fear recurrence and she remained distressed and anxious the remaining time of our study. Ingrid, in contrast, was able to trust the doctor's reassurances once her side effects diminished. However, when we met at the follow-up consultation 5 months after surgery, she declared that she would have preferred if the examination had taken place a month earlier "just to make sure that there's nothing there:"

Can he know 100%? You hear so many stories... that they've found a spot here or they've found something there; that it has spread [...] He said I was cured; yet, there's the question: 'Aaaaargh, is he right? Can he say that 100%?' I still had to go for the scan and x-rays... somewhere in the back of my mind there's a fear that something new emerges somewhere else. Even if you're healthy, you're still a cancer patient, right? [...] If it's something that runs in your body then it might show up somewhere else!

Although Ingrid showed no signs of recurrence and had been declared cured for almost 5 months, her experiences were deeply rooted. In the excerpt above, beliefs and stories about cancer are generalised, forming a field of cultural significance around endometrial cancer—when Ingrid talks about cancer per se within an overarching discourse she confers general meanings to a particular disease. Ingrid had not previously encountered cancer personally—neither through close relations nor others—but this did not matter, as references to stories from the public domain were seen as evidence of cancer's uncertainties and unpredictabilities. Ingrid could not consider herself safe; neither could anyone else—cancer seemed almost inescapable. The women semantically merged cancer in general and endometrial cancer in particular, and the fear of cancer quickly arose again for most women, illustrating the power of the strong cultural linkage between death and cancer.

4 | DISCUSSION

In this article, we have attempted to disentangle perceptions of endometrial cancer among a group of Danish women and to show how knowledge acquisition and the act of bricolage are part of the foundation for attributing significance to illness. Representations of endometrial cancer and cancer in general were continuously intertwined; however, a strong nonspecific disease narrative in which cancer is associated with death played a central role and led to recurring reservations throughout the process of diagnosis, treatment and aftercare.

What is striking in the context of endometrial cancer is the framing of the disease as essentially “good” and of patients with endometrial cancer as “not ill”. This is where we truly see the impact of narratives of cancer as a death sentence—women constantly invoked and established a similarity between cancer and death *despite* favourable prognoses and a rapid cure. Such results argue against the predictions of Sontag (1978), who believed that increased objective knowledge about cancer would replace cancer myths, metaphors and uncertainties (Offersen, 2016, pp. 131–132; Clow, 2001). For this to happen, however, a sharp distinction between scientific knowledge and iconised mythic conceptualisations of cancer in public and private spheres should be the case, which we have illustrated it is not. Instead, objectified knowledge such as survival rates, risk and percentages of outgrowth become entangled with narratives of tragedy and hope, reservations and public discourses, as different perspectives are assembled, alternated and juggled in certain ways. Illness perceptions are constructed as a collection of different ways of knowing and are not simply either/or. Scientific attention to endometrial cancer as solely “good” involves an illusion of certainty that does not correspond well with the uncertainties of everyday life, where cancer is an enigma with a fundamental unpredictability that constantly threatens to ruin life worlds (Offersen, 2016, p. 112).

As argued by Manderson et al. (2005; Markovic, Manderson, & Quinn, 2004; Wray et al., 2007), gynaecological cancers are prevalent worldwide but are neither widely discussed nor part of everyday knowledge and narratives of cancer. As a result, the women in our study lacked familiarity with endometrial cancer and confused it with other gynaecological cancers. They were most familiar with certain aggressive and therefore more exposed cancers, feared because of their impact on the body or low survival. The lack of popular discourses on endometrial cancer led women to juxtapose it with “cancer” in more general terms, framing the latter as common and pernicious. Instinctively, the women made use of a much broader narrative that drew attention to the cultural dominance of cancer characteristic of many Western countries. As Manderson (2015) has demonstrated elsewhere, the women were surprisingly imprecise in the way they grouped more than 200 different diseases under one “frightening banner” (Manderson, 2015, p. 241), although most were aware of the great diversity when asked directly. This implies that cancer as a symbol of death arises in relation to other more aggressive, common and well-known cancers and, hence, that framing endometrial cancer as “good” seemed to the women to be oxymoronic (cf. Ridgway et al., 2016): It contradicted their everyday knowledge of cancer, public presentation and campaigns, and their personal experiences of others who had died from cancer.

The differentiation of diverse cancers tends to be difficult to incorporate in lay illness perceptions, probably due to the continuing lack of public exposure of this diversity. We argue that the close association between cancer and death is very much part of the cultural representation of the illness, as discourses of commonality and unpredictability and the merging of various cancers allow us to disregard pathological differences in genetics, developmental stages, histology and cell type, even though these factors can result in very

different possibilities of treatment, forecasts and outcomes and therefore have social as well as biomedical importance (Manderson, 2015, pp. 242–244). In this way, cancer becomes iconic of a common, widespread illness rather than a particular biological division of cells with a diversity of outcomes. At the same time, the transformation of a corporeal diagnosis of endometrial cancer into a normative condition in terms of not being a “real” cancer is worth paying attention to—after all, the idea that some cancers are “good” or “not really cancer” reinforces the notion of cancer as deadly, with favourable prognoses serving as a central element in this normative shift. Further, while an explicit positive framing of endometrial cancer at the clinics may reflect a wish of invoking hope (cf. del Vecchio Good, Good, Schaffer, & Lind, 1990), it may also result in implicit distinctions between “good” and “bad” patients.

Despite good forecasts, most women were shocked by the diagnosis and reacted in similar ways to patients with less favourable prognoses. Ridgway et al. (2016) argue that framing a cancer as “good” is not always helpful; however, they also claim that this is related to the adverse effects of prolonged treatment with radioiodine/thyroxin therapy on patients’ physical well-being (Ridgway et al., 2016, pp. 348–349). As opposed to Ridgway’s participants, the women in our study were treated only surgically and experienced few protracted complications. Hence, it seems that the impact of a malignant diagnosis upon the individual is rarely favourable *regardless* of treatment type. As in Ridgway’s study, a few women were immediately comforted by the positive terminology surrounding endometrial cancer, but others needed time to comprehend the implications of having a “good” cancer due to the initial shock. For many women, the distress of receiving a diagnosis of cancer was not lessened, and for a few, the positive framing was mostly unhelpful (Ridgway et al., 2016, p. 353).

With time as central, women’s reasoning of endometrial cancer was dynamic, as they turned to medical reassurances for comfort while they also regularly questioned their own outcome. The act of bricolage thus entails pragmatic flexibility as a central feature (Hammersley, 1999, p. 576; Denzin & Lincoln, 1998, p. 3), and the concept is here mobilised to highlight pragmatic individuation: The process is not static, but changes over time. As we have shown, women tried to unite and combine cancer representations from personal experiences and encounters with clinicians within the healthcare system. Often, these representations were complementary, but at times they were contradictory and incoherent because of a concurrent presence of multiple and different representations. This is what happened, for instance, when the side effects of surgery became dominant, as Ann, Ingrid and Susanne experienced them: The women struggled to match biomedical promises of cure with their own experiences, and so thoughts of death arose again. Illness perceptions change in relation to the specific experiences of disease and treatment, with the structure of bricolage altered through the elements involved.

The process of bricolage is thus characterised by ongoing communication—an interface—between different representations of cancer. Conflicts, misunderstandings and constructive encounters may all be part of the interaction of differing perspectives. Regardless of outcome, these are continuing reconstructions, as

individual domains are disturbed and challenged by other domains. By applying the concept of bricolage, this ongoing interaction becomes manifest; in some situations, the almost iconic status of cancer as a death sentence was an underlying context for understanding and managing illness, while at other times, it was paramount, outweighing medical reassurances. Hence, some contexts dominate the experiences of patients to the extent that they are accentuated and transformed into texts. Thus, the perception of cancer as a death sentence is almost always present as a significant part of the women's analytical toolboxes, as context and text constantly change place: What is context in one situation is text in another. The composition of text and context varies individually, making it difficult to conclude which factors condition the privilege of one representation over another. We suggest that temporality is a central element: The closer the women were to the time of diagnosis the more present were thoughts of death, meaning that the disease was conferred different characteristics depending on time in the trajectory of disease. Sometimes, the notion of cancer as equivalent to death is more readily available in the toolbox, while it is more easily stored away later in the process as other important events start to take up space in everyday life.

5 | CONCLUSION

Patients and clinicians merge understandings from different conceptual worlds. Both representations provide an avenue for reasoning about endometrial cancer. However, along with Offersen (2016), we argue that biomedical knowledge about endometrial cancer and popular perceptions of cancer are never “separate ways of knowing objectively and subjectively” (2016, p. 132). Rather, these different ways of knowing infuse each other. The compilation of knowledge may contain medical information, but not exclusively so. An increased biomedical understanding of cancer may merely rearrange uncertainties and perceptions about the disease rather than reduce them (Offersen, 2016, p. 116; Lupton, 1997 [1995]), and, thus, a direct relationship between biomedical knowledge on the positive aspects of endometrial cancer and the ways women respond to and comprehend their illness ought not be taken for granted.

6 | RELEVANCE TO CLINICAL PRACTICE

Professional labelling of endometrial cancer as “good” does not immediately resonate with patients' perceptions of the disease. The knowledge mechanisms behind the reasoning of patients should be kept in mind not to risk minimising the individual experience. No matter how encouraging clinicians are, a notion of cancer as representing death is culturally internalised—this may impede good communication between clinicians and patients due to the former's definitive preconception of endometrial cancer as “good”. Public awareness on the positive characteristics of endometrial cancer must be raised. Further; while inspiring hope through favourable prognosis

is important and may enhance a quicker recovery, attending to the dialectics of this and the multiple publicly available stories about cancer are essential. This requires a dual awareness among clinicians: On one side, clinicians should communicate the positive aspects of endometrial cancer while on the other hand acknowledge that patients' experiences are closely linked to a number of challenges associated with a cancer diagnosis per se. An increased attentiveness to the ambiguity of endometrial cancer combined with follow-up programs that ensure patients the possibility of processing psychosocial and existential aspects, for example through regular telephone or personal contact with an assigned nurse, may improve patients' experiences and enhance greater consideration for women's anxieties.

7 | STRENGTHS AND LIMITATIONS

The study's multiple time-point approach to interviews allows for observations of developments and changes in perspective and captures experiences over time. Hence, such design enhances more nuanced analyses. However, in the second interview round, interviews took place from 1 day–6 weeks after surgery, which should be considered when interpreting results. As argued, temporality is central to understanding cancer experiences and; consequently, the long time span may be limiting to the analysis. Sidenius advocated meeting within 1.5 weeks after surgery, but ultimately the women were free to decide when to meet. One woman was hospitalised for 3 weeks, one preferred to wait until after her pathological results, some women wanted time to rest, and yet other women simply had busy schedules. The difference in timing was the result of pragmatics and taking the situation into consideration. However, we note that the majority of the second round of interviews took place within 2–3 weeks and that changes of experiences are highly individual; it would not have been possible in any case to establish a clear point in time by which a woman's understanding of her situation changes. The distinction between the three temporal changes that structure the results is merely analytical.

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CONTRIBUTORS

Study design: AS, HPH, MR, OL; data collection and analysis: AS, HPH, LM; manuscript preparation: AS, HPH, LM, MR, OL, LMAM.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interests.

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