Feeling lucky: Hierarchies of suffering and stories of endometrial cancer in a Danish context

Running title: Hierarchies of suffering and stories of endometrial cancer

Anne Sidenius1,2, Ole Mogensen3,4, Martin Rudnicki5, Lars Mikael Alling Møller2, Helle Ploug Hansen1

1 Research Unit of General Practice, Department of Public Health, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark
2 Department of Gynaecology and Obstetrics, University Hospital of Zealand, Roskilde, Denmark
3 Research Unit of Gynaecology and Obstetrics (RUGO), Department of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark
4 Department of Women's and Children's Health (KBH), K6, Division of Obstetrics and Gynecology, Department of Women’s and Children’s Health, Karolinska Institutet, Stockholm, Sweden
5 Department of Gynaecology and Obstetrics, University Hospital Odense (OUH), Odense, Denmark
Abstract:

Illness stories are a prime analytical way of understanding patient perspectives on cancer. Nevertheless, limited studies have focused on stories of endometrial cancer. An ethnographic study including participant observation and interviews among 20 Danish women with endometrial cancer was conducted to examine prevalent stories and the ways the women responded to them. In this article, the analysis focuses on two exemplary cases, which present a line of issues related to the kinds of experiences that suffering includes. Findings illustrate that feelings of luck were central to the experience of being diagnosed, treated, and cured, which was related to the way health professionals framed endometrial cancer as favourable through notions of curable/incurable, trivial and gentle/invasive and brutal, and aggressive/non-aggressive. Drawing upon the concept of a ‘hierarchy of suffering’, we exemplify how women tended to scale own experiences of suffering against others’, leading some to believe they were not in a legitimate position to draw attention to themselves nor seek help and support, despite adverse physical, psychosocial effects. Thus, feelings of being lucky were intertwined with a sense of ambivalence. We conclude by discussing how suffering arises within a moral context, suggesting that the ways we speak of cancer may make some experiences unspeakable. This calls for increased clinical attention to more diverse narratives of cancer.

Keywords: gynaecological cancer, illness narratives, moral status, anthropology, cancer survivorship

I have been really lucky. But I don’t understand why I don’t feel as well as I should feel. I mean, I’m cured now, so…but I have these stomach pains. Well…but I’m just fine! I don’t need to talk to someone about it. I don’t feel sick in that way (Karen, 66)

This article is protected by copyright. All rights reserved
Karen is an endometrial cancer survivor. As one of 800 Danish women diagnosed per year, she displays central aspects of receiving an endometrial cancer diagnosis as well as being treated for and cured of the disease: Karen considers herself lucky, but at the same time her story is imbued with emotional and physical challenges and a strong sense of ambiguity.

1. Introduction

Illness stories often stand out as a way to understand cancer experiences from patients’ perspectives, with social science indicating that problematic, normative messages are embedded in most public and medical cancer representations. While such stories have gradually been explored within the last 40 years since the critical commentaries of, for example, Sontag (1978) and Lorde (1980), studies of the most dominant constructions of gynaecological cancers are nevertheless limited, especially in relation to endometrial cancer.

Numerous scholars (Lock 2006; Willig 2011; Jain 2013; Sulik 2012 etc.) observe that breast cancer is still the “biggest disease on the cultural map” (Ehrenreich 2001, p. 45), from the visibility in media to the abundance of research into breast cancer experiences that leads it to influence conceptions of cancer survivorship and provide a main lens through which other cancer patients filter their own experiences (cf. "breast-cancer-isation"; Bell 2014, p. 1260). In 2016, Solbække and Lorem aimed to investigate such processes in Norway. Their study on young women with gynaecological cancers contributes with valuable knowledge in a Scandinavian context on the “discursive premises that underpin the ways people express and live their thoughts (Solbække and Lorem 2016, p. 1260)”. Nevertheless, it provides little knowledge about women with endometrial cancer. With approximately 320,000 cases a year worldwide, endometrial cancer is the fifth most common female cancer; still, literature about these patients’ experiences is limited. Typically, endometrial cancer is grouped with other gynaecological cancers in social science. Demographic and disease related factors are thereby masked (Bowes et al. 2014), though there may be differences in experience due to age, prognoses, and public discourses. For example, cervical cancer mostly affects young, still reproductive women and is associated with promiscuity; ovarian cancer has a high mortality rate (5 year survival: < 40%); and vulvar/vaginal cancers are tabooed due to location (e.g.
Jefferies and Clifford, 2012). While Solbrække and Lorem’s participants are 25-43 years, with “mortality rates […] higher than others (Solbrække and Lorem 2016, p. 1262)”, around 85% of endometrial cancer cases affect women after menopause with an average age of 60 years. Moreover, survival rates are favourable: in Denmark, 80% of patients are diagnosed at stage I, where relative 5-year-survival is about 85%. Studies on gynaecological cancers in general may therefore not be transferable to endometrial cancer, which calls for an increased focus on this group of patients. The overall aim of this article is to address and describe prevailing stories among these women, with a specific focus on stories of luck. We are concerned with psychosocial consequences of being positioned within dominant cancer stories, whereby attention is directed to how moral dimensions and certain expectations shape feelings of not being as eligible for healthcare support as other patients.

The role of narrative

Narratives have gained increasing prominence as one way to relate to both subjective illness experiences and their shaping by cultural patterns and norms. The use of narrative is, for our purpose, analytically; directed towards the way events and experiences are described and assigned certain meanings and contexts. Hence, more or less coherent illness stories frame the experiences of endometrial cancer by emplotment (Mattingly 1998; Ricoeur 1991)—the key is not the events to which the stories refer but rather the reality shaped by the act of storytelling. It was, among others, Kleinman (1988), who brought narratives into medical anthropology with his emphasis on stories as crucial to the patient's attempt to make meaning of suffering. Since then, several scholars have used a narrative approach to legitimize individuals’ illness experiences. The work of Frank (1995) is notable for its attention to survival by highlighting how three specific narratives represent socially accepted ways of talking about illness: the Chaos, Restitution, and Quest narrative (Frank 1995, pp. 78-79). Another early contribution is Little et al. (2002), who points to the tensions of people having survived cancer but unable to achieve a sense of continuity.

Stories are important to create order, because the way illness is spoken of is rooted in bodily symptoms but also experience, expectations, and emotions (Semino et al. 2014, p. 670; Kleinman 1988, p. 49). Hence, stories relate to an interpreted past from a specific position in
the present in a way that provides guidelines for an imagined future, whereby a sense of coherence is sought. Further, different aspects of the teller’s identity and selfhood are constructed, as storytelling provides the opportunity to promote certain images of oneself. Constructing a specific story thus points to how the narrator would like to be perceived (Semino et al. 2014, p. 671; Bamberg and Georgakopoulou 2008, p. 380; Little et al. 2002). Narratives represent individual stories, but are also shaped by the common norms that organize the kinds of subjectivities available (Willig 2011, p. 898) – such discursive context includes biomedical narratives, personal as well as popular versions, and media coverage of ‘survivor’ stories. Hence, greater awareness of dominant stories is needed, as they represent “socially accepted ways of voicing bodily experiences of illness (Solbrække and Lorem 2016, p. 1259)” and thereby become prescriptive. This urges the integration of variety and complexity (Segal, 2012).

Several scholars have illustrated how illness stories generate, reflect, and reinscribe certain expectations for the cancer experience. In 1990, Saillant explored the emergence of a new discourse centred on survival rather than death, resulting in a new category of patients: the cancer survivor. The discourse values a “fighting attitude” and communicates that maintaining hope and good moral is essential (Saillant 1990, p. 83). However, Saillant’s empirical case exemplified how distortions between such discourse and patients’ own experiences are common. In 1994, Batt argued that although the triumphant story of breast cancer as a process of self-improvement might capture one aspect of the experience, it silences others; and in 2000, Wilkinson and Kitzinger explored psycho-oncology literature on coping with cancer, which claims that thinking positive is associated with adjustment to illness. However, such claims rely on self-reported data that are taken as more or less accurate depictions of participants’ internal cognitive state. Through a discursive approach, Wilkinson and Kitzinger challenged such analyses and reasoned that cancer stories are a form of social action, a conversational idiom. In its nature of being a commonplace saying, such idiom differs semantically from the meaning that a literal understanding entails. Thus, the authors did not consider whether their participants actually did think positive or not but focused on why they talked about themselves as if they were thinking positively. Wilkinson and Kitzinger (2000) revealed how patients answer questionnaires as members of a society in which thinking positive is advocated as an appropriate, desirable reaction to cancer. Similarly, de Raeve (1997) showed how the extent to which thinking positive has become a pervasive
societal norm is emphasised by the fact that many patients experience “psychological pressure to think positively about their disease (de Raeve 1997, p. 249)” to fight it. Hence, negative feelings are marginalized or denied, and failure to recover is interpreted as moral failure. Recently, scholars like Jain (2007; 2013), Sulik (2012), Segal (2012), and Bell (2014) have described how the most available, popular cancer narratives are perceived by people with cancer and state that experiences are misrepresented due to the univocal nature of these discourses: ”expectations of particular kinds of cancer stories […] act as constraints on the speakable (Segal 2012, p. 301).” In this article, we will further see that as an act of the present, storytelling is constitutive by establishing models for action and defining notions of right and wrong; that is, morality.

2. Methods

Findings are based on a study examining experiences of women with endometrial cancer in Denmark, centred on ethnographic fieldwork at two gynaecological departments that lacked in-depth knowledge of these patients and therefore initiated the study. From September 2013 to October 2014, Sidenius followed 20 women, aged 48-81, diagnosed with stage I endometrioid adenocarcinoma, through their journey of care: from referral to the department for diagnostic procedures, through surgical treatment and discharge. Formal consultations and informal interactions with health professionals were observed and semi-structured interviews were conducted with each patient two-three times in six months. The women gave written consent before participating, which was continuously confirmed at the outset of every observation and interview. All names are pseudonyms. The study received approval from the National Committee on Health Research Ethics (REG-70-2013).

Field notes and interview transcripts form our dataset. In analysing data, ethnographic principles (Hammersley and Atkinson 1996[1983]) were followed and analytical aspects regularly discussed with the last author. Data were read several times to get a sense of emerging themes. The emic notion of feeling lucky quickly emerged as a repetitively expressed sentiment, particularly related to recovery after surgery and the ability—or lack hereof—to move on with everyday life. Thus, Sidenius investigated the contextualization of this notion by looking at sentences surrounding utterances such as “I’ve been so lucky”. This
approach emphasised content and meaning of speech—‘what’ was said rather than ‘how’ it was said (Riessman 2005)—which was useful for finding themes across participants. Since feelings of luck were intertwined with comparisons of experiences, the analysis draws on a theoretical notion of a hierarchy of suffering (e.g. Charmaz 1999; Joye 2009; Bell and Ristovski-Slijepcevic 2011; Bell 2014), which implies that some kinds of suffering, pain, and misfortune are perceived as more difficult or signify a somewhat unique, superior source of suffering. We employ this perspective to understand how comparisons led to unspoken yet acknowledged evaluations of suffering in which having endometrial cancer entailed a position at the bottom of the hierarchy. Receiving chemotherapy was for example perceived as far worse than having a hysterectomy, which provided patients treated by chemotherapy with a claim to suffering that trumped endometrial cancer. Within a narrative approach, a focus on such “boundary-making practices […] that enable particular orderings of reality” (Kazimierczak and Skea 2015, p. 341) allows an understanding of internal and external processes of identification. Narratives are understood as expressing relations between the individual and the outside world and are thus effective tools in the formation of self and in the way self-perception can be expressed. Much like Kazimierczak and Skea (2015), we argue that notions of curable/incurable, trivial and gentle/invasive and brutal, and aggressive/non-aggressive help constitute a categorization of endometrial cancer as good (Sidenius et al. 2018); causing women to judge certain experiences as abnormal and “consider their own experiences as less serious” (Bell 2014, p. 61).

Findings are illustrated through two exemplary stories to enhance recognisability, accentuate features characteristic of all the women’s experiences, and investigate the complex phenomenon of having endometrial cancer within its real-life context. The story of Emily illustrates the feeling of luck within internal hierarchies founded on comparisons, whereas Susanne exemplifies the very ambivalent nature this feeling simultaneously had for many women, in which their luck and state of cure was questioned. Together, they present a line of issues related to understanding the kinds of experiences that suffering includes. The cases are treated as typical instances of comparable situations, meaning that results analysed analytically generalize to other women in our study and to endometrial cancer patients more broadly. However, the cases are typical but not exhaustive, wherefore other women’s experiences are included at times to add relevant, characteristic nuances to the recurring themes.
3. Emily

Emily was a 69-year-old retired woman, diagnosed with endometrial cancer March 2014. Sidenius followed her trajectory from the consultation, where she was informed of her diagnosis, to her follow-up examination five months later.

The best form of cancer: framing endometrial cancer

At Emily’s first consultation, the doctor simply stated that endometrial cancer was “a good cancer.” In fact, the framing of endometrial cancer at both hospitals was quite positive, related to the fact that it typically displays symptoms (post-menopausal vaginal bleeding), which usually lead to early detection and thus a lower risk of growth. With disease being limited to the uterus at early stages surgical removal is possible, constituting the future as optimistic. Doctors and nurses frequently expressed that “it’s not really cancer” or “they’re not real cancer patients”, and women were informed that they were “cured” or “healed” at the first ward round after surgery, although pathological results from the examination of the uterus needed to confirm this. However, statistical frequencies, cancer survival rates, and percentages were implicated in crafting a qualified notion of endometrial cancer as curable (Kazimierczak and Skea 2015, p. 345):

The low-risk group at stage I have good prognoses with a total 5-year-survival of 90%, which is not significantly different from the background population. It is therefore important to diagnose endometrial cancer, while disease [...] has grown less than 50% through the uterine wall [...] Patients at low-risk have very little risk of recurrence.

These words from a doctor resonate with clinical representations. However, in the words of Kazimierczak and Skea (2015, p. 345), “just as with the statistics that help constitute it, the configuration of what can be considered a curable cancer seems contingent, too”—endometrial cancer was thus often constituted as good in a differential relation to other cancers classified as ‘bad’, for which survival rates are lower. Overall, women were
positioned as privileged in getting this type of cancer over another. When asked to explain her feeling of luck, clinical reassurances manifested through Emily’s accounts:

“It’s gentle […] That’s what they said at the hospital: it’s the best form of cancer… cause it’s in the uterus. [The doctor] said I should be happy that it was [encapsulated]. There’s actually 99.9 % chance that you’ll be cured […] Had it been cervical or ovarian cancer, the situation would have been completely different! If it’s in the ovaries it’ll spread, and that’s crap! You’ll need to start chemotherapy […] and that might not even save you…

By echoing that endometrial cancer is “the best form” and expressing a relief that it was not cervical or ovarian cancer, Emily invoked a hierarchy in which the conceptualization of the future as “cured” was central to her assessment of the situation. While primarily articulating this hierarchy as a gratitude for having survived, the predominance of it also silenced the risk of dying; evident in Emily’s exaggeration of “99.9% chance” of survival. Such predictions of survival brought the future into the present and shaped perceptions, enabling Emily to be outright “happy” about having endometrial cancer. Further, according to Emily, the latter cancers involved after-treatment with side effects considered much worse than surgical intervention. Emily had personally seen the depleting effects of radio- and chemotherapy, when her brother- and mother-in-law was ill with leukaemia and ovarian cancer some years ago. They both suffered severe damages, such as collapsed lungs and a broken sternum, before dying, and Emily described their trajectories as “utterly horrible.” Such memories—as well as public imaginaries of medical treatment as “worse than the disease (Sontag 1978, p. 64)”—confirmed Emily’s view of the matter.

Fixed body: back to normal

Women also compared their circumstances with suffering such as Parkinson, diabetes, or living in a war-torn country. A central point of reference for Emily was her son-in-law with Amyotrophic Lateral Sclerosis. While Emily was discharged the same day as surgery and recovered very well with only three small scars, her son-in-law faced permanent disability. By defining, through expectations, that endometrial cancer patients are not “sick enough” and can easily “move on”, what Stiker (1997) refers to as the empirical norm is established. Societies
socially construct divisions of people through categories such as ‘normal’, ‘sick’, ‘healthy’, or ‘lucky’ (Stiker 1997, pp. 121,134,150-1), influencing both practice and thought. Through such labels, norms become empirical in that they are found in practice: by naming what is deviant and to point it out is to make it exist. Essentially, the norm defines who experience problems, why they experience problems, and what solutions should be. Below, Emily discounts herself from this group: by focusing on her son-in-law’s hardships her own challenges are dimmed:

    Looking at him there’s nothing wrong with me, not a bit! I can breathe; I can eat by myself...I don’t need someone cutting my food. I don’t need someone helping me get my clothes on and wipe my butt! He can’t do anything! With me, there’s no pain [...] Had it been my back, or I couldn’t walk, or my leg was amputated it would’ve been a different situation...but now it’s over! Now it’s gone, so nothing’s wrong with me!

Evaluating the significance of her own experience in relation to what she did not experience rather than what she did, Emily reconfigured her own biography in terms of negative values. The identification of being lucky was thus constructed through the social interaction with her son-in-law, in the demarcation of the two, because a sense of continuity was based on their differences. Unlike her son-in-law, Emily was not physically impaired and felt no traces of surgery:

    The doctor basically told me that I could rake the yard—and I could! If I didn’t know better, I wouldn’t believe I had gone through this...there’s only small scars left and that’s nothing to complain about. I don’t even think about it anymore! Normally, you’ll cut the muscles [...] and feel like you’re being ripped apart; you’re cut open in all directions!

Several aspects of this quote are important in illustrating how endometrial cancer come to be represented as “easily treatable and relatively benign” (Kazimierczak and Skea 2015, p. 347) through a range of configurations related to gentle treatment. Firstly, the doctor’s assurances that Emily would quickly recover and the fact that he was correct added further to the extraordinarily positive framing of endometrial cancer that almost gained mythical character. Secondly, repercussions from laparoscopic surgery were perceived as minimal (“small scars”)
compared to how bad they could have been after traditional open surgery with a larger transverse incision (being “ripped apart/cut open”). At consultations, doctors conceptualized laparoscopic surgery as preferable by praising it for causing fewer complications and shorter hospitalisation. In the quote Emily contrasts the two procedures, evidencing the ways that women came to view traditional surgery as adversely and undesirable, while exalting laparoscopy as something out of the ordinary, outside the ‘normal’. By stating that she no longer focused on it and found it difficult to believe that she had had surgery, Emily highlighted this aspect further, while also referring to the physical limitations of traditional surgery that, according to her, requires a long recovery. Finally, Emily uses the word “complain” to describe the act of drawing attention to oneself. This was rather symptomatic, as complaining was defined as an unreasonable, unjustifiable expression of discontent and thus a somewhat illegitimate act.

Although having lost an essential body part, Emily did not perceive it as such. The suffering of younger women who underwent hysterectomies superseded Emily’s own since they would lose their reproductive abilities, but her own uterus was dispensable since she—post-menopausal—had “nothing to use it for”. Emily tried to maintain a sense of status quo by emphasising a lack of transformation and change:

*Once you reach my age […] you don’t need a uterus…at all! It makes absolutely no difference. I can do everything I used to; the only thing I’m missing is my uterus… I don’t even notice it!*

Moreover, Emily was relieved it was not a mastectomy, internalizing a cultural significance of breasts as a sign of womanhood and sexuality. She did not feel the same applied to the uterus. While such perspective probably reflects a strong breast cancer movement that has almost colonized female identity as ‘pink-ribboned’ and affiliated with breasts (Ehrenreich 2001), it also relates to a construction of womanhood as essentially equated with motherhood (Ryle 2012). Hence, when the uterus lost its main function it also lost its value. A future without breasts, on the other hand, was deemed difficult, as this engendered a more radical transformation in her orientation to life with others. The tragedy of cancer seemed to multiply when a person’s suffering was visible, which was the central difference between the two body parts:
No one can see it [that the uterus has been removed]! There’s no one who can feel it...I think it’s much worse to have breasts removed—it’s more visible—you have to show it to others. The other one [i.e. the uterus] no one sees...

The visibility of a mastectomy added a social dimension to the experience, making a hysterectomy seem easier to handle since no one could see Emily’s physical transformation. Hence, certain forms of suffering were—literally and figuratively—more visible and effectively trumped others. While age and womanhood intersect in Emily’s account, the distinction between breast and endometrial cancer is also constituted through a material-semiotic arrangement (Kazimierczak and Skea 2015) of particular bodies as either dysappearing or disappearing (Leder 1990). The marking of the physical difference between mastectomy and hysterectomy in many ways became synonymous with the identity of needing/not needing psychosocial support: health professionals rarely inquired about emotional aspects of having the uterus removed nor informed of potential side effects.

Finally, although there is a risk of both metastatic and local recurrence, Emily felt certain that there were no places left for cancer to grow after the removal of uterus, ovaries, and fallopian tubes. Her account below suggests that in the context of risk, the future and the present collapsed into each other because the present became connected to a distant future constituted by a lack of risk:

[Recurrence] is not possible ‘cause there's nothing down there [sic]. Had they left my ovaries and cervix there’d still be a risk... Now, the risk is gone! It’s all gone: finished, done, stop! There’s nothing to worry about!

This anticipation of the future as disease-free helped form understandings and reactions in the present by virtue of the way surgery was presented as solving the problem; related to an interpretation of surgery as a treatment able to ‘cut out cancer’ and therefore to “truly eradicate it” (Kazimierczak and Skea 2015, p. 347). This intersects with current medical understandings of the natural course of endometrial cancer as slow growing: “The lengthy survival [...] indicates that the natural progression course [...] is very slow (Levy et al. 2006, p. 454)”. Emily perceived her body as fixed and within 18 days from diagnosis to surgery she could continue everyday life pretty much as before, whereas she expected a more difficult outcome had she had any permanent sequelae.
Together, these aspects generated internal hierarchies that hinged on distinctions between those who had after-treatment, visible or permanent bodily reminders, or reason to worry about recurrence; and those who did not. By scaling such experiences, Emily estimated that having endometrial cancer was “easier” in terms of survival, treatment, and physical wellbeing. Consequently, Emily’s level of trauma was assumed to be low wherefore her experience did not call for further reflection. The natural follow from this line of reasoning seemed to be that she, at this point of her trajectory, could continue her life where she had left off, and since she did not go through medical treatment she was confident that she did not need to heal emotionally either.

The configuration of certain cancers as ‘good’ through a variation of socio-material relations has previously been noted by Kazimierczak and Skea (2015) in a study of urological cancer. As in their study, the construction of endometrial cancer is constituted in certain clinical encounters and activities, guided by nursing protocols and procedures of care. Since clinical stories of endometrial cancer are embedded in an institutional course of diagnostics and treatment with reference to central caring tasks of reassuring patients, they are necessarily success stories. Even when complications arise, the preferred story is, of course, the one leading towards a happy ending, which is why reservations and ambiguities are dimmed (Kazimierczak and Skea 2015, p. 350). The framing of endometrial cancer as ‘good’ is made meaningful—and therefore reassuring—through its distinction from so-called ‘bad’ cancer (Kazimierczak and Skea 2015, p. 344), which depends on certain arrangements of clinical practices and tools, such as surgical progress and statistical measures of survival rates and outgrowth, but also popular notions of ovarian cancer as a disease of severe consequences with painful, unbearable treatment as well as personal memories of radio- and chemotherapy. The distinction underpins the idea that endometrial cancer patients do not require any support or rehabilitation other than treatment itself. On an institutional level, for instance, the endometrial treatment pathway in Denmark includes neither psychosocial support nor follow-up examinations. Women are discharged from hospital the same day as their surgery with the requirement to provide self-care (cleaning wounds, relieving pain, removing stitches). This indicates that they are expected to possess a high degree of agency and mobility and integrate fully into normal life; unlike most other cancer patients, who are offered both support programs and follow-ups. The women are thus discursively and materially discounted from the group of patients expected to experience problems; that is, patients with poorer prognosis;
patients undergoing chemo-/radiotherapy or more extensive surgery; or patients that experience reduced functions or bodily transformations. Empirical norms are thus both highlighted and reinforced by expectations that women cured for endometrial cancer can easily recover. However, the case of Susanne, to whom we now turn, demonstrates that this is not always so at an individual level.

4. Susanne

Susanne, a 59-year-old principal at a small boarding school, was diagnosed at a local clinic and then referred to hospital A, where Sidenius met her four days later. Sidenius attended all Susanne’s consequent consultations and interviewed her and her husband twice.

Side effects: being ambiguously lucky

Parallel to Emily, Susanne perceived herself as lucky, but in a more ambivalent manner. Both women stated without hesitation that they were lucky but looking more closely at the contexts associated with these statements made it clear that their experiences of its significance differed. In many ways, the two accounts reflect opposite poles within the spectrum of being lucky. While Emily felt undisputedly lucky due to a rather unchallenging trajectory, Susanne struggled to verbalise her sense of luck due to factors like side effects and the disappointment of being unable to return to everyday life. In other words, Emily’s account fit into the restitution narrative as summarized by Frank (“Yesterday I was health, today I’m sick, but tomorrow I’ll be healthy again (Frank 1995, p. 77)”), while Susanne was striving to get there. The implications of surviving endometrial cancer were more complex in the case of Susanne, with a powerful sense of inconsistency.

After her surgery, Susanne portrayed herself as lucky in essentially the same way as Emily. When health professionals inquired about her physical or mental condition Susanne’s immediate response was always that she felt “really well”, was “pretty much continuing life as before,” and had “moved on” in terms of no longer spending energy and time on the
experience. This was also the case whenever Sidenius visited Susanne; however, as the conversations progressed feelings of ambiguity were uncovered. Apparently, the interviews provided space for more nuanced accounts of Susanne’s experiences, in which her feeling of luck was infused with hesitance, since she still suffered from intense stomach pains and bloating six months after surgery:

“I’m feeling really well, you know…in fact, I haven’t felt this good in many years… I’ve been lucky…but I’m sure that it’ll also give me some peace if I know what it [i.e., the pain] is and what can be done…I’m sure that if this gets sorted I can move on! Think of how much worse it could’ve been […] I don’t think about it anymore. I really don’t…well… sometimes thoughts hit me, and I start crying. And I ask myself why I think about it, but…I should mention that I’ve tucked down my pants here by the stomach; I’m still struggling with that! It’s really inhibiting [sighs heavily]. I can’t do anything before it hurts! I’m constantly bloated, but sometimes it’s worse…and when it’s really bad, I have to lie down.

As demonstrated above, Susanne constantly moved back-and-forth between the role of the grateful survivor, feeling lucky and looking at the bright side, and the role of a former cancer patient with long-term sequelae; feeling insecure, jumbled, and confused. While pointing out that treatment was successfully completed, her sentences were simultaneously imbued with frustrations and concerns caused by the experience, and, as described elsewhere by Little et al. (2002), a sense of discontinuity emerged from her account (cf. Frank’s chaos narrative).

Sadness and uncertainty: questioning own reactions

Susanne herself also pointed to her conflicting emotions and wanted to know how other women reacted, asking if they felt as confused as her. She admitted often feeling sad and being easily moved to tears, but could not understand why she continued to “feel down”; she was unable to identify any apparent reason for feeling this way, which indicates that she had expected to feel the opposite:

Susanne: I have these episodes where I get upset […] And I really don’t know why! I’ve never cried as much as I do now… I don’t cry every day, but
suddenly I’m just unhappy—it’s so difficult to explain. And then I think I’m a whiner…

Sidenius: A whiner?

Susanne: Yes, then I think: ‘Argh, quit it right now! You don’t have any reason [for crying]….I mean; I’m fine!

Although clearly affected in various ways, Susanne considered her experiences an illegitimate explanation of having become more emotional – she always returned to a feeling of meaninglessness and unjustifiability as quoted above, calling the reaction “abnormal”. The predominance of a hierarchy of suffering, which Susanne implicitly referred to when stating she was “fine”, silenced some of the challenges she faced: having survived cancer but still affected by the experience. Here, empirical norms are associated with experiences of being somewhat abnormal or unusual, deviating from the norm, or experiencing wrong feelings because of the impression that one should feel differently (Stiker 1997). The quote illustrates well how prescriptive standards can be difficult to handle if one’s own experiences do not readily position themselves within the dominant cultural conceptions. This implies a risk of believing you are somehow failing at being cured.

The feeling of being lucky led many women to expect to be back to normal in no time. Susanne went directly from being discharged to returning to work within a couple of hours. Susanne later explained that she, based on the doctor’s descriptions, had come to consider surgery as rather trivial and “didn’t want to make a fuss”. She argued that her situation could not be compared with what she called a “real cancer patient” and did not require any special considerations. However, Susanne’s side effects affected her ability to perform her job at a satisfactory level, since pain and discomfort forced her to rest several times during the day. Six months later, the side effects were even worse; Susanne had now replaced the waistbands in all her trousers with an elastic hem and her husband revealed that she skipped meals due to bloating. Surgery was intended to restore Susanne’s health but when failing to do so frustrations arose:

_I didn’t really feel sick until after surgery! I don’t feel the way I should feel…and now it’s even worse; it feels as if I have a pillow in my stomach! [...] I have to feel_
well ’cause I’m cured! I guess I just believed things would be like before, with work and stuff; just back to work and I wouldn’t feel it anymore...and it’s not like that!

The situation was further complicated by the awareness that past actions perhaps affected her present state: since she was not yet fully recovered, Susanne began reflecting on whether she had acted inappropriately—for instance by returning to work too soon—and whether this had aggravated her side effects or would cause an emotional reaction: “a breakdown because I haven’t taken time to grieve and process”. Thus, Susanne constantly reassessed how she had coped with the situation to figure out what she should have done differently to avoid feeling this way. Implying that endometrial cancer is not a real cancer in terms of treatment and mortality accentuated a position of being at the bottom in a hierarchy of cancer diagnoses. Further, that death was a key referent is evident in Susanne’s allusion to norms of feeling well because she was cured.

**Downgrading the situation: it could have been worse**

Susanne’s side effects challenged her feelings of not being in a position to draw special attention to herself. However, besides confiding in her husband and children, Susanne saw no legitimate need for presenting her experiences; neither to close friends nor a therapist, and she did not wish to contact the hospital either. The account below suggests that internal hierarchies served to elide other forms of suffering that women experienced; this was further confirmed by stories of friends, relatives, and other acquaintances that lost interest in the woman’s experiences, as soon as she was cured. In this case, the presence of a hierarchy cultivated a correlation between expectations and perceptions, and healthcare-seeking behaviour: the feeling of being luckier than others was related to Susanne not seeking any help:

I could just call them, but I have no need, right? The stomach will be fixed. It’s nothing compared to chemo...blood clots, collapsed lungs etc. [...] Once I’m back on top again I think we’ll have an ordinary normal everyday life again...yes [...] I’m feeling really good, you know [...] I’ve been lucky...I shouldn’t be ungrateful; there’s no need for me to complain. Think of how much worse it could’ve been!
As the quote reveals, women tried to maintain the role of the positive easy patient, but were simultaneously aware of the reality of sequelae they were living in. However, while they lived in the present their situation was observed from the vantage point of a future released from such suffering, evident in the fact that Susanne talked about a future without sequelae as naturally given (“will be fixed”, “once I’m back”). At consultations, Susanne toned down the side effects by negotiating their nature and telling herself that her imagination played tricks on her, they were not as bad as she made them out to be, and that they were caused by age or external stress. Several women did not contact the hospital despite feeling unwell. At this point, we briefly turn to Charlotte because her case illustrates the high degree of internalised moral values. Charlotte suffered from severe stomach pains and was still on sick leave five months after surgery. Doctors declared that the pains were likely to be permanent, but despite chronicity and high severity Charlotte felt it was inappropriate to spend time and resources on her problems and she too abstained from seeking the help she needed:

*I don’t want to make a big deal out of it… It’s nothing to worry others with. Besides, they have others to take care of, who are much sicker than me!*

An awareness of staying optimistic was clearly manifest in Charlotte’s account; likewise, Susanne tried to “stay positive” whenever pain disrupted everyday life activities. So-called “negative thoughts” were seen as related to behaviour, often labelled with value-laden words such as “pitying oneself,” “fussing,” “bitching,” “squeaking,” “wallowing;” being “touchy,” “thin-skinned,” “oversensitive;” and being “a cry-baby,” “a chicken,” or “a sop”. Often it was other people who in their efforts to console pointed out that it could have been worse, which suggests that in the fulfilment of moral obligations within the context of endometrial cancer, women were pressured and placed pressure on themselves to not display negativity or express concerns. Such results resemble the study by Young et al. (2002), who found that mothers of children with cancer felt compelled to maintain “cheerful” and not articulate their own needs, which were “subordinated discursively and functionally to those of their sick children (Young et al. 2002, p. 1838). In our study, it was feelings of luck that were intertwined with feelings of guilt or shame; pertinent to the challenges women encountered during recovery, but perceived as unworthy of attention. Hence, guilt also prevented women from expressing their emotions and constrained rehabilitation. The prescriptive nature of norms thus made some
experiences unspeakable (Segal 2012, p. 296), with personal and social implications to follow.

5. Discussion

Our findings illustrate how experiences of endometrial cancer centre on comparisons with feeling of luck as fundamental and that this was related to a hierarchy, in which endometrial cancer was portrayed as harmless and easily cured. Such expectations complied well with most women's experiences of life after surgery and they could return to everyday life. However, feeling lucky was also characterized by ambivalence, as the situation ‘could have been worse’. Many women downplayed, disregarded, and managed physical, psychosocial challenges on their own instead of seeking help. Such results resemble the findings of Solbrække and Lorem (2016), who found that women felt as secondary survivors due to the experience of gynaecological cancer as having a lower status than breast cancer and was socially pressured to be discrete about their disease. Further, while grateful for surviving, this feeling intertwined with being ill-fated due to social stigma, the recognition of having been close to death, onset of menopause, and the possible lack of biological motherhood (Solbrække and Lorem 2016, pp. 1264-6)—hence, ambiguity was central to participants’ stories.

Segal (2012, p. 296) argue that the public function of illness stories is to help us answer the question: “How shall I be ill? (Segal 2012, p. 295).” In similar ways, stories of being lucky answer questions such as How shall I be cured? or How shall I behave now I no longer have endometrial cancer? within a hierarchy of suffering. Such stories then become prescriptive, although this may neither be directly evident or explicit. By transforming a physical disease into a normative condition—in the sense of offering a value judgement of one situation versus another—feelings of being lucky produced moral imperatives on thoughts and action. Thus, our findings exemplify the normalisation of good and bad diseases, where women like Emily came to regard their situation as not worth special attention or support, expected to be well, recover quickly, and thus move on with everyday life as before. Paradoxically, this also applied to cases of rather severe side effects and continued suffering as with Susanne.
Charmaz (1999) state that suffering has a “profoundly moral status”, which “confers relative human worth and measures deserved value or devaluation” (Charmaz 1999, p. 367). This is in line with our findings. The hierarchy of suffering appears to intersect with a hierarchy of values: in the sense of not being “sick enough”, women invoked a series of social norms, which life beyond endometrial cancer is surrounded by and where specific attitudes—such as moving on, staying positive, and being grateful—are considered to be good, and complaining and ‘wallowing’ is bad. These norms are reflected in everyday rhetoric on cancer referring to the disease as good, bad, better, or worse, and while the assertion of rights in relation to one type of cancer is often seen at the expense of other forms the opposite is equally applicable: many women did not consider themselves entitled to support. Thus, implicit moral meanings shaped experiences and the relation between suffering and the self (Charmaz 1999, p. 366), which explains why women instinctively asserted that they felt “good” and often “forgot” what they had been through, although stories of experienced suffering took place just below the surface. In agreement with Wilkinson and Kitzinger (2000), we argue that such statements should not be perceived as accurate reports of internal states but rather as commonplace conversational idioms. The significance of Susanne’s account is not whether Susanne did actually feel lucky, but how it refers to “socially normative moral requirements (Wilkinson and Kitzinger 2000, p. 797)” of how to act after having had endometrial cancer. Recently, Rowlands et al. (2015) reasoned that most women treated for endometrial cancer will not focus on their trajectory 3-5 years after diagnosis: “While typical ‘survivorship’ issues exist […] a proportion of women […] form lives that are not situated within the cancer survivorship culture (Rowlands et al. 2015, p. 21).” This is supported by Jeppesen et al. (2015)’s quantitative study on short-term needs of Danish women surviving endometrial cancer, which indicates that the majority will not need extensive rehabilitation. While this is also compatible with our findings, neither studies delve deeply into the women’s own perspectives and results may express that quantitative measurements are not suitable of including nuances like ambivalence and inconsistency. Such methodological design does not involve spending time with participants or establishing rapport or enough contextualisation to consider matters sufficiently in depth, and the story of Susanne tells us that the process of ‘moving on’ is less easy than expected.

The moral imperative of how to act after endometrial cancer is mixed with stories from public and private spheres that expose cancer as a terrible disease, which one may very likely die
from. Thus, there will always be someone who is worse off—essentially, dying trumps everything. This produces feelings of luck, gratitude, and relief but also of being cumbersome, a “whiner”, and not “sick enough”. The lack of interest expressed by other people demonstrates how they sometimes did not regard the woman’s story as spectacular or special. Such implicit, external assessments of one’s experiences can invalidate the feeling of suffering (Little et al. 2002, p. 176). While only two women explicitly expressed a sense of having their experiences devaluated by others, the feeling of being lucky had consequences for all. The limitations of their space for action and the self-imposed restrictions—such as not contacting the hospital despite a need for help, not taking sufficient time to recover before returning to work, or not sharing feelings of insecurity and frustration—are perhaps the strongest evidence of the power of hierarchies of suffering, because moral values are in this sense both internally and externally generated (e.g. Jain 2007; Segal 2012; Batt 1994).

As noted by Little et al. (2002), survival merges ‘cure’ and ‘normality’ in the common understanding and is thought to have no price too great: ”What seems to be expected […] is endless gratitude within the context of normality (Little et al. 2002, p. 176)”’. While observers want the survivor to move on, the tensions experienced by many survivors seldom meets acknowledgment and understanding. In fact, stories of survival are often only mapped in terms of the heroic quest or restitution narratives. Our findings highlight normative dimensions of certain stories about life beyond endometrial cancer, in which some women struggled with stories that differed from empirical norms – such dissonance made it difficult to share their stories, even with those close to them. Women expected to have an easier trajectory than other cancer patients, but in fact it did not always differ from those with poorer prognosis because of the adverse impact of surgery and emotional vulnerability related to the cancer diagnosis per se (Bell 2014). This calls for an integration of patient perspectives and appeals to more proactive, outreaching support that do not proffer pre-packaged frames for how to experience cancer, but allow for varied, complex, and multivocal understandings of what it means to be treated for and declared cured of endometrial cancer.

Acknowledgements:

This article is protected by copyright. All rights reserved
The study was funded by the University of Southern Denmark, Region Zealand and the Region of Southern Denmark.

Address for correspondence: Anne Sidenius, Research Unit of General Practice, Department of Public Health, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark and Department of Gynaecology and Obstetrics, University Hospital of Zealand, Roskilde, Denmark. Email: asidenius@health.sdu.dk / anne.sidenius@gmail.com

6. References


Bell, K. (2014). The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease. Social Science & Medicine, 110(0), pp. 56-63. https://doi.org/10.1016/j.socscimed.2014.03.031


This article is protected by copyright. All rights reserved


This article is protected by copyright. All rights reserved


This article is protected by copyright. All rights reserved


This article is protected by copyright. All rights reserved


