

Taking Responsibility

Ovarian Cancer Patients' Perspectives on Delayed Healthcare Seeking

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ABSTRACT: Patient-related diagnostic delay has been established as an analytical category in cancer research. This category has come under critique because it postulates linear cause-and-effect explanations of delayed care-seeking. These explanations are based on a one-dimensional idea of causality that neglects the processual character and the contextual situatedness of bodily experiences and care-seeking decisions. Using a notion of causality that is both process-oriented and context-sensitive, this article aims to understand ovarian cancer patients' stories on delayed healthcare seeking. It uses data from a qualitative interview study that investigated ovarian cancer patients' illness and healthcare-seeking experiences. We suggest that the interviewees' retrospective perspective generated a multi-layered notion of diagnostic delay that differs from the definition of patient-related delay commonly used in the literature. Our analysis shows how interviewees negotiate current social discourses on health and (social) responsibility, and thereby situate themselves and their healthcare seeking within a broader socio-economic and political context.

KEYWORDS: causality, diagnostic delay, healthcare seeking, ovarian cancer, sensations, symptoms

A dominant discourse in the field of cancer is that the earlier a tumour is detected the better the chances are to cure the disease (e.g. Evans et al. 2007). Thus, from a biomedical perspective tumours that are diagnosed only at later stages should and could have been diagnosed earlier, which is then considered a diagnostic delay (e.g. Bankhead et al. 2005). Reasons for diagnostic delays are usually linked to both patient- and provider-related factors (Evans et al. 2007). In ovarian cancer, more than 70 per cent of the 8,000 new annual cases in Germany are diagnosed within advanced stages (FIGO IIB-IV), with five-year survival rates of only around 30 per cent (RKI 2013). According to the literature, the most common fac-

tor responsible for late-stage diagnoses are patient-related delays, often aggravated by provider-related delays (e.g. Fitch et al. 2002).

In what follows, we use the example of ovarian cancer to focus on patient-related diagnostic delays, commonly defined as the period of time between the first appearance of symptoms and the patient's initiation of healthcare seeking within the biomedical system (Andersen et al. 1995). Based on the analysis of forty-two ovarian cancer patients' narratives, we investigate the interviewees' views on healthcare-seeking and how in the narratives women construct 'delay' in seeking medical care. The article contributes to a discussion on rethinking biomedical ideas



of causality in a one-dimensional, linear model by focusing on the social and cultural context of individual behaviours (Andersen 2010; Andersen and Risør 2014). It aims at overcoming merely descriptive explanations as to why patients delay care seeking in relation to bodily sensations by investigating if and how women talk about delayed healthcare seeking. We thereby understand patients' notion of diagnostic delay in its various contexts taking '[p]rocess causality' (Andersen and Risør 2014: 8) as analytical basis. The interviewees' retrospective perspective generated a notion of diagnostic delay that appears as a multi-layered phenomenon not congruent with the commonly used definition of patient-related delay. Rather, the interviewees negotiate, reproduce and reflect current social discourses on health and responsibility, situating themselves and their healthcare seeking within a broader socioeconomic and political context.

Patient-related Diagnostic Delays and the Question of Responsibility

Most studies in the field of patient-related diagnostic delays in ovarian cancer, as in other cancerous entities, attribute responsibility for delays to the so-called vague, unspecific nature of symptoms related to ovarian cancer combined with a lack of awareness among patients (e.g. Ferrell et al. 2003; Jayde and Boughton 2012). This combination, authors argue, frequently leads to patients ignoring or misinterpreting symptoms as less serious and more prevalent health problems adversely influencing timely healthcare seeking (Koldjeski et al. 2005).

A key intervention to address the problem of delay in ovarian cancer diagnosis is currently the development of symptom indices and appropriate educational campaigns to improve knowledge and awareness among the general public concerning ovarian cancer-related symptoms (e.g. Jayde and Boughton 2012). However, while such interventions may represent important attempts to tackle the problem of late diagnosis, the sketched 'traditional' perspectives on diagnostic delays and their derived interventions are problematic for several reasons. First, such an assumption neglects that there are many different diseases in which it may be of importance to seek health-care early. Thus, raising awareness for each and every one of them may simply not be practical. Such an approach also leads to the ever-increasing medicalisation of everyday life (Conrad 2007). In line with the medicalisation critique, a second reason is brought forward that argues that such interventions

tend to individualise reasons for diagnostic delays and overemphasise personal responsibility for health and illness.

As a consequence, they are at constant risk of – at least implicitly – responsabilising patients for their late-stage disease, which could promote a self-blaming or blaming-the-victim attitude as has been shown in the context of pregnancy and for a few cancer entities (e.g. Harper and Rail 2012; Yadlon 1997). Finally, in relation to the medicalisation theory one may argue that such campaigns lead to an objectified view on an inherently gendered organ (Einstein et al. 2012) that perpetuates the view of the (female) body as machine (Martin 1987). Overall, such interventions build on a too simple understanding of healthcare behaviours. Such understandings miss a whole level of meaning inherent to symptom experiences and healthcare-seeking processes, that is the processual character and the contextual situatedness of bodily experiences and care seeking decisions (Andersen and Risør 2014).

An Alternative Approach to Studying Diagnostic Delays

Based on the ideas of Maxwell (2012), the anthropologists Andersen and Risør (2014) have introduced an alternative approach to the qualitative research of sensations, symptoms and healthcare seeking, which helps understand and situate 'delayed' healthcare-seeking in the complexities of everyday life. The authors understand causality as inherently and simultaneously processual and context-specific. Such a notion of causality embraces a reflexive stance and seeks to explicate context as an intrinsic property of causal claims. It comprises causal explanations based on identifying and analysing the processes that make up healthcare-seeking decisions in a specific socio-cultural, economic and political context. (Andersen and Risør 2014). Thus, by inquiring into the 'why' and 'how', it allows for an analysis that considers the processual complexity of decision-making and actions in relation to bodily sensations and subsequently supports the development of effective health interventions (ibid.). In line with this approach, as we suggested elsewhere (Brandner et al. 2014), from the retrospective perspective of ovarian cancer patients, healthcare seeking might result out of a complex interplay of bodily sensations with various individual and sociocultural factors where pre-diagnostic sensations are finally converted into worrying experiences by a specific triggering process that prompts patients to seek healthcare.

Material and Methods

Based on the approach of Anderson and Risør, we analysed data that derived from a larger, qualitative interview study on illness experiences of ovarian cancer patients (Brandner et al. 2014) which applied a grounded theory approach (Strauss and Corbin 1990). From September 2011 to February 2013, the first author (SB) interviewed forty-two women throughout Germany with a primary diagnosis of ovarian cancer to learn more about their pre-diagnostic illness experiences and healthcare seeking. Based on a theoretical sampling strategy (ibid.), the sample varied according to age, place of residence, stage at diagnosis and according to themes derived from our data that proved to refine the emerging theory. After forty-two interviews theoretical saturation was reached, meaning that the categories and concepts extracted from the interviews could be comprehensively developed and no additional categories could be identified (ibid.).

The qualitative, open interviews started with the question 'How did the diagnosis of ovarian cancer come about in your case?' and did not contain questions about delayed healthcare seeking. However, when interviewees talked about having delayed consulting a healthcare provider, SB picked up the topic by asking open questions such as 'You said that you could have seen the doctor earlier. Could you tell me more about this?'

The interview data was analysed in parallel to data collection. The analysis was an iterative, inductive and team-based process supported by the software programme MAXQDA[®]10. The topic of this article, delays in pre-diagnostic healthcare seeking, was identified as a major category in the interviewees' reflections on their pre-diagnostic experiences.

Ovarian Cancer Patients' Narratives on Delayed Healthcare Seeking

Prior to visiting a medical doctor, most interviewees experienced bodily sensations that they, in retrospect, associated with cancer and they explained how and why they waited for weeks, months or even years before they sought healthcare related to these sensations. In what follows, we analyse the passages of the interviews that deal with the women's reflections on experiencing these sensations that have not led them to seek out biomedical care. The analysis reveals two major explanatory patterns that shaped these narratives: the notion of the responsible patient 'who should have' and competing social responsibilities.

Both point to social discourses on health that place responsibility on the individual and to the social roles women in Germany inhabit.

The Responsible Patient

The first major pattern that was raised in the interviewees' accounts on having delayed healthcare-seeking included reflections on appropriate reasons for consulting a biomedical professional when experiencing bodily sensations.

Many interviewees stated that they were sometimes reluctant to seek biomedical care as they anticipated being demeaned by others for being a hypochondriac or time-waster. These interviewees assigned responsibility for delayed healthcare seeking to a 'fear of embarrassment' (Smith et al. 2005: 828) when presenting assumed unreasonable reasons to a healthcare provider, as the example of Martha illustrates. Martha experienced feelings of abdominal pressure prior to diagnosis and for months struggled with her decision to seek healthcare:

I am that kind of person, I always think that others might think: 'this woman is completely fine. She just wants to go to the doctor to make herself seem a bit more important.' That people think: 'she doesn't lack anything. [S]he is some kind of hypochondriac.' Yeah, and I didn't want this at all. ... But sometimes it [going to the doctor] is too late then. (Martha, aged 61, FIGO IIIC)

Apart from including reflections on delayed healthcare seeking, Martha's narrative indicates that healthcare seeking and its 'reasonable' timing are contested social phenomena.

From a macro-perspective it could be argued that Martha's reflections show similarities to specific contemporary discourses on health increasingly present in public media, among healthcare professionals and the general public (Schmidt 2007). These discourses prescribe the ideal of a self-responsible and self-governing healthcare user able and obliged to act 'responsibly' towards her own health (Buddeberg 2011). The individual is thereby expected only to seek biomedical care when it is 'necessary' and otherwise constantly to minimise health risks by engaging in self-care and self-optimising practices and by attentively monitoring changes in the body (Lupton 1995; Nichter and Thompson 2006; Rose 2006). Such discourses of responsabilisation (Gray 2009) accentuate personal accountability for health and disease and assume individual configurability of health (Donahue and McGuire 1995; Gray 2009; Guttman and Ressler 2001; Lundell et al. 2013; Roy 2008; Yadlon 1997).

Another illustrative example of how these contemporary discourses resonate in our material is the story of Alice. Her narrative reflects the specific sub-discourse of obesity as a health problem.

At the beginning of the interview, Alice talked extensively about her obesity. Two years before her diagnosis she decided to lose weight, changed her diet and lost around twenty pounds within one year. Although she intended to continue her weight loss, her weight remained constant at 175 pounds and she finally recognised a growing pressure in her abdomen. In the course of her narrative, Alice reflected on why she still did not consult a biomedical professional:

I did not go because it was so unclear! It was simply this fat belly. On the other hand, if I had gone two months earlier, I might have been in stage two. But I couldn't simply go to my doctor and say: 'dear doctor, my belly grew a lot recently.' He might then just have looked at me and said: 'Yes, Alice. As I can see from your record you still have 175 pounds. You used to have 195 pounds. There is still plenty left. (Alice, aged 69, FIGO IIC)

Vague or non-specific bodily sensations, as in the case of Alice, have been widely cited as being responsible for diagnostic delays in ovarian cancer (e.g. Bankhead et al. 2005; Fitch et al. 2002). Furthermore, avoiding consulting with a biomedical professional for putatively inadequate reasons has been shown to be a reason for delayed healthcare seeking in various cancer entities (e.g. Smith et al. 2005). However, Alice's account reveals two other aspects that deepen the understanding of her perspective on her late diagnosis. First, and just as many other interviewees, Alice described the delay in her cancer diagnosis as probably preventable if she had only reacted differently from how she actually did, thereby ascribing responsibility for the delay to herself. Second, her narrative also indicates *why* she appraised her sensation as an inappropriate reason for healthcare-seeking. Alice's explanation of her line of action could be situated within the aforementioned discourse on obesity. Various studies have revealed that both the public and biomedical professionals tend to individualise reasons for obesity. Thereby, both hold individuals responsible for their overweight (Puhl and Heuer 2009). Hence, it could be presumed that the narrated reason for delayed healthcare seeking was not simply Alice's unspecific sensation. By referring to her general practitioner as an imaginary audience, Alice's fear of her sensation being evaluated only in the context of her obesity, holding her accountable for her condition and thus for not taking adequate

responsibility for her health, appears to have influenced her healthcare-seeking decision.

Competing Social Responsibilities

Closely linked to the concept of the responsible patient were the interviewees' discussions of competing social responsibilities that impeded an earlier diagnosis. This is a reasoning that has already been confirmed for patients with other cancer entities (e.g. Scott et al. 2006; Smith et al. 2005). Explaining why they delayed care-seeking, many interviewees referred to a variety of social responsibilities, such as caring for relatives or work-related tasks (see also Brandner et al. 2014). Thereby, the interviewees narratively invented a particular subjectivity, that is the socially responsible mother, daughter, co-worker etc. This socially responsible person sometimes seemed to be in conflict with the ideal of the aforementioned responsible patient who takes full responsibility for her health. Social responsibilities taking precedence over personal needs was of specific importance in this context as the narrative of Mae exemplified:

I didn't take this [abdominal pain] seriously because you really only function for others. And I never said: 'No, I will not do it!' I always functioned. ... If someone asked me: 'Could you?', as a matter of course, Mae always did everything. Both on the job and with the kids. So this is my personal responsibility ... I don't want to pass this buck onto anyone else. (Mae, aged 51, FIGO IIB)

As the narrative of Mae indicates, within the interviews, a socially responsible person was pictured as a person who reliably, continuously and actively enacts her social obligations, while responding flexibly and altruistically to challenges, trying her best to fulfil these obligations. Thereby, the fulfilment of social responsibilities was introduced as a moral ideal. When the interviewees reflected upon their delayed healthcare seeking, however, this moral ideal was challenged by another, namely the self-responsible 'somatic individual' (Rose 2006: 6), governed by a 'somatic ethics' (ibid.: 254) permeating the individual's entire everyday embodied life (Nichter and Thompson 2006). Consequently, in Mae's narrative, her social responsibilities appear as being the cause of the delay and Mae herself as being responsible for the consequences of this delay, as she did not 'adequately' react to her bodily sensation. Moreover, considering Mae's living conditions as a single mother of two children, struggling to feed her family by doing shift work in a canning factory, her account probably adds yet another dimension to the causal explanation of

her late cancer diagnosis. Although not made explicit by Mae herself, it could be argued that the reasons for the diagnostic delay could also be contextualised within Mae's difficult socioeconomic situation, a situation that is known to have the potential to leave particularly women highly vulnerable in terms of financial, social and health issues (RKI 2003).

The Notion of Diagnostic Delay in the Narratives of Ovarian Cancer Patients: A Suggestion

In this article, we have shown that women with ovarian cancer discussed not having gone to the healthcare provider, indicating that an earlier diagnosis may have been desirable. Thus they had a notion of diagnostic delay as part of their illness narratives. This is interesting in several aspects. First, the sociologist Klawiter has shown how in the course of the twentieth century, the female breast has come to be understood by women as a dangerous place that may harbour disease. Health campaigns first focused on urging women to seek healthcare once they experience symptoms. By the 1970s the message had moved to one in which women should actively engage in finding cancer in their bodies (Klawiter 2002). That illness narratives of women in Germany interweave questions of individual responsibility suggests that the idea of early detection indeed has become a master narrative in Germany. Second, the gendered nature of the accounts emerges in regard to competing social obligations. Women are the primary caretakers of family members in Germany (OECD 2014); as such they are also responsible to keep themselves healthy for others. The struggle of when it is appropriate to seek healthcare then becomes a social question as we have shown elsewhere (Brandner et al. 2014).

We suggest that the interviewees' retrospective perspective generated a complex notion of diagnostic delay that is not congruent with the definition of patient-related delay commonly used in various disciplines. The interviewees' neither conceptualised the delays simply in terms of time intervals nor did they define them as being solely related to the first disease-associated symptoms. Rather, most interviewees described their healthcare-seeking decisions in relation to specific sociocultural, biographical, economic and moral contexts linking micro-, meso- and macro levels of their life worlds. Thus, their notion of diagnostic delay appeared as a multicausal and multilinear phenomenon with different registers of meaning, covering aspects of four interrelated dimensions

that were found in various degrees in the narratives, namely aspects of healthcare seeking as a process; the interviewees' life worlds including social norms and values as well as the importance of the social positioning of the sick individual; aspects of potential preventability and, particularly, aspects of responsibility. Most interviewees pictured responsibility as an individualised phenomenon with the interviewees narratively transforming themselves into the main subjects that carried personal responsibility for the negative consequences of incorrect action or omission of action, that is for delayed healthcare seeking.

We suggest that the interviewees' retrospective perspective activated the normative frame of individual, prospective responsibility (Birnbacher 2001) towards health and generated a particular sociopolitically and historically constituted female subjectivity (Klawiter 2002; Robertson 2000) that – also not made explicit by the interviewees – probably shaped the specific notion of delay present in the narratives. Postulating pre-diagnostic delays as potentially preventable and ascribing personal responsibility predominantly to the narrating subject may therefore be both a cause of and a response to current normative discourses on individualised responsibility for health.

The interviewees' notion of diagnostic delay could be interpreted as redefining a delay as an individual failure and of adopting a blaming-the-victim perspective (Dworkin and Wachs 2009; Minkler 1999). However, it could also be argued that via the construction of personal responsibility for diagnostic delays, the interviewees acknowledge and regain agency in their illness narrative and life story. In this way, their notion of delay might be part of a coping strategy enabling the interviewees to deal with the consequences of a delayed cancer diagnosis.

Concluding Remarks

Based on a processual notion of causality comprising a contextual analysis, our analysis indicates that delayed healthcare seeking in ovarian cancer, and likely in other cancerous entities, might be a far more complex phenomenon than most of the literature on diagnostic delay suggests. By demonstrating the complexity of the notion of diagnostic delay, our findings have the potential to guide clinical interventions. Communication strategies and psychosocial interventions in clinical settings could be developed by understanding diagnostic delay as: (1) a particular view on disease and the body which individualises disease experience and suggests simple 'fixes'; (2) a

label which patients consider in struggling with their disease; and (3) a complex social process based on societal views on health and gendered social roles. These clinical interventions could enable healthcare providers to understand and work on the patients' suspected reasons for delayed care-seeking and to facilitate coping with a cancer diagnosis. Our results not only point to improving patients' healthcare in the aftermath of their disease but also for the time of diagnosis. Societal discourses work powerfully to simplify the complex process of a cancer diagnosis implying that earlier diagnosis would have been possible. Guiding physicians that this indeed may be too simple a story and encouraging them to discuss this at the time of diagnosis may further help women cope with their disease. In this context, further (prospective) qualitative investigations and interventions could provide caregivers and public health services with an in-depth understanding of how contextual factors influence healthcare seeking (Andersen and Risør 2014). Future research might also seek to deepen our understanding of the relation between the notion of processual causality and gender-related aspects of healthcare seeking.

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