



Symptomization and triggering processes: Ovarian cancer patients' narratives on pre-diagnostic sensation experiences and the initiation of healthcare seeking



Susanne Brandner ^{a,*}, Jacqueline Müller-Nordhorn ^a, Wiebke Stritter ^a,
Christina Fotopoulou ^{b,d}, Jalid Sehoul ^{b,c}, Christine Holmberg ^a

^a Berlin School of Public Health, Charité-Universitätsmedizin Berlin, Seestr. 73, 13347 Berlin, Germany

^b Department of Gynecology and Obstetrics, Charité-Universitätsmedizin Berlin, Campus Virchow Clinic, Augustenburger Platz 1, 13353 Berlin, Germany

^c European Competence Center for Ovarian Cancer (EKZE), Charité-Universitätsmedizin Berlin, Campus Virchow Clinic, Augustenburger Platz 1, 13353 Berlin, Germany

^d Ovarian Cancer Action Research Centre, Department of Surgery and Cancer, Imperial College London, Du Cane Road, London W12 0NN, United Kingdom

ARTICLE INFO

Article history:

Received 10 December 2013

Received in revised form

16 August 2014

Accepted 18 August 2014

Available online 19 August 2014

Keywords:

Germany

Sensations

Symptoms

Triggering process

Ovarian cancer

Healthcare seeking

ABSTRACT

Ovarian cancer is a malignant entity typically diagnosed in advanced stages, with concomitant poor prognosis. Delayed healthcare seeking is commonly explained by the 'vague' character of the disease's symptoms combined with a lack of awareness among patients. However, research on the social contexts of ovarian cancer patients' pre-diagnostic illness experiences and healthcare seeking is scarce. To explore these topics, we initiated a qualitative interview study guided by the principles of grounded theory and based on interviews with 42 ovarian cancer patients. The study was conducted in Germany from September 2011 to February 2013. Our analysis illustrates how, in the narratives, the interviewees struggled to balance specific bodily sensations with aspects of their life-worlds prior to consulting a biomedical professional. We propose a three-phase model to capture these experiences and demonstrate how the developments of pre-diagnostic sensations were catalysed by the dynamic and complex interplay of the sensations with a variety of individual and socio-cultural factors. To conceptualize these interplays, we introduce the analytical notion of a triggering process, and we elaborate on the different ways in which such a process conditioned the transformation of a sensation into a symptom and decisions to seek healthcare. We finally discuss our findings both in relation to current research on sensations, symptoms and healthcare seeking and in their relevance for understanding diagnostic delays in ovarian cancer.

© 2014 Elsevier Ltd. All rights reserved.

1. Introduction

Ovarian cancer is a malignant entity that is typically not diagnosed until it is at an advanced stage (FIGO IIB-IV¹), and there is thus a poor prognosis (Sehoul *et al.*, 2004). In Germany, approximately 8000 women, predominantly between 50 and 65 years, are diagnosed annually with this disease (Fotopoulou, 2009). As evidence-based screening tools are currently lacking (Menon *et al.*,

2014), ovarian cancer diagnosis usually follows biomedical consultation at the patient's initiative. Therefore increasing attention has recently been placed on symptoms related to ovarian cancer. Various quantitative and a few qualitative studies, mainly situated within a biomedical paradigm, have demonstrated that most patients report having experienced pre-diagnostic sensations, including abdominal bloating, digestional or urogenital changes, loss of appetite and fatigue (e.g. Bankhead *et al.*, 2008; Evans *et al.*, 2007). Within these studies, such sensations are commonly labelled as 'non-specific symptoms'.

Delayed healthcare seeking is predominantly explained by the vague character of any symptoms combined with a lack of awareness among patients (e.g. Goff, 2012; Koldjeski *et al.*, 2004). Most authors conclude that patients falsely attribute symptoms to minor, more common health problems or physiological processes such as

* Corresponding author.

E-mail addresses: susanne.brandner@googlemail.com, susanne.brandner@charite.de (S. Brandner).

¹ According to the classification by the International Federation of Gynecology and Obstetrics (FIGO), Committee on Gynecologic Oncology (www.igo.org/files/igo-corp/docs/staging_booklet.pdf). Last accessed March 18, 2014).

ageing, menopause or stress (Jayde et al., 2009; Koldjeski et al., 2004; Yawn et al., 2004). Despite the fact that most ovarian cancer symptoms have very low positive predictive values (Hamilton et al., 2009), many authors suggest that increasing what the general population know about these symptoms is an adequate strategy for tackling the problem of late diagnosis (e.g. Koldjeski et al., 2004; Lockwood-Rayermann et al., 2009).

In general, a large part of the existing literature on delayed healthcare seeking has recently been criticized for using “an implicit and simplified notion of causality, which impedes reflexivity on social context” (Andersen and Risør, 2014, 3). This critique also applies to the literature on ovarian cancer (Seibaek et al., 2011), where diagnostic delays are often explained in a de-contextualized way, and the mutual influences of individual behaviour and the various contexts in which this behaviour occurs remain unexplored.

To address these shortcomings and to investigate another research gap, i.e. why and when ovarian cancer patients decide to consult a biomedical professional, we conducted a qualitative interview study in which we enquired into the pre-diagnostic illness experiences of ovarian cancer patients in Germany. We found that the interviews were dominated by narratives on how specific bodily sensations developed pre-diagnostically, how the interviewees made sense of their sensations and how the experiences with sensations related to decisions to seek healthcare. In the present article, we analyse the patients' retrospective illness narratives and propose a three-phase model that utilizes an analytical discrimination between sensation and symptom to conceptualize the interviewees' narrated experiences. We finally discuss the relevance of our findings for understanding diagnostic delays in ovarian cancer and their relations to the theoretical background of our study, i.e. research on sensations, symptoms and healthcare seeking.

Within this research, the biomedical assumption that symptoms are part of a pre-cultural, taken-for-granted human biology (Dahmer, 2006) has been challenged for a few decades (e.g. Good and DelVecchio Good, 1981; Kirmayer et al., 1994; Kleinman, 1988). Recently, a new focus on the precursors of symptoms, i.e. the senses and their sensations (Hinton et al., 2008; Howes, 2005), has emerged as part of the ‘corporeal turn’ in the social sciences since the 1990s (Farquhar and Lock, 2007; Hay, 2008). To understand how symptoms come into being as simultaneously embodied and social phenomena, this research has called for the analytical separation of sensations and symptoms (Hay, 2008; Hinton et al., 2008; Howes, 2005; Martínez-Hernández, 2000). Sensations have thereby been described as embodied, lived and felt experiences of a change in sensational information situated in a specific socio-cultural context (e.g. Andersen et al., 2010; Gijsbers van Wijk and Kolk, 1997; Hay, 2008). In contrast, the notion of symptom comprises “a constructed and socially informed cognitive interpretation that indexes but is not itself an embodied sensation” (Hay, 2008, 221).

Hay (2008) has suggested a model of sensations transform into symptoms. Her model pictures this transformation as a relational and tentative process in which the individual draws on specific socio-cultural frameworks to determine sensations that might be symptoms in need of further action (Hay, 2008). These frameworks have been investigated by other authors as well and comprise, for example, ideas on personal vulnerability and expectations regarding the nature and duration of a sensation (Hay, 2008), local perceptions of aetiology and physiology (Hinton et al., 2008; Nichter, 2008) or issues of morality (Hunt, 1998). If a sensation contradicts any of these frameworks, it surpasses the boundary between normal and pathological in sensory experiences and thus becomes a symptom (Hay, 2008). To keep its status as a symptom, a sensation is in constant need of social confirmation both outside

the clinical setting (Hay, 2008; Nichter, 1981) and/or within this setting (Risør, 2011; Halkowski, 2006). Other authors have suggested that processes of “symptomization” (Risør, 2011, 22), i.e. the transformation of sensations into symptoms, do not only depend on socio-culturally informed individual interpretations. Power relations, social status and systems of knowledge also condition symptomization (Risør, 2011; Martínez-Hernández, 2000), and symptoms could construct meaning themselves while being constantly negotiated and exchanged in a social setting (Risør, 2011).

The ways sensations are transformed into symptoms are of particular importance for understanding healthcare seeking² because a symptom “stimulates a quest for an answer” (Hay, 2008, 221), i.e. a diagnosis (Hay, 2008). Research on healthcare seeking has revealed that the mere physical presence of sensations might not be sufficient to seek care in a medical setting (Zola, 1973; Andersen et al., 2010) and that (delayed) healthcare seeking cannot fully be explained by a variety of individual factors such as age, gender, socio-economic status, or knowledge (e.g. de Nooijer et al., 2001; Ramirez et al., 1999). Healthcare seeking could thus be understood as one of several possible consequences of the complex, non-linear and prospective processes during which sensations surpass the socio-culturally defined boundaries of what is perceived a normal bodily expression (Fainzang, 2011; Hay, 2008; Nichter, 2008). By comparison, confirming and extending on the work of Zola (1973), various studies into (delayed) healthcare seeking in cancer tried to identify factors that actually prompted care seeking and conceptualized these factors as contextual and social triggers. Examples of these studies include work on how significant others legitimize sensations as symptoms, thereby prompting individuals to seek biomedical care (e.g. Bain and Campbell, 2000; Scott et al., 2006), and how specific characteristics of a sensation such as a palpable lump and the symptom duration (Gascoigne et al., 1999; Smith et al., 2005) or failing efforts to mitigate sensations (Leydon et al., 2009) could trigger healthcare seeking. Such a focus on healthcare seeking triggers, however, harbours the risk of presenting mono- or oligo-causal explanations as to why individuals seek care for symptoms, blurring the complex and contextually embedded nature of healthcare seeking decisions (Andersen and Risør, 2014).

To avoid these risks, the present article explores the patients' recounted experiences in their (narrated) contexts and illustrates the processual character of care seeking decisions. In this way, our results could contribute to understanding the complex and dynamic nature of these decisions and could thus provide a new perspective to the problem of late diagnosis in ovarian cancer.

2. Methods

The data discussed derive from qualitative, open interviews with 42 ovarian cancer patients in Germany. Interviews were conducted and analysed using grounded theory techniques (Strauss and Corbin, 1990). Given the limited and mainly descriptive literature in our field of study, this methodological approach allowed us to identify the patients' major concerns regarding their pre-diagnostic experiences and allowed to generate a model that conceptualized how these concerns were dealt with in the narratives.

² For the purpose of this article, we narrowly define healthcare seeking as the utilization of biomedical healthcare services.

Download English Version:

<https://daneshyari.com/en/article/7334493>

Download Persian Version:

<https://daneshyari.com/article/7334493>

[Daneshyari.com](https://daneshyari.com)