European Journal of Oncology Nursing 34 (2018) 82–88

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

It is important that the process goes quickly, isn't it?” A qualitative multi-country study of colorectal or lung cancer patients' narratives of the timeliness of diagnosis and quality of care

Marlene Malmström[a,b,*], Birgit H. Rasmussen[a,b], Britt-Marie Bernhardson[c], Senada Hajdarevic[d], Lars E. Eriksson[c,e,f], Rikke Sand Andersen[g], John I. MacArtney[h]

[a] *The Institute for Palliative Care, Lund University and Region Skåne, Sweden*
[b] *Lund University, Department of Health Sciences, Lund, Sweden*
[c] *Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, SE-171 77 Stockholm, Sweden*
[d] *Department of Nursing, Umeå University, Sweden*
[e] *School of Health Sciences, City, University of London, London EC1V 0HB, United Kingdom*
[f] *Department of Infectious Diseases, Karolinska University Hospital, SE-141 86 Stockholm, Sweden*
[g] *Research Centre for Cancer Diagnosis in Primary Care, Research Unit of General Practice & Department of Anthropology, Aarhus University, Denmark*
[h] *Health Experiences Research Group, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK*

ARTICLE INFO

Keywords:
Lung cancer
Colorectal cancer
Time
Multi-country comparison
Narrative analysis
Quality of health care
Patients' experiences

ABSTRACT

Purpose: The emphasis on early diagnosis to improve cancer survival has been a key factor in the development of cancer pathways across Europe. The aim of this analysis was to explore how the emphasis on early diagnosis and timely treatment is reflected in patient's accounts of care, from the first suspicion of colorectal or lung cancer to their treatment in Denmark, England and Sweden.
Method: We recruited 155 patients in Denmark, England and Sweden who were within six months of being diagnosed with lung or colorectal cancer. Data were collected via semi-structured narrative interviews and analysed using a thematic approach.
Results: Participants’ accounts of quality of care were closely related to how quickly (or not) diagnosis, treatment and/or healthcare processes went. Kinetic metaphors as a description of care (such as treadmill) could be interpreted positively as participants were willing to forgo some degree of control and accept disruption to their lives to ensure more timely care. Drawing on wider cultural expectations of the benefits of diagnosing and treating cancer quickly, some participants were concerned that the waiting times between interventions might allow time for the cancer to grow.
Conclusions: Initiatives emphasising the timeliness of diagnosis and treatment are reflected in the ways some patients experience their care. However, these accounts were open to further contextualisation about what speed of healthcare processes meant for evaluating the quality of their care. Healthcare professionals could therefore be an important patient resource in providing reassurance and support about the timeliness of diagnosis or treatment.

1. Introduction

Diagnosing cancer earlier and more quickly has been a longstanding aim of healthcare providers across Europe and is a goal that has received renewed attention in the last decade (Butler et al., 2013). Early diagnosis initiatives have been organised and implemented differently in each country (Brown et al., 2014; Richards, 2009) and have included – but were not limited to – structural reorganisation of services (e.g. Vedsted and Olesen, 2015); public awareness campaigns concerning the importance of early diagnosis (e.g. the Danish Cancer Society sponsored ‘go see your doctor if … ’ campaign; Public Health England's *Be Clear On Cancer* campaign from 2012; and the Swedish Cancer Foundations' regional early diagnosis campaigns); and, use of time sensitive targets (e.g. Moffat et al., 2015). Such early diagnosis initiatives were enacted amongst wider healthcare and cultural changes whereby units of measurement become imbued with moral evaluations, so that more or faster are assumed – when contrary information is unavailable – to be ‘better’ (Moynihan et al., 2012; Rosa, 2003). While the rationale for

---

[*] Corresponding author. The Institute for Palliative Care, Lund University and Region Skåne, Sweden.
E-mail address: marlene.malmstrom@med.lu.se (M. Malmström).

https://doi.org/10.1016/j.ejon.2018.04.002
Received 3 January 2018; Received in revised form 21 March 2018; Accepted 6 April 2018

early diagnosis interventions was clear, the impact upon patient survival and – for this article - care now needs to be considered (Bankhead, 2017; Bastian, 2017; Nicholson, 2017). Therefore we ask how an emphasis on temporal aspects of early diagnosis are reflected in patient accounts of cancer diagnosis and care.

Past research has shown that good healthcare experiences are related to patients' ability to narrate and contextualise their understandings (Bury, 1982; Frank, 2002; Levealahti et al., 2007; Lindqvist et al., 2008; Rasmussen and Elverdam, 2007). However, navigating through healthcare systems, with clinics at different sites (Brown et al., 2014), opaque medical language and specialised knowledge (Andersen, 2017; Salmon and Young, 2017), can present difficulties and opportunities for confusion. Public discussions about timeliness and cost-efficiencies can be found to have problematic implications for patients' understandings of what (and when) is the right time to seek help (Llanwarne et al., 2017). Decisions about how, when and who to consult are therefore not only matters of clinical or diagnostic timeliness (efficiency), but also contain moral dimensions about what it is, or is not, appropriate for a “good patient” to do and what constitutes ‘good care’ (Llanwarne et al., 2017, Ziebland et al., 2011). Such research provides challenges to contemporary healthcare initiatives, such as patient centred care and shared decision making, which are premised upon a patient with the capacity and agency to evaluate and make decisions about their healthcare (Lehman, 2017; Richards et al., 2015).

Understanding the temporal aspects of patient experiences is therefore an important component of providing good and ethical healthcare (Sandelowski, 1999). Studies that place patients' experiences in a temporal frame draw our attention to the ways that patient accounts of good care are contextually and relationally dependent upon disease knowledge and illness experience (Bury, 1982; Levealahti et al., 2007), understandings of the healthcare system (Llanwarne et al., 2017), and interactions with healthcare practitioners (HCPs) (Del Vecchio Good et al., 1994). In particular, such studies have demonstrated the disjuncture between the “clock” time often referred to by the healthcare system and/or professionals, and the patients' embodied feelings of disease time (Davies, 1994, 1996; Lövgren et al., 2010). Furthermore, the movement of time in experiences of cancer diagnosis and care can speed up, slow down, stretch, compress or disorder patient experiences of illness and care (Frank, 2002; MacArtney, 2015; Riessman, 2015). Therefore the focus of this paper is on how evaluative judgements about cancer diagnosis and care are entangled with the relationships between different temporal experiences (e.g. ‘clock’, ‘embodied’, ‘disease’, and ‘healthcare system’ time) and accounts of the movement of time (e.g. quick, slow) (Caldas and Berterö, 2012).

2. Aim

The aim of the study was to explore how the emphasis on early diagnosis and timely treatment is reflected in patient's accounts of care, from the first suspicion of colorectal or lung cancer to their treatment in Denmark, England and Sweden.

3. Method

3.1. Context and design

This study is a part of an international comparative qualitative study of patients diagnosed with lung or colorectal cancer and their experiences of diagnosis in Denmark, England and Sweden (see MacArtney et al., 2017). The study sought to use patients’ accounts to obtain and extend understanding of potentially modifiable factors known to influence long-term cancer survival, including late presentation, delayed diagnosis and referral into specialist care. The countries were chosen based on the results from the ICBP project showing a significant variation in survival rates for lung and colorectal in favour of Sweden compared to both Denmark and England (Coleman et al., 2011).

The analysis presented in this paper focuses on how the emphasis on early diagnosis and timely treatment is reflected in patient's accounts of care. At the time of the interviews (2015) all three countries had, or were in the process of, implementing strategies intending to shorten the time from diagnosis to treatment for these types of cancer. Denmark implemented standardised care pathways with stipulated timeframes for cancer diagnosis from 2009 (Probst et al., 2012). England implemented a fast-track referral process (including ‘the two-week wait’) in 2000 (Department of Health, 2000). Sweden was in the planning phase to implement standardised care pathways similar to the Danish routine for both cancers, and fast track systems were already available in many parts of the country (Brown et al., 2014; Wilkens et al., 2016).

3.2. Recruitment and participants

Adult patients (≥18 years) within six months of being diagnosed with lung or colorectal cancer were eligible to be included in the study. These cancers affect both genders and are two of the most common causes of death from cancer across Europe (Ferlay et al., 2010). Recruitment took place across the whole of each country and a purposeful sample was used that sought to reach a maximum variation across gender, age, urban and rural locations, type of diagnosis, and route to diagnosis. Recruitment was primarily through hospital clinics supplemented with social media campaigns in England and Denmark. A total of 155 interviews were conducted. Demographic data and sample variation is provided in Table 1.

3.3. Ethics

Before participation all participants received an information letter and signed an informed consent form according to the (separate) ethical regulations in each country. In Denmark the Biomedical Research Ethics Committee System Act did not apply to the main project, as the project does not involve the use of human biological materials. Standard ethical protocol according to the American Anthropological Association was followed. In England approval was given by the Research Ethics Service reference 14/NS/1035 and in Sweden by the Regional Ethics Board, Lund, Sweden, reference 2014/819.

3.4. Data collection

All participants who decided to participate had the opportunity to choose where they preferred the interview to take place, with most interviews being conducted in the participant's home. Interviews were conducted one-to-one, although a small number of participants wanted a family member to be present for support. In these cases we agreed to the patients' request but clarified the aim of the study was to focus on the patients' experiences. Interviews took place in the main language used within each country and lasted between 45 and 135 min. Five researchers with backgrounds in nursing (SWE x3), sociology (ENG x1), and anthropology (DEN x1) conducted the interviews. During the

Table 1
Demographic characteristics across the three countries.

		Denmark (DEN)		England (ENG)		Sweden (SWE)	
		CC[a]	LC[b]	CC	LC	CC	LC
Number of participants		28	22	25	20	30	30
Percentage female		46%	36%	48%	50%	47%	50%
Age range	**31–50**	2	0	4	2	2	2
	51–70	19	15	13	12	14	21
	71–90	7	7	8	6	14	7

[a] Colorectal cancer.

[b] Lung cancer.