

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

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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.

Keywords

Lung cancer; colorectal cancer; time; multi-country comparison; narrative analysis; Quality of health care; Patients' experiences

Background

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 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., 2017). 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).

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.

Method

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).

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.

Table 1: Demographic characteristics across the three countries

		Denmark (DEN)		England (ENG)		Sweden (SWE)	
		CC*	LC**	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

*Colorectal cancer; **Lung cancer

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.

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 minutes. Five researchers with backgrounds in nursing (SWE x3), sociology (ENG x1), and anthropology (DEN x1) conducted the interviews. During the planning of the project a semi-structured interview guide was developed aiming to ensure the comparability between the countries and that potential cross-cultural issues were addressed (Chapple and Ziebland., 2017). Patient and public involvement (PPI) representatives in each country were invited to suggest revisions to the interview guide. All interviews began with an open question: 'Could you start by telling me, in your own words and in as much detail as you want, about everything that has happened since you first started to suspect there might be a problem with your health?' and was followed by probing questions to ensure that the pre-defined areas in the interview guide were addressed. Before closing the recruitment process the researchers reviewed the demographic information collected to ensure there was suitable variation of participants. The teleconferences held throughout the recruitment process allowed for discussion of the themes found and therefore the researchers were able to agree when data saturation had been reached. All interviews were audio recorded and transcribed verbatim in the language in which they were conducted.

Data analysis

A thematic approach (Pope et al., 2000) was used to analyse the data within the country where it was collected (MacArtney et al., 2017). Using specialist computer software (NVivo 10), anticipated themes were drawn from the topic guide, and emerging themes were identified during the coding process. During data collection and analysis monthly teleconferences were held to discuss issues and identify emergent themes across the three countries. Three face-to-face workshops were also held between 2015 and 2016 where relevant data from each country were translated and compared, which were further supplemented by individual researchers visiting colleagues in 2016 and 2017.

At the final workshop, an emergent theme related to how timely treatment was reflected in patient's accounts of care was identified and we agreed to (re)code the data to examine the accounts more closely. Once the excerpts were collated, they were read and discussed by four of the authors (MM, BHR, JM and RSA) one of whom (BHR) speaks and reads all three languages fluently. Initial findings were presented to co-authors, who provided further reflections and analysis. During this process similarities and differences within and between countries were discussed, resulting in one main theme; *"It is important that the process goes quickly, isn't it?"* and four sub-themes. Inspired by Sandelowski and Leeman (2012), the theme were translated into thematic sentences, using participant expressions, in an effort to ease understanding of the findings by portraying complete ideas. The interview excerpts were translated and cleaned up with pauses, falterings, and repetitions removed (Riessman, 2008).

Results

"It is important that the process goes quickly, isn't it?"

The importance of timeliness of diagnosis and quality of care in the process of cancer diagnosis was shown throughout the patients' accounts. The main theme *"It is important that the process goes quickly, isn't it?"* related patients experiences of care to how quickly (or not) diagnosis, treatment and/or healthcare processes went. Within this main theme is an ambivalence in knowing what 'quickly' means in relation to how the disease may progress or how the speed of care may affect prognosis. When exploring this ambivalence more closely we identified four sub-themes that allowed us to describe some of the normative and evaluative aspects of temporal narratives in cancer care: *"It's better to be fast, than slow"*, *"It went like clockwork"*, *"There's nothing you can't in an emergency... cancel or stop"*, and *"What has worried me is that everything took such a long time"*.

"It's better to be fast, than slow"

An emergent theme from all three countries was how the *speed* of diagnosis and treatment had become a master frame through which quality of care was evaluated.

For example,

Partner: But it was a rollercoaster from, I think you got cancer to the op, it was, bum, bum, bum, bum, bum and that, wasn't it, with you.

Participant: Yeah, it's better to be fast, than slow.

Partner: It was because they knew... (ENG)

In this excerpt we can see not only how participants' evaluation of care were shaped by temporal narratives (including healthcare process and disease time), but that there was also a strong normative component related to how quickly something happened ("better to be fast"), which was related to a belief about the seriousness of the disease ("because they knew"). In some instances, the message that cancer should be treated quickly was reinforced by HCPs, as this participant recalled being told by a particularly straight talking doctor.

As the hospital doctor told me on Tuesday: "You should be glad that you sent in the screening test and you came [to your appointment], because you came at the last minute. You should not have waited much longer, it would have been a significantly worse situation for you with regard to the spread of cancer throughout the body".
(DEN)

Although some participants (and their clinicians) suggested there was a clear relationship between speed of diagnosis and treatment and good care, others were less sure how to evaluate the temporal significance of what was happening. In particular, we found that some participants' accounts were unsure about how cancer as a disease progresses, as well as ambiguous expectations of how healthcare processes should work. For example,

It felt like that was forever [the time between CT scan and surgery]. Because then they knew that it was a tumour, and I thought, "how much will it be growing while I'll go here and wait?" (SWE)

There's been a two weeks gap from seeing the oncologist to actually starting the proper treatment. And, the fact that's it's already in my lymph nodes . . . isn't a good sign and part of you thinks, "Oh god! Shouldn't they be doing this now?" Two weeks is a long time. But when you look at other people, some people are waiting over a month. But no I think they've been really quick. Really quick. (ENG)

Or, as another participant succinctly put it, "it is important that the process goes quick, isn't it?" (ENG). What is notable is how varying degrees of uncertainty (in relation to disease time) are entangled with questions about the speed of healthcare processes, which are implicitly related to concerns about their chances of survival. Two weeks can be transformed from a "long time" when related to disease growth and progression, to "really quick" when framed by knowledge that others wait "over a month".

"It went like clockwork"

Participants' judgement of timely diagnosis or care often used superlative language such as "marvellous" or "tremendous" when their expectations were met (or exceeded). Participants also used analogies or metaphors to describe their experiences of quick care, for example, "it went like clockwork" or "it was like a hand in a glove". Such metaphors suggest that participants' care took place with minimal or little effort (on their behalf) and this was interpreted as a sign of good care.

Some participants used metaphors indicating they or their care was moving, often quickly, such as "being on a roller-coaster", or being "caught by a whirlwind", or "being on a treadmill". Similarly, a participant in Denmark described the process of care as if he was on a train that moved by itself and could change direction at any time based on the results from investigations or new clinical directives. The contemporary healthcare emphasis of patient centred care might suggest that such loss of agency is understood negatively. Yet when participants were asked to reflect on what these kinetic metaphors meant to them, it was somewhat surprising to find that a loss of agency could also be interpreted as a sign things were going as they should. For example,

I think once you're on [the treadmill], you're on it, and that you're being dealt with really. And I suppose I maybe am one of the lucky ones, that I was dealt with quickly. I don't know. Is there a case of 'Well we think we can do something here', so things are moved along quicker? (ENG)

Being on a treadmill, as above, does not take on the often-assumed negative understanding. Rather it is used to suggest, "we can do something" i.e. the healthcare system is working to the benefit of the participant. Another participant said,

I suppose there is that slight feeling [of a loss of control], but as far as I was concerned, they know what they're doing. So I just went along with it. And unless you want to step off and do your own thing, there's not much you can do. (ENG)

These participants described how they accepted giving a degree of control to the HCPs and healthcare system, as it might get them to their desired destination – treatment and cure – more quickly. As one participant described, "It was like the system knew what it's doing and that I knew my role in it".

"There's nothing you can't in an emergency... cancel or stop"

The context of getting cancer diagnosed or treated quickly was reflected in how some participants accounted for the action they or HCPs had to take, understanding it to be exceptional, out of the ordinary, or done in an "emergency". As one participant said,

They [c]ould have said, 'Come in tomorrow.' And I'd be in there. You know, you can always, there's nothing you can't, in an emergency, that you can't cancel or stop. If they'd have said ["come in now"], I'd have gone in straight away. (ENG)

The expectation that cancer needed swift diagnosis and treatment also meant that some participants would be flexible in their planning to speed up the process, sometimes traveling to different hospitals, or as a participant in Sweden described it, "I put myself on standby" for a cancellation or last minute appointment. Other participants described their efforts to get potential cancer symptoms seen as quickly as possible, which encouraged some participants to take action that they otherwise might not. For example, one participant in Sweden said that he felt he had to "fight" to get access to health care. Having experienced delays, he described how he navigated his way around the system by contacting several different HCPs, to get his appointments more quickly.

The temporal exceptionalism that cancer sometimes engendered was also reflected in some participants' descriptions of the actions that their HCPs took. For example, when a physician told a participant that they would make a "direct referral" this was understood to be different from a normal (i.e. slower) referral. Turns of phrase, such as a HCP saying they "managed" to get the participant an earlier appointment, were taken to mean that the nature of their situation was such that they should not have to wait. Some participants interpreted such quickness to mean the clinical team was acting with a sense of urgency that was related to the seriousness of their prognosis.

The need for timely diagnosis and treatment for cancer meant that some participants would accept (or seek) exceptions to the expectation of continuity of person in the patient-doctor relationship. As one participant said,

If I had been in the situation where I had to wait for the same doctor to treat me throughout, how much time would I have to wait before I could get to talk to the doctor? Is it not better perhaps to make sure that the system works, that [investigations] reported, and the doctors use it, so that when a new doctor comes and needs to talk to me, he or she has familiarised him or herself? Rather than the same doctor coming each time and then maybe causing a week's delay. (DEN)

Although some participants did describe situations where they benefitted from the continuity of a relationship with their HCP, the context of seeking a quick diagnosis (for cancer) suggests that some patients might find a continuity of care more preferable.

"What has worried me is that everything took such a long time"

We have shown how some participants' accounts drew on idea of cancer as a disease where things should move quickly. In particular, periods of time between investigations or care could be experienced as a "delay" in the absence of information that helped to contextualise the wait. Here we explore the role of HCP in this and in assuaging a participant's worry and anxiety. For example, some of the participants who were left without information about how waiting times might affect their prognosis spoke of the fear and anxiety this provoked. A Swedish participant spoke of her worry that something was not right or that she had been forgotten,

Yes what has worried me is that everything took such a long time, during the investigations . . . it always took several weeks in-between [investigations]. So you thought that they had forgotten you, but they did not. They did not forget. But it was just the feeling that you did not hear anything... (SWE)

In moments such as these participants explained that it was not the amount of time that was the key, but that they did not necessarily know what the time might mean in relation to the cancer progression. In contrast, there were accounts of when providing a participant with information and support was found to ease many of the fears and anxieties. For example,

And then I said "a whole week then?" [to wait for an appointment with a surgeon]. "Yes. A whole week?" And then [the doctor] said, "It does not matter. Even if you could think that it has [grown], it has not," she said. And I've always appreciated that straight forwardness as well. (SWE)

The participant's anxiety about having to wait "a *whole* week" is interpreted and experienced differently once the doctor provides reassurance that a week's wait will not mean her cancer has grown significantly. This meant that the participant went from relating to the waiting time as an emergency with a potential life-threatening outcome, to being reassured that a week would not affect her prognosis.

The perceived importance of a quick process was also used to contextualise concerns about waiting for the decision from a multidisciplinary team (MDT) conference. Participants felt comfortable with waiting when they had received explanations about the role and purpose of the MDT, along with details of who would contact them to provide details of the outcomes. However, if there was a deviation between what they have expected (e.g. being contacted the same day as the MDT conference) and what was happening (not being contacted), the fear of being forgotten or that the cancer was growing arose. In such cases delays were experienced as unbearably long.

Discussion

Methodological considerations

The qualitative multi-country comparative study that this analysis draws upon is the first of its kind to study the route to cancer diagnosis across Denmark, England and Sweden (see MacArtney et al., 2017). This research has provided us with a unique sample of participants' accounts of the relationship between timeliness and quality of care. Cross-country research has the potential to enhance understanding of health and illness between countries, however there are potential barriers that needs to be addressed to ensure comparability. It has been pointed out that in cross country research the researchers needs to understand the context within the different countries where the research takes place (Haak et al., 2013) and that it is important that the they agree on the meaning of key concepts and terminology to avoid discrepancy (Bogaert, et al., 2015). To ensure comparability potential hinders were identified and addressed during the process of developing the topic guide. For example, we found that a word that was considered common in one country did not exist in another or that the interpretation of a word was different between the countries. The research group therefore agreed about that the topic guides in each country needed to be similar in that the meaning of each question would be the same, even though this meant that the translation was not literal (Chapple and Ziebland., 2017). The study was limited to participants recall of events of being diagnosed with either colorectal or lung cancer. However, we suggest that our findings may be able to enhance understanding of patient experiences of other cancer and disease types. This is because the trope that early diagnosis might improve survival has been applied to other diseases and cancer types. Further, rather than focus on participants' recall of specific events, we sought to identify narrative themes that shaped participants' understandings of their diagnosis and treatment (Greenhalgh, 2016). This approach allowed us to concentrate on the normative assumptions shaping experiences and to identify how patients understood good care (Greenhalgh, 2016). What emerged during our analysis was that the key similarities and differences in the ways that narratives structured patient experiences within each country were also shared across the three countries. Further discussion and engagement with the literature suggested that the international context of cancer diagnosis and treatment, in which timely urgency is stressed, might be providing a master frame though which experiences in the three countries were being understood.

Result considerations

This study provides insight into how patients' accounts of quality of care can be shaped by the emphasis on timely diagnosis and treatment, which has been an important feature of cancer healthcare in northern Europe. In particular, the context of ensuring a timely diagnosis raises questions about how to understand patient kinetic metaphors concerning the quality of care such as, "whirlwind", "treadmill", or "roller-coaster". On face value, they suggest a loss of agency (Del Vecchio Good et al., 1994), depersonalised care (Day et al., 2017), or that events are happening at a pace beyond the participant's control. However, placed within a narrative whereby cancer is a disease that necessitates early diagnosis and treatment, the participants suggest an alternative interpretation. The speed of care is used to suggest the healthcare system is working, and this can provide a feeling of protection (Lilliehorn et al., 2010; Schaepe, 2011). This is not to say that agency is not important to the participants, but it is notable that it is something that can be withdrawn or limited if it will speed *up* healthcare processes. Indeed, in some cases, narratives of agency (of exerting or taking control), in the context of care being timely, provoked feelings of vulnerability as such actions raised questions about the system not working (cf Lilliehorn, et al., 2010).

The healthcare system working quickly could also be taken as an indication that the participant's illness was something that is being taken seriously, that something can be done, or that a cure was possible (Locock et al., 2016). It is important to note that participants could also interpret such efficiency as a 'bad sign', suggesting that the cancer is even more serious than previously thought. What connects these disparate experiences are not just normative expectations that cancer should be treated quickly, but that the interpretation of timeliness needed to be individualised to the participant's immediate situation for an evaluation of care to be made (Andersen and Risor, 2014). That is, we found that the role of HCPs in contextualising disease and healthcare system temporalities was important for participants in making sense of whether, for example, waiting two weeks for an investigation was too long or very quick (Salmon and Young, 2016). This has consequences for everyday clinical practice and will need clinicians to be aware of the heterogeneity of disease progression for different cancers, as well individualise this information to help and support patients in interpreting what the timeframes mean for their care. There are therefore important implications for practice for HCPs (see Box 1).

Implications for practice

Awareness:

- HCPs should be aware that patients might draw on a wider cultural understanding that cancer should be diagnosed early and treated quickly when evaluating their healthcare.
- Patients could choose to forgo some control over their care as they are seeking to achieve an early diagnosis or timely treatment.

Communication:

- The difference between patient and HCPs understanding of the timeliness of diagnosis and treatment can be a source of anxiety for patients when not discussed.
- HCPs should ensure they have explicitly addressed individual patient concerns about what early diagnosis and timeliness of treatment means (and how it may have changed) at different points in the patients' healthcare pathway.

Box 1: Implications for practice

Ideas of being exceptional or lucky have been argued to be part of patients wish to minimise the impact of a cancer diagnosis (Wilson and Luker, 2006) or are a personalisation of good fortune against a general expectation of poor care and treatment (Ziebland et al., 2011). What our study adds is that use of such language can also indicate that patients see their situation as serious and that what is needed are exceptional circumstances, good luck or fortune so that processes are “sped up”. If they see that they are successful in gaining such good fortune, this may compliment minimisation strategies (i.e. it *is* serious, but it is being treated quickly, so I be will be okay).

The findings also highlight some of the burdens patients can face when seeking a timely diagnosis, raising important ethical questions about the (somewhat) unintended implications of early diagnosis initiatives (see also Llanwarne et al., 2017). In order to secure earlier investigations, diagnosis or treatment some participants were willing to go to great lengths such as: travelling to a distant hospital; place themselves under significant inconvenience and emotional stress (being available whenever the call came); or even forgo direct control or agency over decision making, which has significant legal or ethical implications for how HCPs share decision making (Chan et al., 2017). In the context of specialisation and multi-site care in which cancer care is delivered (Brown et al., 2014), the challenge for HCPs will be to support patients' so they experience their care as coherent and feel safe in the system regardless of how it is organised (Salmon and Young, 2016). It also raises the question for future research of how initiatives that seek to emphasise agency (e.g. patient empowerment, autonomy, and choice) combine with the prioritisation of speed if patients' understanding of agency are associated with feelings that the system is not working (for them) (Salmon and Young, 2016)?

Our findings also provide an opportunity to reflect on circumstances in which continuity of care might supersede clinician's concern for continuity of person. In a setting where patients see the importance of speed of diagnosis and treatment as taking precedence, good care will be judged to be

that which fulfils this criteria. This adds to a growing body of literature that suggests that while continuity on the person level (clinician) may have clinical and systemic benefits (Barker et al., 2017) – as well as being valued by the patient (Klarare et al., 2017) – there are circumstances in which continuity on the care system level is preferable (Andersen et al., 2011).

Conclusion

Wider discourses of timely diagnosis and treatment can have important affects upon many other key aspects of providing healthcare. We found that patients with colorectal and lung cancer treated in three northern European countries may prioritise speedy diagnosis and treatment over other considerations such as agency and continuity. Patients may engage in healthcare with an expectation that speed is important, but what that means for them is something that HCPs can provide reassurance about in terms of both disease timeframes and healthcare system processes.

Conflicts of interest

The authors declare no conflicts of interest.

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References

Andersen, R.S., 2017. Directing the senses in the contemporary orientations to cancer disease control. *Tidsskrift for Forskning i Sygdom og Samfund* 26, 145-171.

Andersen, R.S., Risør, M.B., 2014. The importance of contextualization. *Anthropological reflections on descriptive analysis, its limitations and implications. Anthropology & medicine* 21, 345-356.

- Andersen, R.S., Vedsted, P., Olesen, F., Bro, F., Sondergaard, J., 2011. Does the organizational structure of health care systems influence care-seeking decisions? A qualitative analysis of Danish cancer patients' reflections on care-seeking. *Scandinavian journal of primary health care* 29, 144-149.
- Bankhead, C., 2017. The 2-week wait and other initiatives to improve cancer diagnosis: Has it altered survival? The answer is unclear-the evidence is too weak. *European journal of cancer care* 26.
- Barker, I., Steventon, A., Deeny, S.R., 2017. Association between continuity of care in general practice and hospital admissions for ambulatory care sensitive conditions: cross sectional study of routinely collected, person level data. *Bmj*, j84.
- Bastian, H., 2017. The Disease Prevention Illusion: A Tragedy in 5 Parts, Absolutely maybe: evidence and uncertainties in everyday life. *PLOS, PLOS Blogs*.
- Bogaert, P., Bochenek, T., Prokop, A., Pilc, A., 2015. A qualitative approach to a better understanding of the problems underlying drug shortages, as viewed from Belgian, French and the European Union's Perspectives. *PLoS ONE* 10.
- Brown, S., Castelli, M., Hunter, D.J., Erskine, J., Vedsted, P., Foot, C., Rubin, G., 2014. How might healthcare systems influence speed of cancer diagnosis: a narrative review. *Social science & medicine* 116, 56-63.
- Bury, M., 1982. Chronic illness as biographical disruption. *Sociology of health & illness* 4, 167-182.
- Butler, J., Foot, C., Bomb, M., Hiom, S., Coleman, M., Bryant, H., Vedsted, P., Hanson, J., Richards, M., Group, I.W., 2013. The International Cancer Benchmarking Partnership: an international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom. *Health policy* 112, 148-155.
- Caldas, C.P., Berterö, C., 2012. A Concept Analysis About Temporality and Its Applicability in Nursing Care. *Nursing Forum* 47, 245-252.
- Chan, S.W., Tulloch, E., Cooper, E.S., Smith, A., Wojcik, W., Norman, J.E., 2017. Montgomery and informed consent: where are we now? *Bmj* 357, j2224.
- Chapple, A., Ziebland, S., 2017. Methodological and practical issues in cross-national qualitative research: Lessons from the literature and a comparative study of the experiences of people receiving a diagnosis of cancer. *Qualitative health research* [Online preview].

Coleman, M.P., Forman, D., Bryant, H., Butler, J., Rachet, B., Maringe, C., Nur, U., Tracey, E., Coory, M., Hatcher, J., McGahan, C.E., Turner, D., Marrett, L., Gjerstorff, M.L., Johannesen, T.B., Adolfsson, J., Lambe, M., Lawrence, G., Meechan, D., Morris, E.J., Middleton, R., Steward, J., Richards, M.A., 2011. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *The Lancet* 377, 127-138.

Davies, K., 1994. The tensions between process time and clock time in care-work. The example of day nurseries. *Time and Society* 3, 277-303.

Davies, K., 1996. Capturing women's lives: a discussion of time and methodological issues. *Women's Studies International Forum* 19, 579-588.

Day, S., Coombes, R.C., McGrath-Lone, L., Schoenborn, C., Ward, H., 2017. Stratified, precision or personalised medicine? Cancer services in the 'real world' of a London hospital. *Sociology of health & illness* 39, 143-158.

Del Vecchio Good, M.-J., Munakata, T., Kobayashi, Y., Mattingly, C., Good, B.J., 1994. Oncology and narrative time. *Social science & medicine* (1982) 38, 855-862.

Ferlay, J., Parkin, D.M., Steliarova-Foucher, E., 2010. Estimates of cancer incidence and mortality in Europe in 2008. *Eur J Cancer* 46, 765-781.

Frank, A.W., 2002. *At the Will of the Body: Reflections on Illness*. Mariner Books, NY.

Greenhalgh, T., 2016. Cultural contexts of health: the use of narrative research in the health sector, Health Evidence Network synthesis report 49. WHO Regional Office for Europe, Copenhagen.

Haak, M., Himmelsbach, I., Granbom, M., Lofqvist, C., 2013. Cross-national and multi-language qualitative research: Challenges and recommendations. *British Journal of Occupational Therapy* 76, 333–336.

Klarare, A., Rasmussen, B.H., Fossum, B., Furst, C.J., Hansson, J., Hagelin, C.L., 2017. Experiences of security and continuity of care: Patients' and families' narratives about the work of specialized palliative home care teams. *Palliative & supportive care* 15, 181-189.

Lehman, R., 2017. Sharing as the Future of Medicine. *JAMA Intern Med*.

Levealahti, H., Tishelman, C., Ohlen, J., 2007. Framing the onset of lung cancer biographically: narratives of continuity and disruption. *Psycho-oncology* 16, 466-473.

Lilliehorn, S., Hamberg, K., Kero, A., Salander, P., 2010. 'Admission into a helping plan': a watershed between positive and negative experiences in breast cancer. *Psycho-oncology* 19, 806-813.

Lindqvist, O., Rasmussen, B.H., Widmark, A., Hyden, L.C., 2008. Time and bodily changes in advanced prostate cancer: talk about time as death approaches. *Journal of pain and symptom management* 36, 648-656.

Llanwarne, N., Newbould, J., Burt, J., Campbell, J.L., Roland, M., 2017. Wasting the doctor's time? A video-elicitation interview study with patients in primary care. *Social science & medicine* 176, 113-122.

Locock, L., Nettleton, S., Kirkpatrick, S., Ryan, S., Ziebland, S., 2016. 'I knew before I was told': Breaches, cues and clues in the diagnostic assemblage. *Social science & medicine* 154, 85-92.

Lövgren, M., K Hamberg, K., Tishelman, C., 2010. Clock Time and Embodied Time Experienced by Patients With Inoperable Lung Cancer. *Cancer Nursing* 33, 55-63.

MacArtney, J.I., 2015. At the will of our stories, in: Tansley, L., Maftei, M. (Eds.), *Writing Creative Non-Fiction: Determining the Form*. Gylphi Press, Canterbury, UK.

MacArtney, J.I., Malmström, M., Overgaard Nielsen, T.L., Evans, J., Bernhardson, B.M., Hajdarevic, S., Chapple, A., Eriksson, L.E., Locock, L., Rasmussen, B.H., Vedsted, P., Tishelman, C., Andersen, R.S., Ziebland, S., 2017. Patients' initial steps to cancer diagnosis in Denmark, England, and Sweden: what can a qualitative, cross country comparison of narrative interviews tell us about potentially modifiable factors? *BMJ Open* 7, e018210.

Moffat, J., Bentley, A., Ironmonger, L., Boughey, A., Radford, G., Duffy, S., 2015. The impact of national cancer awareness campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in immediate key symptom awareness and GP attendances. *British journal of cancer* 112 Suppl 1, S14-21.

Moynihan, R., Doust, J., Henry, D., 2012. Preventing overdiagnosis: how to stop harming the healthy. *Bmj* 344, e3502.

Nicholson, B.D., 2017. Detecting cancer in primary care: Where does early diagnosis stop and overdiagnosis begin? *European journal of cancer care* 26.

Pope, C., Ziebland, S., Mays, N., 2000. Qualitative research in health care: Analysing qualitative data. *Bmj* 320, 114-116.

Probst, H.B., Hussain, Z.B., Andersen, O., 2012. Cancer patient pathways in Denmark as a joint effort between bureaucrats, health professionals and politicians--a national Danish project. *Health policy* 105, 65-70.

Rasmussen, D.M., Elverdam, B., 2007. Cancer survivors' experience of time: time disruption and time appropriation. *Journal of advanced nursing* 57, 614-622.

Richards, M.A., 2009. The size of the prize for earlier diagnosis of cancer in England. *British journal of cancer* 101 Suppl 2, S125-129.

Richards, T., Coulter, A., Wicks, P., 2015. Time to deliver patient centred care. *Bmj* 350, h530.

Riessman, C.K., 2008. *Narrative methods for the human sciences*. Sage, Thousand Oaks, CA.

Riessman, C.K., 2015. Ruptures and sutures: time, audience and identity in an illness narrative. *Sociol Health Illness* 37, 1055-1071.

Rosa, H., 2003. Social Acceleration: Ethical and Political Consequences of a Desynchronized High-Speed Society. *Constellations* 10, 3-33.

Salmon, P., Young, B., 2017. A new paradigm for clinical communication: critical review of literature in cancer care. *Medical education* 51, 258-268.

Sandelowski, M., 1999. Time and qualitative research. *Research in Nursing and Health* 22, 79-87.

Sandelowski, M., Leeman, J., 2012. Writing usable qualitative health research findings. *Qualitative health research* 22, 1404-1413.

Schaepe, K.S., 2011. Bad news and first impressions: patient and family caregiver accounts of learning the cancer diagnosis. *Social science & medicine* 73, 912-921.

Vedsted, P., Olesen, F., 2015. A differentiated approach to referrals from general practice to support early cancer diagnosis - the Danish three-legged strategy. *British journal of cancer* 112 Suppl 1, S65-69.

Wilson, K., Luker, K.A., 2006. At home in hospital? Interaction and stigma in people affected by cancer. *Social science & medicine* 62, 1616-1627.

Ziebland, S., Evans, J., Toynbee, P., 2011. Exceptionally good? Positive experiences of NHS care and treatment surprises lymphoma patients: a qualitative interview study. *Health expectations : an international journal of public participation in health care and health policy* 14, 21-28.