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Public & private accounts of help-seeking: The implications of research methods on the presentation of narratives

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Abstract

For people with symptoms that could indicate cancer, prompt presentation to a health care practitioner facilitates early diagnosis, improves survival, and is encouraged by public health agencies and cancer charities. Nevertheless, time to presentation from symptom onset (the patient interval) is known to vary widely. We report findings from a mixed-methods study examining help-seeking among people with symptoms of lung or colorectal cancer. Patients referred for urgent investigation invited to complete a questionnaire about their symptoms and help-seeking experiences; 26 of these participants then took part in a semi-structured interview.

Discrepant accounts of help-seeking were reported through the different research methods, with longer ‘patient intervals’ reported in interviews. We use the concept of ‘public and private accounts’ to reflect upon why socially conforming accounts of early presentation were presented in the questionnaires, whilst accounts of longer ‘patient intervals’ tended to be presented within an interview encounter.

Keywords

mixed methods, public accounts, private accounts, cancer, help-seeking

Introduction

Describing, understanding, and explaining diagnostic delay has been a key focus of cancer research efforts, with early diagnosis remaining central to UK cancer policy for over a decade (Department of Health, 2007). This is because of the association between time to diagnosis and survival (Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999; Tørring et al.,
as diagnostic intervals increase so does the likelihood that a cancer will be diagnosed at a more advanced stage (Sant et al., 2003; Tørring et al., 2017). In this paper we discuss a study which sought to understand the range of factors that influence when, and why, people seek help for symptoms suggestive of cancer, by examining the length of patient intervals and reasons for consultation (Dobson et al. 2018). A key finding was that there were discrepancies in the length of time reported from symptom onset to first presentation between questionnaires and follow up interviews, with all but one of the participants reporting a longer interval in their interview than they had in their questionnaire. We explore why that might be, and how the different methods used may have resulted in different responses from the same intervals, using the concepts of public and private accounts (Douglas 1966, Cornwell 1984).

The Cancer Diagnostic Pathway and the Patient Interval

The diagnostic pathway (the term used to describe a specific period in a patient’s cancer journey, from the onset of symptoms to the cancer diagnosis) is made up of three component intervals; the patient interval (time from symptom onset to first presentation with a health care practitioner), the primary care interval (time from first consultation to specialist referral) and the secondary care interval (time from receipt of referral to diagnosis) (Burgess, Ramirez, Richards, & Love, 1998; Weller et al, 2012). Accurate description and measurement of the diagnostic pathway, and its component intervals, is vital for transparency and comparison across studies, but the field has been dogged by differing theoretical and methodological approaches (Weller et al., 2012). A wide range of factors have been identified as impacting on the length of time it takes someone to seek help for symptoms suggestive of cancer, including the sanctioning of help-seeking by friends and family (Pedersen et al., 2011), competing priorities (Andersen et al., 2010) and cancer fear (Dubayova et al., 2010). This period in the cancer diagnostic pathway has received much attention as it is potentially
modifiable, therefore increasing the likelihood of earlier diagnosis and improved chances of survival. Interventions to reduce the length of the patient interval have primarily focused on raising awareness of cancer symptoms and stressing the importance of early presentation. The most notable of these was the Be Clear on Cancer campaign (BCOC) (Cancer Research UKa), which used multiple media formats to encourage people to seek help early for a range of symptoms associated with cancer.

People are aware of expectations to consult promptly upon identification of cancer symptoms and the discourse around ‘catching cancer early’ is also reinforced by screening programmes for bowel, cervical and breast cancer in the UK (NHS, 2018). Both awareness raising and screening programmes emphasise the responsibility of the individual for the effective management and identification of cancer. This devolution of responsibility for early diagnosis, located in the ‘new public health’ approach to health promotion and prevention, is based on the premise that the dissemination of information about healthy behaviours will inevitably lead to the ‘correct’ actions among citizens (Seale, 2002). Within this ‘new public health’ approach the ‘knowledgeable’, self-motivated individual comes to represent the quintessential ‘good patient’ or ‘good citizen’ (Granek & Fergus; Llanwarne, Newbould, Burt, Campbell, & Roland, 2017; Offersen, Vedsted, & Andersen, 2017). As consulting for symptoms of cancer promptly is constructed as the morally acceptable course of action, not behaving in this manner, (i.e., by taking a long time to present) jars with societal expectations for appropriate responses to possible cancer symptoms.

Examining the Patient Interval
Researching the length of time it takes for an individual to consult after symptom onset is not a simple task. Symptom onset is a difficult moment to pinpoint. People experience deviations from usual bodily functioning on a daily basis; however, only certain experiences transcend the status of sensation to become symptoms (HEATH, 2008). There is also the potential for participants to be conscious about the construction and presentation of their help-seeking behaviour, aware that their accounts may, or may not, conform to social expectations. Therefore, the methods used to examine these experiences can potentially impact on the type of account presented.

The anonymity of questionnaires may mean that people are more willing to report attitudes and behaviours that do not wholly conform to the behaviours of the ‘good patient’, than they would be in a face-to-face interview (Bloch 2004), where they may feel a need to provide responses that are more socially acceptable. However, interviews provide an opportunity to reflect, explore and explain in ways that questionnaires do not.

Recent debates have highlighted the need to consider how data are produced in interviews. While the ‘radical critique’ (e.g. Atkinson and Silverman 1997, Atkinson (2015), Silverman (2017), Whitaker and Atkinson (2019) of interviews suggests that interviews cannot produce reliable data about behaviours in a way that observation can, research into symptoms would be very difficult, if not impossible, to conduct as observational studies. Therefore, in order to gather data about how people have responded to symptoms which also provides them with an opportunity to explain their decision-making processes, interviews are a preferable method. However, we still need to be cognisant of the interview as a social encounter and the need for an interviewer to be skilled in their craft (Seale 1999). As Hughes et al (2020) argue, an interview is a form of evidence, and one which enables researchers not just to explore what individuals tell us about themselves, but also what that tells us about the social world. An
interviewee’s reflexivity about ‘the biographical work that interviews require’ (Blakely and Moles 2017:169) enables the researcher, with careful analysis, to see how they place themselves in the world, and what aspects of a particular social world, in this case the societal assumptions about cancer symptoms and being a ‘good patient’, bring themselves to bear on their biography.

The radical critique does caution us to remember that interviews do not produce ‘the truth’, but yield information (Atkinson 2015); in this paper we are interested in exploring our finding that two different methods of enquiry resulted in two different pieces of information being produced, but not in whether one or the other method produces ‘truth’, but rather, why different answers were given and what might have been happening in the interview in particular that might have led to this.

Public and Private Accounts of Behaviour

One lens through which we can think about the reporting of behaviours that are imbued with societal expectations is by employing the concept of ‘public and private accounts’.

In her seminal work Mary Douglas (1966) considered how people respond to anomalies based upon their extant schema. She argued that culture provides standardisation of communal values, whereby ideas and values are tidily ordered through the provision of basic categories and concepts within society. This system of communal values has authority, as individuals are obliged to assent to it because others within the community also assent. The public nature of this classificatory system makes its components rigid, as definitions of these components are a public matter. However, definitions and boundaries can be revised within an individual’s personal life, so long as the individual maintains assent to the cultural classificatory system publicly.
‘A private person may revise his pattern of assumptions or not. It is a private matter. But cultural categories are public matters. They cannot so easily be subject to revision.’ (M. Douglas, 1966, p. 48)

Cornwell (1984) undertook ethnographic research in the East End of London in the early 1980s, which explored residents’ experiences of health and illness, alongside housing and employment transitions (Cornwell, 1984). Throughout her fieldwork she found that participants would provide different accounts during different encounters. She believed that the substantially different accounts were not due to failures of memory but were the result of changes in the relationship between herself and the participant, as well as the different interviewing techniques which she employed. Cornwell drew on the concept of public and private realms to argue that, depending on the circumstances of the encounter, participants provided either their ‘public account’ or their ‘private account’, of a particular event or experience.

Cornwell found that ‘public accounts’ were most common when people were uncertain of their position in relation to others and so coped with this by putting on their ‘best face’. These ‘public accounts are sets of meanings in common social currency that reproduce and legitimate the assumptions people take for granted about the nature of social reality’ (Cornwell, 1984, p. 15). This ‘best face’ is not necessarily deceptive but is simply the reproduction of a culturally normative pattern, whereby people are able to stick with the relative security of a ‘public account’, knowing that what they say will be socially acceptable to whoever they are talking to. ‘Private accounts’ on the other hand ‘spring directly from personal experience and from the thoughts and feeling accompanying it’ (Cornwell, 1984, p. 16). They represent how people would think and react if not considering the reactions or perceptions of wider society.
The concepts of the ‘public’ and the ‘private’ describe a world in which cultural classificatory systems exist, which must be assented to publicly, however, are able to be challenged and revised by individuals privately. People present socially acceptable ‘public accounts’ when they are less clear of their position in relation to others, when there is a strangeness and untrustworthiness in the encounter. Whereas ‘private accounts’ are more likely to emerge when an individual is in a position of relative privacy and less concerned about adhering to wider social classifications and perceptions, because of the trustworthiness of their environment.

Methods

To examine the length and nature of participants’ patient intervals, a mixed-methods approach was employed, comprising a questionnaire and semi-structured interviews. This approach meant that different types of data could be used to concurrently produce a ‘bigger picture’ (Barbour, 2014; Gray, 2014), revealing different dimensions of the patient interval, highlighting its complexities and enriching our understanding of this time period (Moran-Ellis et al., 2006). The study used a pre-validated, self-administered questionnaire to elicit information of symptom experience and help-seeking. Semi-structured interviews explored barriers and triggers to help-seeking, along with date of symptom onset and date of first presentation, to allow us to gather more detailed accounts of participants’ help-seeking journeys. The examination of date of symptom onset and date of first consultation in both the questionnaire and the interview enabled us to calculate two versions of patient interval length.

Patients referred to the University Hospital of North Tees (UHNT) for urgent specialist assessment (also known as a ‘two week wait’ referral) of symptoms suspicious of a lung or colorectal cancer were invited to take part in this study. Lung and colorectal cancer are the
most common cancers affecting both men and women in the UK, with the average ten-year survival rate for lung cancer being 10% and for colorectal cancer being 53% (Cancer Research UKb; Cancer Research UKc). UHNT serves people residing across a large area of Teesside and County Durham, with great variation in levels of affluence and deprivation within the hospital’s catchment area (Department of Health, 2010). This area also faces some of the poorest health outcomes in the country, with low life expectancy and high cancer incidence (Department of Health, 2010; Office for National Statistics, 2014b).

Over a 12 month period, 1390 patients were identified as eligible (aged 40 years and over, deemed capable of providing informed consent) and invited to take part in the study. Eligible patients were sent information about the study, including a questionnaire, which also asked for expressions of interest for participation in a follow up interview. Of those invited, 164 patients returned a completed questionnaire (11.8% response rate) and 26 participants were interviewed; 12 with symptoms of lung cancer and 14 with symptoms of colorectal cancer.

This study used the pre-validated questionnaire from The Symptom Study (Walter et al. 2015) to obtain patient reported date of symptom onset and first consultation with a health care practitioner, along with demographic characteristics. Participants were able to provide either exact or estimated dates, with the protocol for calculating pseudo-exact dates utilised when estimated dates were reported (Neal et al. 2014). An additional questionnaire, the pre-validated Reaction to Symptoms (RSQ) questionnaire, was also included, which sought information about perceived social support during the symptomatic period (Pedersen, Olesen, Hansen, Zachariae, & Vedsted, 2011). Questionnaire responses were anonymised and patient interval length was calculated for each participant, along with tests of association between patient interval length and patient characteristics.
Semi-structured interviews were used to explore people’s symptomatic experiences, appraisal of symptoms and help-seeking decisions. Interview participants were purposively sampled for diagnosis, symptom type and length of the patient interval, in order to engage with a range of help-seeking experiences, as well as differing underlying pathology. The semi-structured approach ensured that key topics were covered, whilst allowing the interviewee and interviewer the freedom to discuss unexpected and novel topics. The topic guide for the interviews, was initially developed by the study team, including patient and public representatives, and was informed by existing evidence. This topic guide was revisited and revised as the interviews progressed, with emerging pertinent topics from earlier interviews incorporated into the topic guide for exploration with subsequent participants. The interviews explored people’s symptomatic experiences (e.g., “can you tell me a bit about the symptoms you experienced?” “when did your symptoms start?”), appraisal of symptoms (e.g., “what did you think was causing your symptoms”, “did you try to find out more information about the symptoms you were experiencing?”, “did you talk to anyone about your symptoms?”) and help-seeking decision-making (e.g. “what made you think you might need to go to the doctor?”, “when did you decide you needed to see the doctor?”, “how long after you decided you needed to see the doctor was it before you were able to go?”), with relevant probes used to follow up individual answers to questions.

Theoretical sampling was used to explore topics and questions emerging as important during early analysis (Charmaz, 2006, 2014), particularly the significance of blood as a symptom. Interviews generally took place in people’s homes, with a small number being conducted on university premises, as per the interviewee’s choice. Most interviews consisted of the interviewer and participant, however, in some cases where the interview took place at home a spouse was also present. Where spouses contributed to the interview, written consent for their participation in the study was obtained at the end of the interview. The interviews were
digitally recorded and transcribed verbatim, with all interviewees, and individuals mentioned within transcripts, assigned pseudonyms to protect their identities. Interviews ranged in length from thirty minutes to two hours, with the majority lasting approximately one hour. The length of the interview was largely influenced by the length of the participants’ patient interval, as those individuals who sought help shortly after symptom onset had fewer experiences to recount, whereas those who had longer patient intervals had more to discuss, including multiple occasions of symptom (re)appraisal, accounts to share of the impact of their symptoms on their lives, as well as discussion of multiple and varied barriers and motivators to help-seeking.

Analysis occurred concurrently with fieldwork and coding and memo-ing was undertaken throughout the research process, in line with a constructivist grounded theory approach (Charmaz, 2006, 2014). Interviewing continued until emerging theories were repeatedly supported by new data, with subsequent interviews no longer challenging or altering analysis, (Glaser & Strauss, 1967), and a point of ‘accuracy’ was felt to have been reached (Barbour, 2014; Charmaz, 2004). The length of the patient interval was calculated for all interviewees, after identifying date of symptom onset and date of first presentation within each transcript.

Ethical approval for this study was obtained from the NHS National Research Ethics Service (NRES) North East Committee (REC Reference: 13/NE/0319).

Findings

Patient Interval Length

Analysis of questionnaire data showed that patient interval length ranged from the same day as symptom onset, to five and a half years later. The mean patient interval for people with
symptoms of lung cancer was 50 days, whilst the mean patient interval for people with symptoms of colorectal cancer was 74 days. Experiencing ‘bleeding’ as a symptom (either rectal bleeding or haemoptysis (coughing up blood)) was associated with shorter patient intervals, however, experiencing ‘pain’ was only associated with shorter patient intervals for people with symptoms of lung cancer. Amongst interviewees, the length of the patient interval ranged from the same day as symptom onset to 4-5 years later.

The majority of participants (74%) reported differing patient interval lengths, dependent upon the research method employed (see table 1). Discrepancies in time to presentation ranged from one day to three and a half years. For all except one of these participants (Arthur), the length of the patient interval reported in the questionnaire was shorter than that reported in the interview.

Of those participants who reported longer patient intervals in the interview setting, the mean difference in patient interval length was 191 days and the median difference was 27.5 days.

The Importance of Early Presentation

Many people discussed an awareness of the importance of consulting early for symptoms that may be cancer. For some individuals, such as Mary, this came from personal experience, whereas for others their beliefs about the importance of early presentation appear to be based on an assimilation of public messaging.

What actually prompted this was my husband. He had urinary bleeding and he went [to the doctor’s] immediately and he had bladder cancer. So that triggered me, you know, how important it was to go straight away, because he’s clear now. (Mary, rectal bleeding, diverticulosis)
Well the reason they [health care professionals] want you to go and check it out is because they want to check it out to make sure it isn’t...you know... (Eleanor, rectal bleeding, diverticulosis)

It was when I heard, saw, all the adverts about bowel cancer, that’s what sort of pushed me into going to the doctor’s. (Fred, change in bowel habit, No abnormalities detected)

Whilst participants were aware of the importance of early presentation, this information was often assessed alongside other factors, such as recent participation in cancer screening, in their assessment of the necessity of consultation.

Harry’s Wife: If you have symptoms go straight to the doctor’s

Harry: But then I had screening and it was fine so then we thought differently from that.

Harry’s Wife: But then it didn’t go away and we know you have to go early if it is that [cancer]

Whilst people may feel comfortable deviating from the initial ‘early presentation’ norm in their appraisal of symptoms and help-seeking decision making, the societal obligation to consult early meant that decisions about how to report symptom length to the GP presented a challenge to some.

I’ve had diarrhoea for a year and half, but when I went to the doctors.
six weeks ago I only told him it was six months...[why did you tell him you’d had the symptoms for six months and not over a year?]...Well embarrassment I think more than anything else I would say. If I’d have probably said ‘well over a year’ he would have probably ‘oh’, but I just told him it was six months. Even then he went ‘six months!’ because mainly I think it didn’t bother me. I thought well if I said over a year he might say ‘why didn’t you come to see me before now?’ Yeah, that’s a long time, and I just said ‘I’ll shorten it, six months’. But I’d had it well over a year. (Roy: persistent diarrhoea, spirochetosis)

Discussion

In the questionnaire responses, participants with symptoms of a lung or colorectal cancer reported mean patient intervals of 50 days and 74 days, respectively, which supports the findings of previous studies ((Lyratzopoulos et al. 2015). Participants in the study were aware of public health messaging on the importance of early diagnosis and often referred to this in their accounts of their own decision-making and behaviour.

There was a high prevalence (74%) of discrepancy in reported patient interval length through the two research methods. Whilst it is inevitable that there will be differences in accounts and narratives that are constructed and presented in different contexts, from this data we can identify a clear pattern of discrepancies in the reporting of patient interval length. Rather than question which account is ‘true’, we believe that it is more pertinent to explore why different accounts exist; and what is happening if ‘multiple constructed realities’ (Seale 1999:474) are presented in different settings.

Public and Private Accounts of Help-Seeking
As has been discussed earlier, the obligation to present early upon identification of possible cancer symptoms is acknowledged by the general public. The belief that ‘good patients’ act swiftly on symptoms of cancer in order to ‘increase their chances’ is built upon both personal experience of early and late diagnosis of cancer amongst family and friends, and through public health messaging on early diagnosis. There is a social expectation that all individuals will act swiftly upon identification of possible cancer symptoms, as responsible citizens actively and expertly manage their health. Early presentation with cancer symptoms aligns with society’s expectations of appropriate management of illness episodes that may represent cancer and so we can conceive of such reports as being representative of archetypal ‘public accounts’. Taking a long time to seek help, however, jars with societal norms and expectations, and reporting of such behaviours would be representative of ‘private accounts’.

The reporting of shorter patient intervals, which conform to the socially acceptable response to cancer symptoms, was much more common in questionnaire responses, suggesting these responses represent participants’ ‘public accounts’, whereas, long patient intervals were more commonly reported in interviews, suggesting that interview narratives represent participants’ ‘private accounts’.

Questionnaires and the Reporting of ‘Public Accounts’

There are a number of factors that may have contributed to the tendency towards presentation of ‘public accounts’, conforming to social normal and expectations, within the questionnaire responses. Participants received a pack of documents when they were invited to take part in the study, containing an invitation letter which was signed by the clinician, as well as all documents having the logos of the local NHS Trust and the University printed on them. These symbols are commonly included in study documentation, in order to formalise and
validate them, by demonstrating endorsement of the research by these respected bodies.

However, this may have overly formalised the documents, emphasising their official nature.

The clinicians’ signature on the invitation letter may have given the impression that the study was led by the clinician, which may have compelled participants to present an account they were happy for the clinician to see. We know that patients feel an obligation to present themselves as ‘good patients’ to their doctors (Andersen, Tørring, & Vedsted, 2014; Offersen, Vedsted, & Andersen, 2017) and so the belief that their clinician was heavily involved in the research may have prompted participants to report shorter patient intervals, in order present a ‘best face’ version of themselves. A study of patient satisfaction of an open-access flexible-sigmoidoscopy service, which used three different methods to elicit feedback from patients, found that participants often raised concerns in the interview setting about issues such as the delivery of results, and pre and post procedure communication with the doctor, despite reporting high levels of satisfaction in the questionnaire (Dougall et al., 2000). They argue that patients feel obliged to present responses to health professionals which will be perceived as ‘correct’, because of a loyalty to the medical profession, and a fear that a negative response could result in the withdrawal of resources and services.

The closed nature of the questionnaire may have also reinforced its formality, as participants were expected to produce precise answers, with no opportunity for explanation or commentary around a question. The format was restrictive, forcing participants towards numerical representations, asking for date, or estimated date, of symptom onset and first consultation. The impact of closed styles of questioning on the types of response provided was also identified by Cornwell (1984), who found that participants generally responded to closed questions with a public account of their beliefs and behaviours.

Interviews and the Reporting of ‘Private Accounts’
Private accounts, on the other hand, can incorporate non-conformist information and values, as individuals do not need to perform to socially acceptable values in this space. During the interviews participants were able to talk directly to an individual, and not with an abstract, semi-authoritative organisation, as was the case in the questionnaire. The interviewer spoke to each interviewee at least once prior to the interview, and so a level of trust and rapport had begun to be established, as well as a greater familiarity with the study purpose. Cornwell (1984) found that it was often only in later interviews, after a subject had already been broached once that a private account was presented. The interviewer was also local to the region, presenting a familiar accent and a degree of shared local knowledge and cultural references, which again would have contributed to the development of rapport and fostered an open discussion. She was also young, like Emslie (Richards and Emslie 2000) in her late twenties at the time of the interviews, which may have meant she too was seen as ‘the girl from the university’ (2000:73) and as such, interviewees may have felt able to present a private account rather than the public account or ‘best face’ version they had produced when dealing with the formality of the questionnaire. The majority of interviews took place within peoples’ homes, meaning that they had a greater degree of power in the encounter and were familiar with their surroundings. Within the privacy of one’s home rules and expectations can be revised and deviated from and private accounts can be shared (Douglas, 1966).

Interviews were discursive and open, with participants allowed to ‘tell their story’ far more than they were able to when responding to the questionnaire. The opportunity to retain control of the construction and presentation of their narrative allowed them to meander in and out of topics and to explain their experiences, feelings, and behaviours. In this sense, the participants were engaging in reflexive identity work (Blakely and Moles 2017) that enabled them to rationalise, justify and explain their behaviour, in a way that was not possible within the questionnaire. This may also enable us to draw a conclusion, based on Hughes et al.’s
argument ‘that is necessary to move beyond equating what people tell about themselves at interview with what interviews can be used to tell about the social world’ (2020:560). The findings from this study suggest that a social world exists around cancer whereby people have absorbed messages about being an active self-manager of their health, and a ‘good patient’.

Whilst not all participants conformed to the early presentation of symptoms, they all had explanations for why their chosen course of action was appropriate. In that sense, they were able to retain a moral claim to being a good patient, particularly when their explanation connected to a wish not to waste scarce NHS resources, waste doctor’s time, or duplicate tests.

For example, Roy reported in the questionnaire that he had been experiencing symptoms for 6 months (interestingly, the same symptom time frame which he reported to the GP), whereas in the interview he said that the symptoms had been present for a year and a half. Similarly, in the questionnaire Harry said it had taken him three months to present to the GP about his change in bowel habit, whereas in the interview he said that he took up to five months to present. During the interview he was able to discuss his reasoning around the timing of his consultation, outlining factors that he drew into his assessment of cancer risk and the subsequent perceived necessity of consultation. He talked about how he was a very active man, who ate a healthy diet and had never smoked or drank. These factors made him feel that faced a substantially smaller risk of cancer than someone who had engaged in these ‘risky’ behaviours. A key part of Harry’s assessment of the necessity of help-seeking was the fact that he was invited to take part in the national bowel screening programme during his symptomatic period. His response to his symptoms, although discordant with the socially acceptable narrative of ‘early presentation’, was based in logic and reason, through his assessment of multiple pertinent factors. The opportunity to explain his reasoning behind the length of time it took him to consult after becoming symptomatic may have made Harry more...
willing to present an account of behaviour that did not adhere to societal rules of early
presentation, as he was able to present his behaviour as rational and reasonable. Within the
questionnaire there was no such opportunity to justify how long it took to consult and so
Harry, and others, may have felt pressured to present an account that confirmed and presented
themselves as competent managers of their health.

The implications of discrepant reports of patient interval length

The concept of public and private accounts offers a useful lens for understanding the
discrepant accounts presented by participants in this study and offers explanation as to why
participants may have reported less socially desirable behaviours during interviews, than they
did in the self-administered questionnaires.

In the field of early diagnosis of cancer research a large number of studies examining the
patient interval use validated questionnaires, as this is believed to be the most effective and
rigorous approach (Weller et al. 2012) to gathering accurate data on time to presentation.
However, the findings from this study suggest that such data may underestimate the actual
length of patient intervals, as people may feel compelled to produce a ‘public account’ of
reduced patient interval length within questionnaire responses. If this is a systemic problem in
the reporting of time to presentation within questionnaires, there may be significant
underestimation of how long people tolerate symptoms for before seeking help, which has
clear implications for the design and evaluation of interventions to increase early
presentation. It also has implications for the comparability of datasets internationally, as we
do not know whether patients in other countries face similar social obligations and discourses
to present early with symptoms of cancer. Analyses and interpretations of such datasets need
to be mindful that the data being used is a presentation, or version, of help-seeking which
participants have felt willing to share within that research environment. The data gathered through self-administered symptom questionnaires is likely to represent participants’ public accounts and so may systematically under-report patient interval length. This study also highlights the importance of robust qualitative research into help-seeking, as the accounts produced in interviews appear to be more likely to represent ‘private accounts’. These accounts may more closely mirror peoples’ lived experiences, as they are constructed and presented in an environment in which individuals are able to challenge and diverge from social rules and norms. Interviews appear to be more astute at exploring actual responses to symptoms, as they enable people to share accounts of behaviour which did not conform to the expectation for early presentation. However, the accounts presented in interviews did conform to the individualist ‘self-management’ requirement of current public health messages, which was facilitated by interviews offering a space where people could provide explanations for their actions and justify the choices they had made about how they had reacted to symptoms and what had led to the decision to consult.

Conclusion

This study found consistent discrepancies in the reporting of patient interval length, dependent upon the research method employed. Participants reported ‘public accounts’ of patient intervals in questionnaire responses and ‘private accounts’ of time to presentation within the interview setting. The formal nature of the invitation letter, endorsed and signed by the clinician, and the closed nature of questions, may have induced participants to present public accounts in their responses to the questionnaire. Whereas the building of trust and rapport between interviewer and interviewee, location of the interviews, the open style of questioning and the opportunity to justify one’s choices and actions created an environment in which participants were able to present their private accounts of help-seeking within the
interview encounter. These discrepancies highlight the importance of reflection and transparency about the methods employed to investigate accounts of time to presentation and the necessity of consistency for both empirical research and the development and evaluations of interventions to achieve earlier diagnosis.

Researchers should be aware that data on the patient interval generated from questionnaires may systematically underestimate the actual length of time it has taken symptomatic individuals to seek help for symptoms suggestive of cancer.

**Declaration of Interest**

The authors report no competing interests.

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