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## **Illness identity as an important component of candidacy: contrasting experiences of help-seeking and access to care in cancer and heart disease.**

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### **Abstract**

How and when we use health services or healthcare provision has dominated exploration of and debates around healthcare access. Levels of utilisation are assumed as a proxy for access. Yet, focusing on utilisation conceals an important aspect of the access conundrum: the relationships that patients and potential patients have with the healthcare system and the professionals within those systems. Candidacy has been proposed as an antidote to traditional utilisation models. The Candidacy construct offers the ability to include patient-professional aspects alongside utilisation and thus promotes a deeper understanding of access. Originally applied to healthcare access for vulnerable populations, additional socio-demographic factors, including age and ethnicity, have also been shown to influence the Candidacy process. Here we propose a further extension of the Candidacy construct and illustrate the importance of illness identities when accessing healthcare. Drawing on a secondary data analysis of three data sets of qualitative interviews from colorectal cancer and heart failure patients we found that though similar access issues are apparent pre-diagnosis, diagnosis marks a critical juncture in the experience of access. Cancer patients describe a

person-centred responsive healthcare system where their patienthood requires only modest assertion. Cancer speaks for itself. In marked contrast heart failure patients, describe struggling within a seemingly impermeable system to understand their illness, its implications and their own legitimacy as patients. Our work highlights the pressing need for healthcare professionals, systems and policies to promote a person centred approach, which is responsive and timely, regardless of illness category. To achieve this, attitudes regarding the importance or priority afforded to different categories of illness need to be tackled as they directly influence ideas of Candidacy and consequently access and experiences of care.

**Keywords: United Kingdom; candidacy; illness identities; access; cancer; heart failure; secondary analysis.**

## **Illness identity as an important component of Candidacy: contrasting experiences of help-seeking and access to care in cancer and heart disease.**

Understanding access to healthcare has always been demanding. Traditional approaches that have sought to explain healthcare access have presupposed that, where healthcare systems supply services that meet user demands, 'access' ceases to be an issue (Mooney, 1983). Such utilisation approaches contend that if services are made available, the potential for use is present and access is possible. Others have argued that even universal healthcare systems, albeit unintentionally, foster (if not exacerbate) health inequalities and there is a need therefore to dig beneath the surface of access (Gal, 1998; Le Grand, 1982; Mackenzie et al., 2013).

In critiquing what we might call utilisation approaches, which focus on the provision, availability and use of health services, Dixon-Woods and colleagues offer 'candidacy' as a mechanism to better capture the complexity of access (Dixon-Woods, Mary et al., 2006). Here the emphasis is on the interaction between individuals, professionals and systems and how these dynamic relationships are negotiated and navigated. This concept of Candidacy was the product of an interpretive synthesis of literature relating to healthcare access among socially disadvantaged groups. Healthcare systems are viewed as imposing a series of demands that some people struggle to meet. Candidacy is characterised as a process punctuated by various demands and tasks, which begins with identification of the need for professional advice or healthcare and culminates in adjudication from health professionals.

For many the process is far from smooth and is beset with barriers that compromise candidacy. Barriers are not confined to socially disadvantaged groups. For instance, other researchers have extended Dixon-Woods' concept and adopted the Candidacy lens when exploring healthcare access across a range of social groups (Hunter et al., 2013; Klassen et al., 2008; Koehn, 2009; Kovandzic et al., 2011; Mackenzie et al., 2013; Purcell et al., 2014) and propose additional dimensions (race,

gender, symptom-type), often alongside social disadvantage, that similarly impinge on the Candidacy process.

Our aim in this paper is to propose a further dimension – illness identity – that extends the Candidacy framework. We argue that illness identity is central to the way in which Candidacy is identified, negotiated and maintained and that the relative ‘smoothness’ of the Candidacy process is contingent on the illness type and the way in which that illness is collectively understood. Our contention is that illness identity at the level of cultural understanding seeps into healthcare systems and ultimately impacts (Good, 1994) on the patient experience at the point of delivery. We draw on accounts from colorectal cancer and heart failure patients to illustrate our argument.

### **Illness identities**

Cancer and heart disease are both described and recognised as chronic illnesses, which according to the World Health Organisation (WHO, 2002), are characterised by a shared need for on-going patient and professional management and co-ordination of health and social care and therefore:

*The demands on patients, families, and the health care system are similar, and, in fact, comparable management strategies are effective across all chronic conditions, making them seem much more alike than different. (WHO 2002)*

Although such thinking leans towards emphasising the similarities in the experience of chronic illness (and there are many), doing so risks obscuring illness specific understandings. By focusing on what makes illnesses ‘alike’, the ways in which individual illness identities are formed and reinforced may differ and are being eclipsed by the emphasis on chronicity. Bury (1988) highlighted the dual meanings of illness and suggested that illness is experienced not just in terms of its **consequence** but also in terms of its **significance** (Bury, 1988). Here **consequence** refers to the broad similarities, the daily lived experience of illness and its associated demands, including dealing and coping with symptoms. **Significance**, however, applies to the wider socio-cultural meaning attached to illness

and is an integral, but often overlooked, part of how diseases are perceived and experienced by individual patients and across social groups. Disease itself is socially and culturally constructed. Timmermans and Hass' (2008) case for the inclusion of the sociology of disease into the broader genre of sociology of health and illness is relevant here. A sociology of disease would examine the influence of the disease on the social world and how in turn this reflects back onto the health of patients. An exploration of 'the dialectic interaction between social life and specific diseases aiming to broadly examine whether and how social life matters for morbidity and mortality and vice versa' is encouraged (Timmermans & Haas, 2008).

Studies within the sociology of health and illness often seek to capture the experience of illness and focus on accounts of the consequences of illness or what it 'feels' like to live with and manage the demands of an illness. Examples across a wide range of illnesses are available and the successful healthtalk online has been prolific in this area (<http://www.healthtalk.org>). That the 'social' influences illness experience is well-recognised. Illness episodes are understood in the context of past experiences which facilitate expectations of current and future episodes (Chrisman & Kleinman, 1983; Kleinman, 1981; Lupton, 1994). These expectations are rooted in the social world, and supply us with an understanding of what we are experiencing: we each sift through a 'repertoire' of health beliefs to find apt descriptions of the sensations that are present. Repertoires are drawn from many levels including personal narratives, community level experience and the socio-cultural context, and together they are intertwined to form an idiosyncratic belief system (Chrisman, 1989). There are, however, fewer studies that emphasise the significance of illness and the impact this has on the wider patient experience.

Sontag's (1978) formative description of the relationship between illness and metaphor established a clear association between the experiences of cancer, the illness and its social representation. This in turn precipitated interest in the cultural symbolism of cancer. Historical studies confirm cancer's longstanding status as amongst the most feared of diseases (Aronowitz, 2001; Jasen, 2002;

Moscucci, 2009; Patterson, 1989), and cancer continues to maintain this status (CRUK, 2011).

However, over time the tone of cancer metaphors has changed. Now the emphasis is firmly on the positive fight against cancer, and both the lay public and health professionals adhere to this discourse (Hanne & Hawken, 2007). Conversely, coronary heart disease attracts little fear or dread in the public psyche and is more often seen to represent a good, and crucially, quick death (Emslie et al., 2001).

In reality, when heart disease or more specifically heart failure is described by patients and families, the picture is of an extreme condition with a range of negative consequences (Clark et al., 2012).

How and whether these cultural differences extend to differences in service provision is not widely researched. However, comparisons between end of life care for cancer and heart failure patients routinely show a disparity in the care received, in favour of cancer patients (Gott et al., 2008; Murray et al., 2005). Indeed, Gott and colleagues found that 'agonising and wasting cancer deaths' dominated heart failure patients' perceptions of dying which ultimately compromised the provision of palliative care in a range of non-cancer conditions (Gott et al., 2008).

### **Candidacy**

Patienthood brings demands that require considerable management and often signals the beginning of a long-standing relationship with healthcare professionals and systems. How that relationship is entered into, shaped and maintained is based on social interaction. As already noted, successfully attaining access to health care can prove challenging for patients and the complexity of access is well-established. Four decades ago Aday and Andersen (1974) highlighted various problems associated with conventional examinations of healthcare access: a) the lack of definition; b) the emphasis on availability and utilisation of services; and c) the focus on system entry rather than outcome (Aday & Andersen, 1974).

Yet distinguishing between 'having' and 'gaining' access alone does not solve the problem of access, which can be impeded by personal, social, organisational and structural factors (Gulliford et al., 2002). Simple supply and demand measures hide the interplay between access, inequity and inequalities and obscure the fact that 'gaining' access in itself is not sufficient evidence of needs being met. Instead a 'degree of fit' between services and patients is needed (Penchansky & Thomas, 1981), but requires patients to identify their needs appropriately. Patients' ability and indeed desire to do so is, however, contingent on perceptions of illness and past experience of health care (Mechanic, 1976). Access is multidimensional, but simply recognising this does not facilitate a deeper or more nuanced understanding of the problems of access.

Dixon-Woods and colleagues' critical interpretive synthesis of the literature on healthcare access for marginalised groups revisited the area of access and emphasised the difficulty of assuming that 'receipt' is an adequate response to 'need' (Dixon-Woods, M. et al., 2005; Dixon-Woods, et al., 2006). A blinkered focus on supply and demand approaches to access missed the essential component of social relationships and interactions between individuals and professionals that shape the access experience and provide a blueprint for subsequent exposures to healthcare. Candidacy is unique in drawing together help-seeking, structure and access. The concept of Candidacy is described as:

*The ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services.... [It] is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, including how 'cases' are constructed. Accomplishing access to healthcare requires considerable work on the part of users, and the amount, difficulty, and complexity of that work may operate as barriers to receipt of care. The social patterning of perceptions of health and health services, and a lack of alignment between the priorities and competencies of disadvantaged people and the organization of health services, conspire to create vulnerabilities (Dixon-Woods et al. 2006: 11)*



Dixon-Woods' Candidacy framework (adapted in Figure 1) outlines a trajectory punctuated by potential barriers. Individuals must first identify Candidacy by appropriately appraising symptoms, which in turn will inform their decisions around which services may meet their needs. Accessing the services requires navigation of the system. An awareness of the services on offer and the employment of practical resources, such as transport, or the need to contend with disruptions (e.g. time off work), are also required. Individuals' appearance at health services 'involves asserting their claim to candidacy' by providing an accurate description of the problem in order to justify its appropriateness to health professionals. Individuals then experience adjudications from health professionals who decide the suitability of the candidate and the problem. All such negotiations occur in a health care culture where some services are more permeable than others.

Figure 1: adaptation of Dixon-Woods' Candidacy model

A number of notable applications of Candidacy have been published (Hunter et al., 2013; Klassen et al., 2008; Koehn, 2009; Koehn et al., 2014; Kovandzic et al., 2011; Purcell et al., 2014) which extend the original model and contribute an additional dimension to the challenges of access. Both Koehn and Klassen emphasise the importance of social norms apparent in elder minority ethnic communities on the Candidacy process, and Klassen goes on to demonstrate that these, along with issues of racism and socio-economic disadvantage, construct a series of interrelated barriers to the enactment of Candidacy (Klassen et al., 2008; Koehn, 2009). Kovandzic's study of mental ill health and healthcare access illustrated that symptoms themselves together with socio-demographic factors conflate to punctuate the Candidacy process with additional illness related hurdles (Kovandzic et al., 2011).

## **Method**

### **The original data**

The data presented here are comprised of a series of anonymised transcripts from three studies carried out between 2006 and 2011.

The **Colorectal Cancer (CRC)** study (Browne et al., 2011; Gray et al., 2011) aimed to explore colorectal cancer patients' experiences of psychosocial problems and their management in primary and specialist care. Twenty four patients with a definitive diagnosis of colorectal cancer in three hospitals in the West of Scotland were interviewed immediately following diagnosis and 19 of those were interviewed again 12 months later. Participants were interviewed in their own homes and the interviews explored the roles of primary care and secondary care professionals, families and self-management. Ethical Approval and informed consent was given by the Multi-Centre Research Ethics Committee for Scotland, Committee A.

The **End stage heart failure (ESHF)** study (Browne et al., 2014) aimed to understand patient, carer and professional experiences of coping with end stage heart failure (ESHF) with a particular focus on the management of crises and unscheduled admissions but also addressing issues of prognostication and potential gaps in current service provision. Thirty patients with end stage heart failure and 20 of their carers were interviewed. Ethical approval, including informed consent for potential use of data in future research was obtained from the West of Scotland Research Ethics Committee.

The **Stable heart failure study (SHF)** aimed to uncover the work involved in living with heart failure. Thirty patients with heart failure were interviewed, recruited via the specialist nurse service in NHS Greater Glasgow and Clyde. Patients were asked about their experience of heart failure and in particular their strategies for self-management. Ethical approval, including informed consent for potential use of data in future research was obtained from the West of Scotland Research Ethics Committee.

Throughout the patient interviews, individuals offered retrospective narratives and stories about their interactions with health services, often providing a great deal of detail. Such stories are ideal

for an analysis of pre-diagnostic access to health services, but also, importantly, post-diagnosis, allowing a novel exploration of “in service” access, which we define as access following diagnosis which requires those with chronic illness to have successive access experiences.

While Dixon-Woods’ original concept of Candidacy can be applied to any encounter between patients and health care systems, the implicit emphasis within the model is the first or primary encounter with healthcare. The experience of access for patients with chronic illness travelling through systems and indeed managing illness is under-developed. Looking at our data through the prism of Candidacy allowed us to develop and extend the Candidacy model as the breadth of data lets us explore the relative influence of illness significance on Candidacy and on the patient experience of chronic illness.

### **Methodological considerations and Analysis**

As Irwin and colleagues (2012) note, secondary analysis of qualitative data has great promise but it is not without challenges (Irwin et al., 2012). Despite burgeoning work in the area there is some dispute about whether meaning can be derived from re-visiting or re-analysing qualitative data. At the heart of this disquiet is the acknowledgement that in qualitative research context is paramount and data generated are unique to specific research settings. Mauthner, Parry and Backett-Milburn (1998) urge caution when revisiting qualitative data and demonstrate that returning to their own data raised epistemological questions (Mauthner et al., 1998). In short, they argue that re-analysis fails to capture the original interpretation and reflexivity of the data and strays into ‘realist’ territory (Mauthner et al., 1998). Yet many difficulties associated with secondary analysis could equally apply to primary analysis (Hammersley, 2010).

In this analysis, the problematic issue of context was overcome by having the original researchers working with the re-analysis. The data were generated first in the CRC study and then in the ESHF

study by SB. Indeed, early observations on the different patient experiences provided impetus for the re-analysis. SM carried out the interviews and analysis amongst the SHF data set. In re-visiting the data across a series of data sets we conducted what Heaton (2008) refers to as an amplified analysis (Heaton, 2008), and indeed other applications of the Candidacy framework have also utilised secondary data (Koehn et al., 2014). Having team members who are familiar with all the data sets provided useful context but crucially no team member was familiar with all the data. Such a balance minimised the risk of losing context but facilitated critical enquiry (May et al., 2004).

One of the key concerns about secondary analysis is data fit (Irwin et al., 2012). Across the included data sets the interviews are essentially a series of stories of illness and patienthood, which hold rich descriptions of experience and access to health care from the appearance of symptoms through to diagnosis and care, and as such we believe that these data are well placed to inform this present study's objectives.

### **Selection of participants**

The original studies generated a total of 103 in-depth interview transcripts and the team had to arrive at a method for reducing the analytic task without compromising the rigour of analysis. We were aware that much of the data included narratives of access, and indeed, as we already noted some of those informal comparisons prompted to us to re-visit the data. We adopted a largely deductive approach (Irwin & Winterton, 2011) which began with each data set being read individually by team members (HF [DB], CRC [EC; SM], ESHF [SM]). Early discussions centred on the description of contrasts between pre- and post-diagnostic experiences. Thereafter, we purposively sampled ten transcripts from each data set to include those that provided both pre- and post-diagnostic accounts.

### **Participant Vulnerabilities**

It should be noted that although we have provided socio-demographic attributors to data extracts to provide information on age, gender and socio-economic status for readers, we did not account for such differences in the analysis. Given that the original Candidacy framework sought to demonstrate the vulnerabilities that health systems can create in the access process we recognise that such factors can add layers of vulnerability for patient groups. Yet, it is also worth stressing that across our data, colorectal cancer patients, when compared with heart failure patients, were more likely to live in areas of high socio-economic disadvantage, which we would expect to have a detrimental impact on securing and maintaining candidacy.

### **Analytic Process**

Drawing from the literature on Candidacy we developed an initial model that allowed us to consider Candidacy at key points in the illness journey. Figure 1 shows the patient journey and the points at which Candidacy is negotiated and re-negotiated. These *a priori* assumptions provided the basis for our analysis. Each selected set was analysed individually (HF [DB], CRC [EC; SM], ESHF [SB; SM]) and it became clear that there were pivotal points in the process: first, around the time of diagnosis, and again at the point of entry to secondary care. We then returned to the data and each dataset was subjected to additional thematically driven coding that focused on experiences of care and relationships with health professionals. Dixon-Woods' emphasis on Candidacy as the cyclical negotiation and re-negotiation between patients and health services allowed us to map our key themes to the stages of Candidacy process while remaining mindful of the centrality of the linear stages of the illness journey (diagnosis - treatment - management). The coding framework therefore progressed through an iterative process and emerged as a framework divided into two time periods – pre and post-diagnosis – each mapped on to the stages of candidacy.

### **Findings**

The initial phase of the Candidacy process, where individuals begin to identify their need for, and seek, medical intervention, was similar across the data sets. Essentially, the pre-diagnostic phase for both cancer and heart failure is comparable and though individual experiences are varied and nuanced the accounts describe a time where individuals' and health professionals' key activities are centred around a response to the **consequences** of illness. Much of this pre-diagnostic activity focuses on the interpretation of bodily sensations, the process of symptom recognition and journey to diagnosis. Thereafter, accounts begin to diverge and the point of diagnosis represents a critical juncture as the **significance** of illness (as described by Bury, 1988) emerges as an important influence on patient experience.

After diagnosis, the Candidacy process is smoothed for colorectal cancer patients and they discuss repeatedly the lengths that professionals go to, to ameliorate a trying and difficult time. This is not the picture portrayed by heart failure patients. Diagnosis of heart failure, if indeed the term is used by professionals and understood by patients (it is often not), marks the beginning of a challenging process characterised by uncertainty and fragmented care. What emerges is the tangible impact that illness category has on the ways in which patients receive treatment and access services. To illustrate this we present the findings as two distinct phases – pre- and post-diagnosis – though we recognise that experiences are unlikely to be uniformly linear.

### **Pre-diagnosis**

#### **Identification of Candidacy**

Identification of Candidacy often occurred in parallel with the process of symptom appraisal.

Symptom appraisal is commonly described as a process where bodily sensations gradually begin to be viewed as a deviation from the norm and begin to require attention. The initial response may simply be to think about the symptoms or feelings rather than seeking professional help. Across the three data sets patients describe attributing early symptoms to benign conditions, co-morbidities,

ageing or a combination of all three. Steadily participants began to reformulate these sensations as problems that required professional assistance.

Though not unusual for heart failure patients, the progressive nature of symptom appraisal was more commonly described by colorectal cancer patients. However, heart failure might also be diagnosed many years after a significant event, such as a myocardial infarction. The identification of Candidacy was, therefore, somewhat protracted for all patients, either because symptoms were atypical or could be explained easily as a benign condition. As a result many patients across the three studies did not appreciate the significance of these early symptoms though some re-evaluated these symptoms post-diagnosis:

*it was June, July last year that I really started to feel done in, absolutely no energy at all, you put a lot of that down to your age, you know, and how busy you've been at work and things like that but there was an underlying cause to it which I just didn't [did not] recognise at the time although hindsight's always twenty-twenty vision isn't it. I can see now that it was probably everything just working on me at the same time and that's where we are (CRC22, 55 Male SIMD2).*

***Navigation, appearing at services and adjudication.***

Following the identification of candidacy, Dixon-Woods and colleagues' process moves to 'navigation' which describes the work involved in decision-making and help-seeking. Navigation requires not only an understanding of the services available and their function but also the mobilisation of practical resources needed to appear at the service. After navigating the system, individuals attend the service and again draw on their capabilities to adequately assert their candidacy; their assertion is then 'adjudicated' by the relevant health professional. In the original Candidacy framework these components are presented as discrete stages, though Dixon-Woods and colleagues also emphasise candidacy's 'dynamic' and 'contingent' nature.

Our data holds accounts of often lengthy journeys to diagnosis where, following the identification of candidacy, participants' accounts describe an iterative process where boundaries between these component parts are hazy and indistinct. It is possible that this haziness is an idiosyncratic feature of these data given the substantive focus on events leading to diagnosis. Nevertheless, the accounts do exemplify the continuous negotiation and re-negotiation of Candidacy as characterised by Dixon-Woods et al.

Navigation was relatively straightforward for both colorectal cancer and heart failure patients. Consistent with gate-keeping healthcare systems, the first point of contact for the majority of participants across all three studies was general practice and primary care. Some with more severe or worrying symptoms also utilised Accident and Emergency (A&E), either as a first point of contact or in parallel with primary care. Participants then assert their Candidacy by describing their symptoms which are in turn evaluated by medical professionals. For a few participants, Candidacy for additional care and investigation was established almost immediately, as the following extract highlights:

*Give him his due, he knew right away there was something. So he told me he was going to send a letter to the [local hospital] and then they would get back to me. If they didn't get back to me within fourteen days to phone him up. But how and ever I got a letter to go the following week and then I got a phone call asking if I could go on the Saturday. So obviously I went on the Saturday and there was another three people in but when the Doctor actually did the bowel investigation he told me right away, he said to me he wanted me to stay behind. (CRC4,64, Female SIMD3)*

For most though the outcome of navigation-appearance varied and it was usual for participants to seek help from their general practitioner on a number of occasions and describe, as the following extract illustrates, a gradual mutual realisation that the original presenting problem was not routine:



*Well, I was attending my own doctor, for what he thought was a chest infection and I went back to the doctor... the doctor noticed the swelling on the ankles. What I had was when I was lying down at night there was a gurgling sound coming from my voice and when I was trying to breathe it was a gurgle, you know, I'm trying to think – it was so loud that I couldn't sleep. And, em, when he checked me, first he couldn't find anything on the chest but he thought maybe it was, a viral, a viral infection ...'I'm out of breath' I really, I said 'I'm absolutely knackered'..... Yes, that was part of it as well. Because I was never tired, I was always on the go and I was always doing things... So, em, the doctor, as I said, the doctor said 'right, okay, let's see your ankles' and of course I'm saying 'what the heck has my ankles got to do with the way I'm feeling?' You know. Not knowing at that time that there was a link. He said 'your ankles are pretty swollen, I'll give you water tablets' and of course when you start thinking about the gurgling noise coming from your chest, you say 'why is he giving me water tablets?' But, again, not noticing the sort of link there altogether at that time. (SHF23, 61 Male SIMD4)*

Less commonly, participants talked of health professionals' failure to meet their assertion of Candidacy in a manner which prompted any further action. Here, details of adjudication, the next stage in the Candidacy process, begin to emerge. In the following extract the participant tells of multiple visits to the general practitioner:

*So there's been many, many appointments kind of since December, you know, right through. At least a dozen times, I was there three times in the same week sometimes... Can't see past IBS as far as I'm concerned. (CRC19, 53, Female SIMD1)*

The participant then describes an escalation of symptoms which prompted a visit to Accident and Emergency:

*it was just a bit of tummy ache...[then] I had that rectal bleed...the rectal bleed was serious, I wasn't going to hang about anymore (CRC19, 53, Female SIMD1)*

This participant's account introduces an additional important aspect of the Candidacy framework. Central to navigation is the notion of permeable or porous services, categorised as those 'which require few qualifications of Candidacy to use them' and are comparatively easy to navigate and access. Within a universal health system, as in the United Kingdom, both general practices and Accident and Emergency departments (A&E) are thought to be the most permeable or porous because they are readily available and easily understood, i.e., it is clear that a visit to either will result in a consultation with a health professional.

As the above extract shows this patient began the process of navigation by presenting to one porous service – general practice – yet despite her best efforts to assert Candidacy the problem remained unresolved. The appearance of more serious symptoms then prompted a re-thinking of identification, the need to navigate the system again to present to Accident and Emergency, the most porous of services, which crucially offers a potential gateway to secondary care.

We would expect participants to present to the two most porous services, but our data lack detail on the practical experience of presentation. Within participants' accounts there is little information on the intricacies of navigation with regards to limited transportation, time pressures or financial barriers. The Candidacy framework was originally developed in the context of socio-economic disadvantage and more recent applications have extended the framework to demonstrate the importance of other factors, such as racism. We recognise that participants across our studies were unlikely to have uniform experiences of help-seeking and access and that some participants will have been more or less able to navigate the system and assert their candidacy, which would in turn have impacted on adjudication. In the following extract the participant describes her utilisation of an additional resource, the availability of finances, to 'go private' and therefore begin the navigation process afresh to assert Candidacy and gain access to specialist care:

*I went to her I think four times and she told me everything was okay [Doctor] 'Nothing to worry about. I'm not a bit worried about you', even when I told her that I had passed blood, what did she*

*think it was? And that's when I thought 'no I don't think this is right' and I had all the classic symptoms. (CRC8, 67 F SIMD 2)*

Given her continued discomfort with the doctor's inaction, the participant goes on to describe how she asserted her candidacy:

*I decided to go to the (private hospital) and em of course when you phone up they just ask which Surgeon you want or who you want, you know, when I told them that it was something to do with my bowel and I had no idea who to pick. So I picked a Mr X and I picked him for odd reasons, one he was at the local hospital so I thought at least he'll be handy, you know, if I have to keep going and the second was because he was slightly more expensive than the others so I thought that he might be the best (Laughs)*

Later in the interview the participant explains why she believes her Candidacy was compromised:

*I think it is it's because it's women who are, you know, not in the first flush of youth and I think they just think 'Oh a fusspot' I genuinely think that because I've had experience of it before with GPs. I think I told you about the one that I went to I wasn't feeling great I can't remember, was it my stomach yeah I think it was, and eh she wanted to take a blood test do you know I can't remember why I went to see her that's terrible. And when she took the blood test I said 'What's the blood test for?' she said 'I'm not going to tell you because you're such a nervous person' that's the truth... she was horrible. (CRC8, 67 F SIMD 2)*

While our data show that the experience of asserting Candidacy and becoming a 'warrantable' candidate for further investigation was not uniform, they also highlight that irrespective of illness identity the pre-diagnostic Candidacy process was analogous. However diagnosis marked a significant change in the experience of Candidacy and at this point illness identities begin to provide a structure to the continuation of the Candidacy framework in the context of specialist care.

### **Post-diagnosis**

Diagnosis marked a recalibration of the Candidacy process. Post-diagnostic variation between heart failure and colorectal cancer patients is notable and participants' descriptions of subsequent treatment and relationships with health care professionals differed greatly. What emerges from colorectal cancer patients' accounts is the depiction of a personalised model of care where patients established partnerships with health care professionals that continued throughout treatment and beyond. Conversely, heart failure patients describe the beginning of a process beset with difficulties underpinned by a lack of understanding of heart failure and a lack of transparency around prognosis. Their experience is characterised by poor communication and fragmented care.

### **Identification of candidacy**

Colorectal cancer patients typically recounted a diagnostic event. A cancer diagnosis is clear and unambiguous, and even where ambiguous terms, such as 'mass' were used, patients were keenly aware of their cancer and the potential implications of diagnosis. Heart failure patients, on the other hand, were often unaware of their diagnosis; the term 'heart failure' was rarely used explicitly. Such contrast is illustrated in the following extracts:

*He told me all about the cancer and how I'd need to get operated on and cut out and all the rest of it, you know, and showed me what would happen and everything and then I could have got it done before Christmas (CRC11, 48 Male SIMD5).*

*Things are, certain things are not explained to me, for example I didn't know I had heart failure until [heart failure specialist nurse] told me, I don't know how long I've had heart failure for (SHF10, 66, Male SIMD1).*

### **Navigation**

With diagnosis came treatment and the need for patients to navigate an array of new services and consider a range of treatment options. Unlike the pre-diagnostic experience of candidacy, where the onus of navigation is on patients, in the post-diagnostic phase at least some of the responsibility is

absorbed by the system, for example appointments are arranged rather than sought. Gaining access to information about the services represented a major navigation task for patients post-diagnosis, alongside the need to commit to attending a series of appointments.

Here, again, we see contrasting experiences across the data sets. While the majority of colorectal cancer patients, as well as a handful of heart failure patients, were assigned a specialist nurse, it was only for colorectal cancer patients that specialist nurses acted as navigators. Cancer patients were provided with telephone numbers and 'named' individuals to contact with questions, which was hugely appreciated and reassuring:

*...you do know that you can phone, you know, like I had phone numbers and so I was never really so worried because I knew I could always phone somebody if I was really, really worried about anything. And that you don't need to phone because you've got that in your head that you don't need tae [to] worry (CRC4, 64 Female SIMD3).*

For heart failure patients, getting information about their diagnosis was a more gradual process of realisation rather than the event described by cancer patients. Initially, following the onset of what were often referred to as 'heart problems', patients struggled to name their condition and few were aware of its prognostic implications. It was not unusual for patients to deduce their diagnosis from their medication, perhaps because of the experience of a relative or friend. Even with the input of a heart failure nurse, patients provided examples of care that was fragmented and lacked continuity, particularly in relation to the primary-secondary care interface. As the following extract sums up, the patient had to keep the professional abreast of developments and changes in her treatment plan because of poor communication between systems, and essentially had to act as navigator for both herself and her general practitioner:

*They communicated okay I think, but I think it's mostly, you know the internet there, you know. But I think there were times when there was, a bit of a lack of communication, you know. I would go speak*

*to my doctor and tell him I'm on such and such and he would say 'I've not had any word about that'. And that's part of the problem, you get a prescription which, or a pre-printed prescription, which has like your, for instance if I was on 4.5 mgs of Bisoprolol and they were putting it up to 7.5, often the liaison between the hospital or the heart failure people possibly and the doctors wasn't all that good (SHF23, 61 Female SIMD 4).*

### **Permeability of services**

We have extended the original use of permeability in the Candidacy model to include the description of timescales. When patients have gained access to and have a prolonged relationship to health services by virtue of their chronic illness, services could be regarded as permeable if they are appropriately responsive to patients' needs. Responsiveness is manifest in short timescales and easily accessible information. Heart failure patients' care and access to care was slow. One reported that it took two years to achieve the right balance with his medication. In secondary care they typically waited months between appointments, frequent emergency admissions were characterised by long, uncertain waits; in sharp contrast to the experiences of colorectal cancer patients, whose accounts demonstrate immediacy, thus making the service ultra-permeable:

*Yes I have [nurse's] telephone number from the hospital, which is direct telephone, and if she's not there, I left a message and she just gets in touch with me very quick and she tries just to sort out the problem because she gets in touch very quickly with the consultant, you know (CRC2, 50 Female SIMD1).*

Equally having ready access to healthcare professionals, both within primary and secondary care, illustrates the permeability of the service. Colorectal cancer patients were keenly aware of the significance of their illness and could, if necessary, foreground it and use it to their advantage. The following extract shows the very importance of the word 'cancer':

*That [cancer] gets me past you see, I'm not taking any messing now I'm not standing for. Here's me saying I'm not really very strong but if I want to see a Doctor, if I feel I need to see a Doctor and I've gone through all that in the past year then I will see one, you know. It's awful isn't it just mention the word cancer. (CRC19, 53 Female SIMD 1)*

Such unhindered relationships were not always enjoyed universally by heart failure patients who, far from receiving any special treatment, struggled to access health professionals:

*...receptionists seem to take the attitude they will decide if it's an issue or not and I think that these days shouldn't be happening. I think there should be something, surely in this day there should be a wee button on your, if you give your date of birth that comes up and says, 'okay Mrs X has heart failure plus COPD and asthma, try and fit her in'. (SHF24 62 Female SIMD 1)*

### **Asserting candidacy**

Continued access was not always straightforward. Again what emerges from patient accounts is a quite different experience for each patient group. As already noted, colorectal cancer was regarded as a 'door-opener', negating the need for patients to continually assert their candidacy. Colorectal cancer patients had unfettered access to both primary and secondary care but, crucially, this was unrelated to individual patient need. The provision of prognostic information was rare across data sets and health professionals seemed reluctant to be explicit about prognoses. Again, prognostic-themed discussions appeared to be more forthcoming for patients with colorectal cancer than for those with heart failure, as the following extract from a heart failure patient typifies:

*I think, it seems to me, not like cancer where they say you've got five months to live or you've got a year but nobody has said that. I wonder whether that is good strategy or what? I don't know but I really like answers (ESHF8, 76, Male SIMD4).*

Arguably asserting one's Candidacy is compromised if patients are unclear about what their diagnosis means and their prognostic situation. For colorectal cancer patients, at the point of

interview and early in the illness trajectory there is potential for cure or remission, although individuals are left with considerable uncertainty and the spectre of relapse. In heart failure the trajectory is invariably towards deterioration but this is not always reflected in patients' experience of care. Laying one's claim to Candidacy is made harder (or easier) by the illness itself, as the following extracts illustrate:

*[I]f you have a heart issue you have to be able to shout and speak for yourself and keep at somebody. Now I had to keep at them that whole time, 'can I see a doctor? Can somebody...?' And if you're not feeling well that's not what you want to be doing, you want to go in there and say 'okay, I'm in hospital, the nurses are working hard, the doctors are doing what they can – they're taking their tests and I'll wait and see.' You shouldn't have to be watching doctors go by and say 'maybe this doctor will give me, will listen to my chest, or maybe this doctor will help me' (SHF24, 64, Female SIMD1).*

*'It's treatable and curable and we'll do everything we can' and then the nurse took me through to her wee office and she said 'I'll arrange for scans' and she was telling me what was happening. I was taking it all in but I wasn't, you know, and eh then they followed it up and that was coming up for Easter weekend and the following Tuesday I had a CT Scan and an Ultrasound and I thought that was really quick and we began to worry 'well why is it so soon?' but the girl that did the Ultrasound said 'Well we give you this service because you're going to be treated and it's okay we don't know that there's anything terribly wrong but we must do this'. And it wasn't until it was a CT Scan they're looking for whether the cancer had spread to any other organs (CRC3, 70 Female SIMD5).*

### **Adjudication**

In the original Candidacy framework, (Dixon-Woods et al., 2006) the adjudication stage refers to the interaction that takes place in health care consultations. However, as we have already noted, the framework, albeit implicitly, better describes the pre-diagnostic phase of patient journeys. If,



however, patients have been through the initial process of identification, navigation, assertion and adjudication and reached the point of diagnosis, adjudication occurs again as patients enter specialist care. In this context we suggest that adjudication is influenced, not only on the characteristics of the patient but also, importantly, by the significance of the illness.

Colorectal cancer patient accounts detail relationships with health professionals that are accessible and equal, routinely facilitated by specialist nurses who in essence design individual care packages suited to individual needs. While some heart failure patients could access specialist nurses who often acted as conduits between secondary care specialists and patients, the input was less intense, more ad hoc and as one patient described, stopped unexpectedly and without notice. Moreover the onus was often on heart failure patients to act as conduits between secondary care and their GP.

## **Discussion**

Chronicity has altered the way in which both patients and professionals interact with illness (May, 2005) and though patients with chronic illness are frequent users of health services, the implications of chronicity for access are under-explored. We drew on three data sets to explore the patient experience of access in two chronic illnesses – heart failure and colorectal cancer. Our analyses, guided by the Candidacy framework, show that until the point of diagnosis, patient experiences of access in all three studies were similar.

Diagnosis marked a critical juncture for patient experience, and it is at this point, we illustrated, that the significance of illness begins to dominate and shape the post-diagnostic patient experience. Re-analysis of interview transcripts highlight that colorectal cancer patients receive quick, efficient and person-centred services that are responsive to individual patients' needs. Patients feel that they are recipients of optimal care. Heart failure patients describe quite a different experience, one in which information is frequently lacking, communication is poor (both with and between professionals),

there are often lengthy waits between appointments and, towards the end of life, a series of distressing emergency admissions for exacerbations. In short, care is fragmented.

Post diagnosis colorectal cancer patients are fully aware, not only of their diagnosis but also the likely prognostic implications of their cancer. Though doubtless a worrying time, colorectal patients worked in partnership with their care team and discussed treatment and management options.

What is apparent, though, is that little needs to be said, cancer is ubiquitously understood. Cancer is a disease that is universally feared but paradoxically experienced in the context of a hope narrative. Indeed the provision of palliative care across illnesses is shaped by the cancer experience (Gott et al., 2008). For heart failure patients, however, many were unaware of their diagnosis for some considerable time and few, even at the end of life, had ever discussed prognostic implications with a health professional, instead discovering the seriousness of their illness via personal research or accident.

This contrasting experience is important for our understanding of access. We illustrate that, when retrospectively discussing the process of help-seeking required to arrive at a diagnosis, each of the stages in the Candidacy framework are apparent but difficult to disentangle. Yet, there is a uniformity of experience, as general practitioners employ the 'watchful waiting' approach central to their gate-keeping function. We have also presented data that show that additional factors such as age or gender can impact on how professionals respond to and adjudicate asserted candidacy. However, it is in the realm of post-diagnosis that our data provide an additional important dimension to the Candidacy framework: illness identity.

We argue that post-diagnostic in-service access assumes a different emphasis and is less dependent on the patient-professional interaction than the significance of illness. Cancer has greater social significance than heart failure and therefore the patient experience is assumed to be better understood. The status of cancer as the most serious of serious illnesses facilitates the establishment

of a partnership relationship between patients and professionals. Such collective understanding aids the journey through the system.

We used and extended the Candidacy concept of access to guide our analysis because it usefully removes the conventional focus on utilisation and allows us to look more closely at the relationships contained within the process of access. Others have similarly extended the Candidacy model to incorporate additional dimensions, such as age, gender and ethnicity which coalesce to make the Candidacy process less smooth. Beyond socio-demographic characteristics, additional features such as symptoms can impede the Candidacy process. Our work demonstrates how the cultural representation and understanding of illness can also impact and shape the experience of healthcare and therefore the illness.

Our findings also contribute to our understanding of the cultural representation of illness. Though cancer continues to be identified as one of the most feared of diseases, the historic focus on the taboo of 'the Big C' appears to be waning. Cancer metaphors, we would argue, continue to shape the experience of the illness, but the positive personal fight now dominates the cancer rhetoric. The heroism apparent in the description of cancer patients noted by Seale (Seale, 2001, 2002) has become the norm in the cultural representation of cancer (Hanne & Hawken, 2007) and has influenced the way in which both patients and professionals react to a cancer diagnosis.

Colorectal cancer patients in our study were clear about the substance of their fight. Heart disease conversely draws little socio-cultural attention, and when it does it is strangely positive. Heart disease is often misconstrued/misinterpreted as a single heart attack and has been previously described as the favoured 'way to go'. Heart attacks are seen as fast and painless rather than the long, painful cancer experience (Emslie et al., 2001). Yet heart failure is a terminal illness and has been described as more 'malignant' than cancer (Stewart et al., 2001). This is not reflected either in the representation of heart disease or the way in which patients experience heart failure (Browne et al., 2014; Gallacher et al., 2011).

### *Strengths and limitations*

Our work has a number of strengths and limitations. We present a secondary analysis of qualitative data and the validity of such an approach has been questioned. Removing the data from the context in which they were generated is thought to strip the meaning and substance. However, we believe that by drawing on three rich data sets that held accounts of access but were not generated for that purpose adds strength to our work. We have presented an additional and new argument from the data rather than simply providing a new description.

Access is socially patterned and we are cognisant that a number of social and demographic factors can and do influence the access process, however we did not consider such factors in our analyses. Although these factors are likely to intersect to shape the access experience of the patients in our studies, adding dimensions such as socio-economic status and gender would introduce an additional complexity; our aim was to focus on the influence of illness identity.

Comparisons of the differences between cancer and heart disease are not new (Murray et al., 2005) and it is clear that heart failure patients continue to fare particularly poorly. Previous literature has suggested that differing illness trajectories and problems of prognostication may underpin differences in experience, though others have suggested that health service organisation may be an important explanatory factor (Browne et al., 2014). We argue that our collective understanding of the significance of illness impacts on the priority afforded to different illness categories and therefore directly influences the acceptance and the warrantability of candidacy.

### **Conclusions**

It is important that we do not underestimate the ways in which our shared understanding of the significance of illness influences patient experiences of care and, importantly, access to care. The person centred approach taken with colorectal cancer patients that emerged from our analyses is to

be applauded but needs to be extended to those with serious life limiting chronic illnesses, like heart failure. The fact that heart failure and colorectal cancer differ greatly in terms of disease trajectories (Murray et al., 2005), particularly in relation to prognostication, should not be viewed as an insurmountable barrier to providing a person-centred approach that is responsive and timely. Illness category should not be allowed to determine quality of care.

However, in order to achieve such a goal, policymakers, professionals, health care systems and voluntary organisations need to first acknowledge that bias exists depending on illness category. Raising awareness of the problem and taking practical steps to overcome inherent biases will need a multifaceted approach that will include: a) providing educational support for professionals to lessen the risk of inappropriate adjudication based on illness category; b) taking steps to improve public understanding of heart failure and other similarly serious chronic conditions, so that patients and their carers can be clear that their need for care is legitimate; and c) greater collaboration across sectors (health and social care/primary and secondary care) to address the fragmentation that makes services less accessible.

Modern health care systems are notoriously difficult to navigate (Mair and May 2014; May, Montori and Mair 2009) and we need to ensure greater efforts are made to signpost services and increase transparency about how to access services so that system level barriers are minimised. Most importantly, there needs to be a commitment to making holistic care the norm regardless of illness category.

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