



## 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.

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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 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

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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.

## 1. 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 Haas (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 and 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 and 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 (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 and 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).

## 2. 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 and 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 and Thomas, 1981), but requires patients to

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