

Cancer as a chronic illness? Reconsidering categorization and exploring experience

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This article explores the different ways that user experience is defined and conceptualized, and the various policy and professional contexts in which emphasis is placed on exploring users' views. We go on to examine the experience of cancer as a chronic illness and argue that, although there are common features in the experience of cancer and people with chronic illness, the differences are too significant and cancer should not be defined as a chronic condition. We conclude with a consideration of the methodological difficulties of documenting user experience and identify the need for further methodological development.

Keywords: chronic illness, patient experience, theory, impact of illness, lay expertise, quality of healthcare.

INTRODUCTION

The aim of this brief article is, first, to explore the different justifications for the importance and benefits of researching and documenting the experience of cancer and, second, to highlight the distinctiveness of the experience of cancer and commonalities with other chronic conditions. We conclude with some methodological reflections about the challenges to capturing users' experiences in a way that does justice to their multivalent nature and also allows valid analysis and the importance of such findings for both policy and practice.

WHY RESEARCH USER EXPERIENCE OF CANCER?

There is a growing appreciation of the relevance of evidence from the experience of illness for identifying and meeting the needs of those affected by cancer. Clearly, such evidence is based on the experience of patients but

must also incorporate the experiences of those who care for them as well as those who provide treatment, care and support. This broader definition of 'users' is necessary if we seek to capture the complexity of the relationships and interactions that are embedded in the experience of treatment and living with cancer. Similarly, we must distinguish between the public or citizen's perspective and the user's perspective (Calnan 1997). There are a four interrelated contexts in which the importance of considering user's experience has been identified.

The first of these is in the context of the quality of health care and ensuring that users' experiences of cancer contribute to the evaluation and development of services, which continues to be stressed, particularly by governments (see, for instance, UK House of Commons 1993). In Britain, the publication of the NHS Plan set a statutory duty for the NHS to involve and consult the public when planning or changing services. This was subsequently enshrined in The Health and Social Care Act 2001 and is a key aspect of The National Health Service Reform and Health Care Professions Act 2002. Patient experience and acceptability is arguably, along with clinical effectiveness, economic efficiency and equity, an outcome measure that should be used to evaluate the quality of the health care. Alternatively, patient experience has been presented in terms of the process of care and is linked to

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outcomes, for instance the way in which user evaluates their health care may be associated with outcomes such as health status and quality of life.

A second context relates to the impact of increased longevity and the demographic transition, which has led to the growth in the burden of chronic illness and disability. Chronic illness necessitates the and their carers engaging in self-management, and this philosophy is promoted in recent UK government policy (Department of Health 1999, 2000a, b, 2001). However, with the decline in the length of hospital in-patient stays, there has been an increase in the emphasis on self-management for more acute conditions and the involvement of the patient in treatment planning.

The third context in which user experience has been emphasized is in relation to ethical concerns to inform patients about their treatment and the risks involved. More recently, this has been extended to the opportunity for patients to be actively involved in decisions about their care (Department of Health 2000a, b). The locus of control in a clinical encounter is important as it has a direct bearing on patients' relationships with their physicians (Benbassat *et al.* 1998; Ruston *et al.* 1999) and greater patient participation may limit psychological morbidity (Fallowfield *et al.* 1994; Davison & Degner 1997). But not all patients wish to make decisions, and variation relates, in part, to condition (Beaver *et al.* 2000). However, this concern for shared decision-making could also be seen as driven by political agendas promoting clinical governance and professional accountability to managers and can be seen as politically expedient as they can serve to legitimate decisions (Entwistle *et al.* 1998).

Fourth, and clearly connected to the previous context, professional ideology or values, particularly in some branches of medicine such as general practice, have emphasized the importance of holistic or biographical care (Fairhurst & May 2001) and increasingly embraces the treatment of patients through complementary therapy. Such approaches must implicitly take account of users' views even though the interpretation of experience is mediated by professional agendas (Holden *et al.* 2002). Pressure from policy makers is likely to force health providers increasingly to take explicitly account of users' views and experiences in the organization of their services.

Each of these contexts is relevant to the study of chronic illness (Cheah & Heng 2001). The context and perspectives portrayed in the above relate to top-down initiatives and do not take into account the so-called consumer movement and its impact. In the context of chronic illness, this relates to the emergence of self-help groups,

which act as advocates for disempowered users sometimes challenging professional models of care.

CANCER AS CHRONIC ILLNESS?

It is only recently that cancer has been categorized as a chronic illness, and such labels appear to have been exported from the United States. Like other chronic illness, it is argued that cancer can be disabling, cause intense pain, cause embarrassment and be stigmatizing (MacDonald *et al.* 1984; Koller *et al.* 1996; Department of Health 2001).

The definition of cancer as a chronic illness has some significant consequences for the role of patient and carer. The implication has been that people with cancer, like individuals with other chronic illnesses, are so-called experts in their own condition. Their knowledge is based on the constant burden of their illness that they have to continually manage in their everyday lives. For example, as Holman & Lorig (2000: 26) state 'When acute disease was the primary cause of illness, patients were generally inexperienced and passive recipients of medical care. Now that chronic illness has become the principal medical problem, the patient must become a co-partner in the process'. The recognition of this expertise, based on user experience, should change the process of treatment decision-making and could change the outcome (Sainio *et al.* 2001). This may be exacerbated by the 'claimed' general decline in public trust about medicine, and that trust and faith now must be earned and cannot be taken for granted (Haug 1988; Annandale 1998) However, this transformation of the diagnostic and treatment process depends on whether the clinician recognizes, and is sensitive to, the position of the patient and, second, whether the patient wishes, or is able, to exercise an influence.

The recognition and acceptance of patient expertise and a willingness to share decision-making by health care professionals would not eliminate underlying inequalities. There are, as with other areas of health and illness, marked occupational and gender inequalities in chronic illness, for example significantly more men report a long-standing illness than their professional male counterparts (46% versus 40%) but this occupational difference is more significant for women (49% versus 38%) (Erens & Primatesta 1999). The lack of resources such as finance, time and energy are associated with deprivation and inequality and clearly have an impact on the experience of the user, and this is exacerbated by the shift to self-management and social care in the NHS.

As with other chronic illnesses, the role of informal care is central to the experience of people with cancer and is, as

with other conditions, gender biased, with carers predominantly being women. However, what appears to be unique to cancer is the central role of the voluntary sector in the provision of information, support and services, for instance Macmillan nurses and Cancer BACUP information leaflets. This changes the relationship between the person with cancer and the health professionals providing their treatment as, increasingly, care is based on informal sources rather than overseen or provided by the NHS. Hospices provide a classic example as only a minority of their funding is derived from the public sector and they are dependent on charitable donations for the funding of core services like buildings and staff. The centrality of the voluntary sector in cancer care contrasts with the minimal role played by the private sector.

There are other characteristics of cancer that appear to distinguish it from most other chronic illnesses. First, cancer is not an illness but rather a categorization, at the cellular level, of a characteristic uncontrolled replication. Thus, cancer covers a range of different diseases that exhibit this similarity but are distinctive in terms of incidence, mortality and forms of treatment, for instance the treatment of childhood leukaemia is markedly different from that of adult leukaemia. Although such collective identification of illness is apparent in chronic illnesses such as schizophrenia, most are far more unique and clearly defined. We should also note that some cancers are also distinct from chronic illnesses as they, from a medical perspective, can be 'cured'.

Second, the complexity of cancer treatment, involving multiple medical disciplines (histopathology, oncology, surgery, radiotherapy, palliative and pain care, occupational, physical, and for some, speech, therapy) contrasts with the majority of chronic illnesses such as arthritis, diabetes, asthma, back pain, epilepsy, multiple sclerosis and heart failure. Similarly, these complex multidisciplinary treatments are provided in different sites and include specialist and general as well as in-patient and out-patient facilities.

Although people with cancer do experience their illness at certain points as chronic, these points are interspersed with acute episodes requiring multiple intensive interventions. Although the same could be said of other chronic illnesses, this raises the issue of the adequacy of the medicalized term 'chronic'. It can be argued that many chronic illnesses also have acute episodes but the consistency of the pathway in the treatment of cancer contrasts with that of most chronic illnesses. The initial diagnosis of cancer is clearly acute and yields a speedy and often fast-tracked response, and this contrasts with the typical response to a diagnosis of chronic illness, which may emerge over time

and rarely leads a speedy referral for expert evaluation and treatment. It is the repetition of these two categories of illness, acute and chronic, and the consequent and repeated shift in individual patient's self-perception that may make the labelling of cancer as 'chronic' inappropriate. The portrayal of the patient as both passive and dependent as well as active and independent is evident in the career of the person with cancer. Certainly, there is little scope for self-management during acute phases of cancer and the return to a chronic situation remains tinged with uncertainty and the scope for managing their situation.

There are at least two other ways in which cancer can be distinguished from other chronic illnesses. The first of these is the meaning of cancer for the public as a whole. The association of cancer with mortality means that a newly diagnosed patient often feels that they have been given a death sentence. This certainly results in biographical disruption (Bury 1983, 1988) but typically far more extensively than in classic chronic illnesses. That is, being diagnosed with cancer, for many, provides a justification for radically transforming their lives seeking to achieve their lifelong ambitions in what appears to be a significantly truncated existence (Barley *et al.* 1999). This has consequences for all those around them and is exacerbated by the reaction of others to the pollution of cancer and its inevitable association with imminent mortality.

The sense of pollution is both an internally felt experience of the cancer eating up the inside of the individual but also the stigma that marks out the individual from others (Goffman 1963). This stigmatization results in the loss of friendships and often the erection of barriers between the patient and their close family or the retreat into the discussion of everything but cancer isolates the individual from their social context (Grahn & Danielson 1996). The social response to the stigma of cancer, associated with a fear of infection and death, is different from that associated with other chronic illnesses and disability, which tends to be characterized by a sense of embarrassment.

Cancer has a high public and media profile fanned by moral panics over the risk of cancer from multiple environmental, behavioural and food sources previously regarded as safe, for instance saccharine, nuclear power and benzene. Similarly, the interest in heroic and tragic tales of cancer sufferers either 'beating the odds' or succumbing to the illness leaving a broken and destitute home is constantly reinforced in television, newspapers and magazines (Seale 2001). Such media accounts also fuel debates about health care resourcing and the funding of cancer services. In particular, the emphasis on breast cancer is disproportionate to either the incidence or mortality of the condition and yet is promoted as far more disruptive

and challenging than other forms of cancer (Browne 2001). It could also influence the nature of the doctor-patient encounter in that women with suspected breast cancer may be more assertive than those with other forms of cancer. This results in more vocal and effective charity and agenda-setting campaigns and arguably undermines the opportunities for similar action to meet other cancer needs. This high profile inflates the public perception of risk and informs and reinforces the stigmatization of cancer. However, it is difficult to judge whether lay ideas about cancer causation have taken on these environmental or behavioural explanations or whether they still rely on types of explanations centred on inherited factors. Certainly, it has been argued in the past that what characterized cancer was the uncertainty and mystery that shrouded its onset (Calnan 1987).

ELICITING USER EXPERIENCES: METHODOLOGICAL CONSIDERATIONS

It is clear that the need to take into account users' experience of illness and health care has become increasingly important. This has led to debates about the most appropriate way of documenting users' experience. A managerialist agenda spawned a plethora of patient satisfaction studies using standardized questionnaires. Equally, complaints were seized upon as a mechanism for highlighting users' views on quality of care. Both approaches have been shown to have major limitations, not least their insensitivity to the way users evaluate their care (Fitzpatrick & Hopkins 1993; Mulcahy & Tritter 1998).

This led to two developments, both of which involved qualitative methods. One of these suggested that qualitative methods such as informal face-to-face interviews was the most appropriate way of eliciting users' views, as they allowed users to set the agenda comment on both positive and negative aspects as well as contextualizing their experience (Williams & Calnan 1996; Ruston *et al.* 1999). The second approach suggested that qualitative methods could act as complements to quantitative methods, acting either as precursors to surveys, thus attempting to make a survey questionnaire more sensitive, or as a follow-up to explain the meaning of relationships found in survey data. One example of this latter approach is the use of the QUOTE instrument to measure user views about quality of care for a range of different services (Calnan *et al.* 2001). This instrument is made up of a set of core questions that are generic and a further set of questions that are specific to the service being studied. The latter questions are derived from focus groups with users of that particular service.

These different methodological approaches have implications for policy. The dominance of the positivist paradigm in the thinking of doctors, health service managers and policy makers clearly favours statistical evidence. The justification for qualitative methods (focus groups, face-to-face interviews) is that these techniques ensure the voice and empowerment of marginalized groups, or at least is an attempt to respond to inherent power differences and the democratic deficit (Oakley 2000). However, there are clear differences in participation rates that relate to underlying demographic, socioeconomic and disease-specific characteristics.

CONCLUSIONS

User experience of illness is increasingly important in the health policy agenda. We have suggested ways in which the conceptualization of user experience incorporates a number of different but interconnected aspects. The overlap between both the definitions of user and experience is complicated by ways in which such evidence may be used to justify frequently highly politicized reforms of policy and practice.

Despite the current high public and political profile of user experience, little attention has been paid to methodological developments that can help to explicate the variations in experience between different categories of users and between those affected by different kinds of cancer. More research is needed to help us to understand the tensions between the acute and chronic aspects of cancer and commonalities between some users of cancer services and users of other kinds of health services. Research that elaborates the particular features of cancer must be based on greater attention to the experience of those touched by the condition.

Cancer and the user experience, despite having aspects in common with other chronic illnesses, is distinctive. The categorization of cancer as a chronic illness might do a disservice to those affected by the illness and fails to take account of the non-chronic aspects of cancer and potentially to discount the ways these impact on the lives of different types of users.

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