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Recent UK government initiatives aim to increase user involvement in the National Health Service [NHS] in two ways: by encouraging service users to take an active role in making decisions about their own care; and by establishing opportunities for wider public participation in service development. The purpose of this study was to examine how UK cancer service users understand and relate to the concept of user involvement. The data were collected through in-depth interviews, which were analysed for content according to the principles of grounded theory. The results highlight the role of information and communication in effective user involvement. Perhaps more importantly, this study suggests that the concept of user involvement is unclear to many cancer service users. This paper argues the need for increased awareness and understanding of what user involvement is and how it can work.

Keywords: user involvement, cancer care, communication, information, decisions.

INTRODUCTION

The right of service users and the wider public to be involved in the planning and delivery of health care is recognized and promoted by international organizations [WHO 1978] and by most European governments. A review of the literature in English reveals little evidence of evaluation of how user involvement works in practice across Europe. In the UK user involvement is at a relatively advanced level in policy terms [Department of Health 2000a] and has an increasingly high profile in health services policy. Indeed, it is one of the core principles of the new National Health Service [NHS] plan: ‘The NHS will shape its services around the needs and preferences of individual patients, their families and their carers’. [Department of Health 2000b, p 7]. This paper examines user involvement in the UK context by looking at the forms which user involvement can take and some of the elements that are necessary for it to take place effectively. We explore the ways in which cancer service users from one cancer network in south-west England relate to the concept of user involvement, as evidenced by a series of in-depth interviews.
BACKGROUND

Cancer services have been specifically identified as an area of health services that should be developed in a patient-centred manner: ‘The development of cancer services should be patient centred and should take account of patients’, families’ and carers’ views and preferences as well as those of professionals involved in cancer care.’ (Department of Health 1995, p. 6). Within this aim lies the desire to promote user involvement at two levels: firstly, by enabling patients and carers to take part in decisions affecting their own care; and secondly, by encouraging greater public involvement in the strategic planning and evaluation of health care services.

Despite widespread agreement with the principles of public participation in health service planning, it has proved difficult to develop effective ways of achieving this as a result of a number of complex issues, including those of power and representation (McDonald 1998). National Health Service reforms emphasize the role of the public as consumers of health care services in purchasing decisions (Department of Health 1999, 2000b), although traditionally this has been mediated through Community Health Councils (Department of Health 1990). A range of methods have been employed to encourage wider public participation in health service development and planning including citizens juries, health panels, focus groups, questionnaire surveys, interviews and complaints procedures. It has been suggested that many of these structures have so far failed to produce real change, concentrating as they do more on consultation than active involvement (Pollitt 1989; Peckham 1992). The government has recently announced the introduction of statutory Patients’ Forums and the Commission for Patient and Public Involvement in Health (Department of Health 2002). A report on the National User Involvement Project (Lindow 1999) concluded that health service users were typically not being involved in commissioning decisions. Factors that have been identified as potential barriers to user involvement include a lack of the necessary consultation skills to incorporate users’ views (Neve 1996), professional resistance (Hoyes & Means 1994) and the one-off nature of many consultations (Jordan et al. 1998).

Shared decision making is increasingly promoted as the best model of treatment decision making in relation to health care, and there is evidence that this model can lead to benefits for both patient and doctor (Charles et al. 1997; Gattellari et al. 2001). As well as increasing user involvement in terms of the evaluation and development of health services, the government is also committed to offering real treatment options to patients (Department of Health 1998, 2000b), and yet, more patients in the UK feel excluded from decision making than elsewhere in Europe and USA (Kendall 2001). A review of US research studies concluded that patients want to be informed of treatment alternatives and to be involved in treatment decisions (Guadagnoli 1998), although it is important to recognize that not all patients who want information necessarily wish to take an active role in decision making (Leydon et al. 2000; Wenrich et al. 2001).

Much research suggests that cancer patients commonly fail to achieve their desired level of involvement in treatment decision making (Degner et al. 1997; Stevenson et al. 2000). An important element of this process is the extent to which service users can access the necessary information on which to base their decisions. A number of factors have been identified as barriers to this happening, including lack of time and encouragement by health care professionals and patient ignorance and shyness (Sainio et al. 2001). This paper focuses on two factors in relation to user involvement in cancer services: access to relevant information and effective patient-professional communication. We argue that these two factors are essential both to treatment related joint decision making and to wider public involvement in the evaluation and development of cancer services.

THE ROLE OF INFORMATION

There is a growing awareness of the importance of patient information to user involvement (Department of Health 2002). The complexity of health care systems can be a barrier to effective user involvement (Fallowfield et al. 1997; Wilson 1999), emphasizing the importance of providing accurate, reliable and understandable information (Sainio et al. 2001). A majority of patients express a desire to receive information from health care professionals (Mesters et al. 2001), particularly concerning medical/nursing matters and organizational structures/procedures (Eriksson & Lauri 2000). Cancer patients report high levels of dissatisfaction with the information provided to them (National Cancer Alliance 1996), as recognized by recommendations for national guidelines on information provision (Department of Health 1995).

Among the main reasons identified for inadequate information provision are lack of staff training, pressures on staff time and poor retention of information by patients (Mills & Sullivan 1999). The information needs of patients vary according to a number of factors including age, the seriousness of their illness (Small & Rhodes 1998), and stage of treatment (Rees & Bath 2001). Patients’ ability to assimilate information is also affected by the timing of
PATIENT–PROFESSIONAL COMMUNICATION

The making of treatment related decisions has been identified as one of the main purposes of doctor–patient communication (Ong et al. 1995) and the specialized nature of medical knowledge means that information provision is a crucial part of communication with patients (Gamble 1998). It has been calculated that a typical oncologist is likely to conduct up to 200 000 consultations during a 40-year career (Fallowfield & Jenkins 1999). This highlights the importance of communication skills to both the provision of effective care and the facilitation of user involvement.

Doctor–patient communication problems are particularly evident where patients are consulting about chronic physical problems (Barry et al. 2001), and the highly emotional nature of issues relating to cancer and its treatment can create a barrier to effective communication between patients and nurses (Kruijver et al. 2001). There is some evidence that patients are dissatisfied with much of their communication with doctors (Fallowfield 1998), often as a result of the perceived ineffectiveness of doctors’ communication skills (Ford et al. 1996; Wenrich et al. 2001). Another potential barrier to good patient–doctor communication is the unpreparedness of some health care professionals to contemplate sharing power and knowledge with their patients (Poulton 1999; Wilson 1999).

Effective user involvement depends on the provision of adequate resources. The lack of time and training available to clinicians to form partnerships with patients is a substantial barrier (Wilson 1999). Health care professionals themselves have recognized the need for increased focus on communication skills training (Dosanjh et al. 2001), while a Canadian study (Bakker et al. 2001) concluded that communication skills workshops do promote the professional skills which are valued and expected by women with breast cancer. Clinicians would benefit from training in working and communicating with all types of patients and working with groups of service users (Jordan et al. 1998). Similarly, patients also need support in playing a full part in consultations (Bottomley 1997; Taylor 2000).

METHODOLOGY

Data were generated by means of in-depth interviews with 36 cancer service users within one cancer network in south-west England. Interviews are acknowledged as an excellent method for eliciting patient accounts of their experience given the sensitivity of the topic (Entwistle et al. 2002). A face-to-face interview ensures confidentiality and that the account that is gathered is respondent-led rather than overly structured (Arksey & Knight 1999). Interviewees were recruited in four ways: from an Inter-Professional Cancer Education Course, from voluntary sector groups; through posters and leaflets in general practitioner surgeries; and from a hospital Prostate Cancer Clinic.

Following approval from eight local research ethics committees and one multicentre research ethics committee, semi-structured interviews were conducted according to a prepared schedule by four members of the research team between September 2000 and July 2001. The aim of the interviews was to explore knowledge, experience and importance of user involvement to people with cancer and their carers. The topics covered in the interview included: the meaning and personal understanding of user involvement, awareness of existing mechanisms for user involvement, experiences of user involvement (nature, extent, outcome, benefits, etc.), methods for involving users in developing cancer services, the extent of user involvement, measuring the success of user involvement. Interviewees were offered the choice of either their own home or Health Authority premises as a venue for the interviews, which took between 40 and 120 min and were tape recorded and transcribed verbatim.

The interview sample included 31 people who had cancer and five with carers of someone who had cancer (Table 1). Respondents covered a range of cancer types (including breast, prostate, tongue, bone, ovarian, bowel, liver and lung) and treatments (including radiotherapy, chemotherapy, surgery and hormone therapy). The interviewees comprised 18 men and 18 women, with ages ranging from 39 to 81 years. All but seven interviewees had some experience of user involvement, including questionnaire based service evaluation or feedback, voluntary sector activities, drug trials, making a complaint and fundraising. The sample was self-selected and was structured in relation to respondents’ experience of user involvement activities. We were particularly keen to explore the impact of user involvement and therefore over-selected for...
users who had some experience of involvement. We also sought to include the experiences of ethnic minority users, but with only limited success. In total we interviewed seven patients with no experience of user involvement, 24 with some experience, five carers and three ethnically distinct patients. This provided us with a broad understanding of the complex responses to the opportunities and experience of involvement by users.

Content analysis (Strauss 1987) was used to identify key themes using ATLAS.ti (version 4.1 Scientific Software Development, Berlin). Three interviews were independently reviewed by three members of the research team to develop an initial coding structure. The interviews were then analysed using this structure by the researcher who had conducted the majority of the interviews. This resulted in 18 initial themes that were reviewed and refined by four members of the project group. Further analysis was used to explore the relationships between the different themes and underlying demographic and cancer experience characteristics. This article draws primarily on four main themes: definition of user involvement, aims of user involvement, the role of health care professionals, and communication issues. Our approach sought to overcome some of the issues associated with intercoder reliability by drawing on the combined expertise of four members of the research team. While the analytical approach we adopted was not classically grounded theory (Glaser & Strauss 1967) it is based heavily on those principles which were adapted in the interests of team-based research and the application of computer aided qualitative data analysis.

As a multidisciplinary research team (including medical, nursing, sociological, psychological, managerial and scientific disciplines) our approach to and understanding of these data reflects a broad array of theoretical frameworks. Primarily sociological, medical and psychosocial concepts frame our work, although we draw heavily on organizational and managerial literatures and recognize the central importance of voluntary organizations in supporting and delivering cancer services in the UK. We sought to document users’ experiences from their own perspective and do not view them as any less authentic or valid than other constructions of the cancer experience (medical, nursing or psychological).

**FINDINGS**

**User involvement: beyond individual care**

User involvement for respondents in our study meant participating in decisions about treatment but, for a small minority, it also related to being involved in the evaluation and development of cancer services. When asked about the role of users in the development of cancer ser-
vices, interviewees gave a wide range of responses. Several found it difficult to answer to this question:

Well, to help people, help, eh, I don’t really know, no. [P26. Male cancer patient]

Q: The term user involvement, does that mean anything in particular to you? R: Well, not particularly. [P32. Male cancer patient]

Some related to a broad meaning of user involvement in terms of public involvement in planning:

The National Health need to get the opinions of people to improve services, by giving feedback and suggestions. [P22. Male cancer patient]

However, many respondents provided a more limited interpretation of user involvement in terms of patients taking part in decisions about their own care or being involved in drug trials:

Well I suppose being, eh, being associated with a decision making process on your treatment and your future. [P28. Male cancer patient]

There was also some interpretation of user involvement as simply a process of receiving information and support:

Having places that you can go to when you need help and advice and encouragement. [P23. Female cancer patient]

Service user involvement in decision making about their own care

The interviews provided considerable support for the idea that service users require appropriate information in order to take part in decisions about their own care:

Just the knowledge, it is so important before you make any decisions to have as much knowledge as possible because you can’t make a decision without it. [P3. Female cancer patient]

Some service users were clear that they did want to be involved in the decision-making process:

I’m the kind of person that needs to ask a lot of questions and needs to understand what’s going on and be given lots of information and also to take responsibility for what’s happening. [P4. Female cancer patient]

Others expressed a desire not to be involved at this level. There was evidence of a belief that they did not have the necessary skills to do so:

I’ve got no idea of anything medical. I’m absolutely raw and I would rely on that doctor and I would believe him, whatever he said, but to try and make my own mind up I couldn’t, I’m not that . . . I wouldn’t be able to do it. [P26. Female cancer patient]

. . . this person is now god and ‘my life is in your hands’, type of thing and ‘whatever you say I will just do’, and you just don’t question it. [P3. Female cancer patient]

There were examples of service users feeling that their desire to be involved in the decision-making process was accepted by health care professionals:

But sometimes I would decide no, I don’t need that. You know, I am not taking it and they respected my decision and it was great. They were super, they were really super. [P4. Female cancer patient]

However, a greater number of service users felt that no opportunity to take part in treatment decisions was offered:

I didn’t realise that there could be a choice when I had my treatment. I was literally just told what I would have, and I went along with it. [P23. Female cancer patient]

The role of the service user’s relationship with health care professionals

Several interviewees indicated that communication with professionals was an important factor in the encouragement of user involvement in health care services. There was evidence that the development of a good patient–doctor relationship can encourage service users to ask for information and discuss options:

I’m lucky’cos I’ve got, I think I’ve got a good rapport with him, I think. I can ask him anything. [P5. Female cancer patient]

Many of the experiences reported by service users suggested that health care professionals didn’t always welcome their attempts to be involved:

It was almost as if I’d just called him a complete and utter . . . because his face, he sort of looked at me as if to say who do you think you’re talking to. You know, and I, I felt like I was a naughty schoolboy. [P19. Male cancer patient]

One member of a support group felt that professional attitudes created a real barrier to user involvement:
We really thought that, Oh god, are we a threat to these people? Of course we are not. We didn’t get a lot of co-operation. [P28. Female cancer patient]

Some interviewees indicated that they did not want to play an active role and were happier to leave decisions in the hands of the health care professionals caring for them:

it all comes back to the fact that I don’t want to know anything, there’s nothing I want to know, I’m quite happy with my situation. [P27. Male cancer patient]

For those who may have wanted to be more involved in decisions about their own care there was evidence of a common perception that health care professionals had insufficient time:

‘I can’t come to Mr . . . and say I’ve got a load of questions I want to ask you because he’s a busy man isn’t he? [P27. Male cancer patient]

Desire for information

A large majority of the service users interviewed expressed a strong desire for information about cancer, cancer services and their own treatment:

Just the knowledge, it is so important before you make any decisions to have as much knowledge as possible because you can’t make a decision without it. [P4. Female cancer patient]

The sources of information varied and patients accessed both those made available by the hospital and a range of outside sources:

The cancer information centre, that’s brilliant now, the way it’s open plan and it’s open all the time. [P5. Female cancer patient]

Having been told I had, I did have cancer, I then went on the internet and I bought books and I rang up drug companies and I spoke to charities. I just wanted to find out as much as I can, I’ve always been that way. [P5. Female cancer patient]

For many respondents the doctor was the key source of information, but there were examples of other professionals who took on this role:

Sometimes you find the nursing staff weren’t quite sure about something but they would go away and ask, so that’s good, yeah that was good.

While some interviewees were satisfied with the information they had received, the majority reported that they had not received sufficient information, particularly about their own illness, different treatment options and possible side effects:

I was just told, I was told that I would have chemotherapy and radiotherapy, um, I was actually given very little information about what they had found. [P23. Female cancer patient]

One thing that . . . would have been useful, I would have appreciated . . . Would have been if I had been told the long-term affects of the treatment. [P12. Female cancer patient]

There was also a feeling that individuals were not always given information when they wanted it, but rather at a time to suit the organizational structures: Information seemed to be necessary for people who participate in decision making and often needed to be provided at particular points during treatment. At the time of diagnosis appeared to be one point at which service users found it difficult to assimilate information, and this had implications for their opportunity to participate in decisions about their treatment:

the consultant will say to you, right, would you like to ask me any questions? and you’re sort of thinking I’ve got cancer. I can’t think of anything now because I’ve got cancer and so the mind’s wiped everything off. [P18. Female cancer patient]

DISCUSSION

The responses of our interviewees support earlier findings that the majority of health service users want to receive information about cancer services and treatment options [Mesters et al. 2001]. The current study extends this finding more specifically to the area of cancer services. However, the evidence also demonstrates the complex nature of information provision and use. A lack of information about cancer services in general, and treatment options in particular, appeared to be a barrier to service user involvement in treatment related decisions. The timing of information provision is also an important issue, with service users expressing a desire for flexible access to information rather than having to fit in with organizational structures and timetables. This study indicates that the information needs of cancer service users differ widely, supporting calls for more flexible assessment and monitoring of service users’ informational requirements [Leydon et al. 2000; Sainio et al. 2001].

Respondents were evenly divided between those who did and did not want to be involved in making decisions
about their own care. Some had accepted the opportunity to take part in treatment decisions, but a greater number felt that no such opportunity had been given to them. As a result, some service users had felt the need to insist on the ‘right’ of involvement. The importance of communication with health care professionals, as identified in earlier work [Ong et al. 1995], was confirmed by the current study and related specifically to cancer services. Both the perceived resistance of professionals to user empowerment and the continued prevalence of the traditional paternalistic patient–doctor relationship appeared to act as barriers to involvement for many service users. It is interesting to note that despite vigorous policy support for user involvement there appeared to be an overall lack of any structure within which it can take place. This meant that the attitude of individual professionals towards user involvement was often crucial:

He as an individual twigged it but I think, you know, structurally they don’t seem to be anyway to have an input. [P7. Female cancer patient]

This study has identified a range of factors that can influence the extent to which cancer service users are encouraged or discouraged from being involved in service development and delivery. These include better access to information, more opportunities to take part in treatment decisions and improved communication with health care professionals. Perhaps more importantly, this study suggests that the concept of user involvement is an alien one to a significant proportion of cancer service users. Among those who did provide a clear definition, the majority felt that it meant patients and their carers taking part in making decisions about their own care. If the government is to achieve its wider aim of increasing public participation in strategic health care planning, there will need to be much greater awareness on the part of patients, the wider public and health care professionals as to how user involvement works and the development of more accessible systems within which it can occur.

REFERENCES


