

User involvement in palliative care: motivational factors for service users and professionals

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Background: Few studies shed light on what motivates or discourages patients, carers and professionals for participating in user involvement activities.

Aim: To identify motivational factors that affect the engagement of service users and professionals with user-involvement activities.

Methods: As part of a larger scoping study of user involvement in palliative care, 51 semistructured interviews were conducted with service users, palliative care professionals and experts to explore experiences of user-involvement initiatives. Four user-involvement programmes were also observed. Data were analysed using a thematic analysis technique. A subsequent consultation meeting with 48 service users and professionals discussed the preliminary findings.

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Results: User involvement has been predominantly developed through a 'top-down' professional agenda. A few highly motivated individuals, both service users and palliative care professionals, are extremely influential in starting and maintaining user involvement. Reported benefits include personal satisfaction and status but barriers are tokenism and time pressures.

Keywords: Palliative care, user involvement, patients and carers, health professionals.

Healthcare services are becoming less medically led and paternalistic across most European countries. New notions of citizens' rights and democracy within the European Union, central and local government, mean that there has been a shift in the relationship between patients and families (called service users) and people who provide services. User involvement is widely promoted within British and European health and social care policies as an effective means of developing patient-centred services. However, many health providers in palliative care only began seeking the views of patients or trying to involve them in developing services relatively recently (1). In the UK, the *Health and Social Care Act* (2) placed a duty on all NHS trusts and strategic health authorities to involve and consult with service users and the public about all aspects of service provision and service development. This is firmly reinforced by the supportive and palliative care guidance issued by the UK National Institute for Clinical Excellence (3).

Drawing upon an analysis of NHS structures (4) has argued that the emergence of a user voice in health service decision making can be traced to organisational changes and to new conceptualisations of citizenship in the UK. Shifts in the engagement of NHS institutions with service users can be characterised in three periods of development (4):

1. 1948 to 1989 – the NHS was based on geographical regions led through centralised top-down directives. The structures were hierarchical, service planning and care provision paternalistic.
2. 1989 – the introduction of the market economy positioned patients as consumers of care who could make

choices. However, choices were commonly the prerogative of GP fund holders.

3. 1997 – ‘New’ Labour took power which has seen a change of rhetoric with a newly developing notion of citizenship. The public are positioned as active citizens with rights and responsibilities, including the shaping of health and welfare services.

Listening to local patients’ voices and working in partnership with advocacy and support groups has a long history in areas such as the disability rights movement, mental health services, learning disability and maternity care (5,6). However, user involvement in services for people with physical health problems have been slower to emerge and the development of user involvement in palliative care remains relatively new (7,8). Although many palliative care services, especially hospices, have historically developed out of the wishes of local communities to improve end-of-life care, actively involving service users in the development of these services has been seen as problematic (9).

A systematic review of user involvement in general healthcare found little high-quality evidence about the benefits of involving patients in service development decisions (10). Most of the reviewed literature was based on case study designs and reflected the opinions of project managers. Interestingly, the review did not include patients’ informal caregivers. This was a major failing because patients, especially those with chronic conditions or disabilities, may be heavily reliant on the care provided by friends and relatives. The reliance on articulate patients in much of the literature on user involvement, and the lack of the carers’ voice, is problematic and reflects wider difficulties with the conceptualisation and implementation of user involvement. However, user involvement has been widely accepted as relatively easy to achieve and assumed to be beneficial.

The increasing literature on user involvement in palliative care is predominantly written by health and social care professionals providing descriptive accounts of involving service users in research (11), or of user involvement initiatives (see Table 1). Very little of it is written by service users themselves (12). There are particular problems in defining the remit of palliative care service users as it is likely to include those accessing general and specialist palliative care provision and to include patients with conditions

other than cancer (13). Moreover, it can not be assumed that patients who are nearing the end of life will necessarily see any benefits or purpose in participating in the development of services which they are unlikely to live long enough to partake of (14). However, there is evidence that some patients and carers gain benefits and are keen to be involved despite the challenges of their condition (7,15). Because user involvement is peppered with multiple assumptions and poorly defined, user involvement is interpreted differently and user involvement initiatives are formulated and carried out in multiple ways. The aim of the present study is to reach a deeper understanding of what motivates or discourages patients, carers and professionals for participating in user-involvement activities.

METHODS

The methodological design of this study was underpinned by a respect for, and valuing of, the multiple perspectives of patients, carers and health professionals as service users. User involvement was defined as the way in which people, who use health and social care services, are involved in making suggestions and taking decisions about how different services are run and developed.

The cross-sectional study design used face-to-face or telephone semistructured interviews with patients, carers and professionals to elicit their perceived motivational factors and barriers to user-involvement activities. This was followed up with a consultation meeting, hosted by St Christopher’s Hospice, during which preliminary findings were discussed. This was part of a larger scoping project conducted between 2004 and 2005 that aimed to shed light on user-involvement activities within palliative care in the UK (12). Ethical approval to conduct the research was obtained from an NHS Multicentre Research Ethics Committee.

Identification and recruitment of participants

In collaboration with the National Council for Palliative Care Steering Committee on User Involvement, we identified an initial purposeful sample of service users, professionals and academic experts who had expertise about user involvement in palliative care. Recruitment and subsequent data collection was undertaken by Anita Sargeant (AS), an experienced palliative care professional and researcher.

Table 1. Summary of problems with the user-involvement literature

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- Most published papers are descriptive accounts, with little rigorous evaluation
 - Little critical evaluation of the effectiveness of user involvement processes from the perspectives of patients, carers or services
 - User involvement has been accepted as a relatively unproblematic concept
 - User involvement is based on unclear assumptions
 - Some user involvement excludes carers and families
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Further recruitment of participants was undertaken using snowball sampling methods and identifying services with user involvement activities listed in the Hospice Information Directory (16). In total, 19 patients, 6 carers, 22 palliative care professionals and 4 academic experts were interviewed. Two people declined (one patient and one professional), giving a response rate of 96%.

Data collection

Patients, carers and professionals were invited to participate in either face-to-face interviews, usually conducted in their home or work place, or telephone interviews with the researcher (AS). AS identified herself to participants as a palliative care researcher from the University of Sheffield. This was to reduce the sense of compulsion that some patients and carers may feel to participate when approached by a health professional or care organisation. This approach was also taken with health professionals to attend to potential power dynamics at work within the interview process (17).

Interviews were recorded with their permission. Questions relating to motivation included:

1. *How did you become involved with user involvement?*
2. *What were your reasons for becoming involved?*
3. *Can you tell me about your experience of being involved?*
4. *What do you think may be the benefits/problems of involving palliative care service users?*

In addition, four visits to hospices enabled non-participant observation of user-involvement initiatives and assisted in the recruitment of participants. Field-notes were made following each visit.

Consultation meeting

Following the interviews and observations, a consultation meeting was held at St Christopher's Hospice in London to discuss the initial findings. A total of 48 participants attended including: 17 patients, 12 carers, 2 volunteers, 13 palliative care professionals, 4 academic experts, and included some people who had already contributed data. All patients had advanced conditions including cancer, heart disease, respiratory disease and neurological disease; of these, three also had learning disabilities. Four people failed to attend, giving a response rate of 92%. Overnight accommodation and transport expenses were provided. Participants were invited to: (i) discuss the preliminary study findings; and (ii) identify new ways of involving service users.

We used group work to explore these and other issues and 'post-it' notes were provided to enable participants to leave anonymous comments if they wished.

Data analysis

Interviews were transcribed verbatim and checked for accuracy. Each participant was given a code and identifying information was removed from each transcript to anonymise the data. The interview transcripts and field-notes from the observational visits were entered on to a QSR NVIVO database. The data were thematically analysed. This involved a detailed and careful reading of each transcript, identification and labelling of commonalities and differences related to the research aims (18). Initial codes were agreed by AS and SP, and AS applied them to the rest of the data. Subsequent data from the consensus meeting were added to the dataset and contributed to the analysis.

Excerpts of transcribed text have been included to illustrate certain themes discussed in this paper. These quotes were selected on the basis of two criteria. First, they illustrate the issue being discussed and second, an attempt was made to utilise a spread of participants rather than rely on a few individuals. After the excerpt from an interview, the participant is identified by their status as professional or service user.

RESULTS

The findings will focus on the self-reported motivational factors in terms of rewards and barriers for service users and palliative care professionals for engagement with user involvement.

Motivations for service users

The rewards

Service users predominantly became involved through invitations from health professionals rather than from their own initiative. Most had been invited to join regular local groups by professionals. Often those already attending local groups were then invited to join regional and national user groups. Some service users initially sought support from a locally advertised group and became more involved as time went on. Other service users had been involved in *ad hoc* consultation groups or research studies.

Service users reported being motivated by a desire to 'put something back' and to do something worthwhile that would make other people's illness experiences easier (see Table 2). There was a desire to help prevent other patients or carers going through some of the problems accessing information or services that they had experienced.

'When I was diagnosed then after a while I joined the MS Society, and I went along to – they have branch meetings, and I went to a branch meeting, and I got involved at branch level on the committee' (service user).

'What made you want to become involved?' (AS)>

Table 2. Motivational factors for service users

Rewards	
•	Putting something back
•	Feeling of empowerment
•	Sense of being valued for one's skills and knowledge
•	Improvement of services and facilities
Barriers	
•	Tokenism: the nominal 'user'
•	Lack of change or slowness of change
•	Timing/location of meetings
•	Dominance of professional agendas
•	Time commitment and expectations viewed as unpaid employees traditional values – not voicing opinions
•	Physical and mental debilitation due to advanced illness

'To put back, well yes, to help. Obviously my experience in teaching and taking early retirement due to ill-health, I felt that there's a job that needs to be done and maybe I have the skills to do it' (patient – service user).

People reported feeling empowered through their involvement. Those who had lost jobs through ill-health found attendance at regular user-involvement meetings enabled them to retain a sense of self-worth, and they could use, and be valued for, their skills and knowledge. For a few service users, regular user-involvement activities took the place of full-time employment and had similar responsibilities as a job. For most service users, a key driving factor was the opportunity to contribute to improvements in services. People cited examples of changes including: improving parking, increasing disabled access, developing information leaflets, and bringing about organisational changes by developing easily readable name badges for staff.

'So we decided whatever we do decide to tackle we're going to be able to tackle something that we will be able to, that will make a difference, that is actually viable, you know that will actually be something that we can achieve' (carer – service user).

The barriers

A number of barriers resulting in de-motivation were reported. Some service users cited feeling frustrated and disempowered because of perceived tokenism at local and national levels of the NHS. These service users felt that, in some circumstances, their contribution was not valued and was merely ticking a box on a check list or official record.

'I'm not sure that our voice was ever listened to ... we've had two people who have resigned from the group because of this frustration' (patient - service user).

The perceived dominance of the professional agenda and an apparent unwillingness of professionals to work in

partnership with patients meant that user-involvement meetings were held at the convenience of the palliative care service rather than the service users. Meetings were often held between 9am–5pm, Monday to Friday and, therefore, excluded many patients who worked or carers who needed support for their patient at home.

'I work full time, and all the meetings of course are during the daytime, so I can never go to any meetings' (service user who was both a patient and a carer).

There was also awareness by one service user that, as a group, they were not representative of the wider community or reaching groups from different ethnic backgrounds:

'we were talking about this because we're all, to put it bluntly, we're all white middle class and people with time' (patient – service user).

While some service users reported enjoying regular meetings, others described feeling like an unpaid worker, and that their involvement resulted in huge time commitments and work loads. This is particularly problematic for palliative care patients due to the progressive nature of their illnesses and disabilities.

'Some patients can't give a view because they're too poorly. Or some just didn't find it easy to tell us what their expectations were; it was kind of not within what they would expect as a culture within the health service' (palliative care professional).

Motivations for palliative care professionals

The rewards

Professionals reported a combination of personal and professional values acted as intrinsic motivators, as shown in Table 3. They described wanting to empower patients and carers and wishing to improve services to ensure they fitted with service-users preferences and needs. However, for most professionals, their initial motivation came from external service directives to implement user involvement as a mechanism to achieve integrated consultation and decision making in the NHS. Clinical governance directives were reported as a main driver.

'When I first started in my role as Head of Clinical Governance, we looked at all the aspects of clinical governance – user involvement was one of them. And at that time, my previous experience wasn't specifically in user involvement ... it was really important that we defined who was going to take on responsibility for the various aspects, and that's when it was agreed organisationally to have user involvement facilitator post, which I felt was very progressive way of taking it forward' (palliative care professional).

PROGRESS IN PALLIATIVE CARE

Table 3. Motivational factors for health and social care professionals

Rewards
<ul style="list-style-type: none">• Fits with personal and professional values• Improvement of services and facilities• Adherence to governmental directives and regulatory requirements• Service review ratings
Barriers
<ul style="list-style-type: none">• Seen as difficult and time-consuming• The power of professionals may be threatened• Seen as an 'add on' to current roles• Services may lack the will, resources or managerial processes to take ideas forward

'I see it as a very valuable way of being able to give people what they need if it's possible without having to go through a mass of bureaucracy ... It also gives me an opportunity of ensuring that any new things that we do, like refurbishment, etc., there's now a forum there that if I want to get some consultation then I've got it' (palliative care professional).

'User involvement is not about meetings, it's about a living process of valuing and empowering people – it needs a real cultural change' (anonymous 'post-it' note).

The barriers

Health professionals expressed the view that palliative care patients were perceived as too difficult to engage, too ill and that people had better things to do with the time they had left to live. Setting up user involvement initiatives was considered to be too time consuming and sometimes done in addition to their already heavy work load.

'I think one of the things ... who does the posters, who does the flyers, who tells people about it, it's getting the room ready and things, and a lot of those things are gradually, you know, I've done quite a lot of them, just like the behind the scenes type things. And do that on top of my job' (palliative care professional).

Organisational barriers were also key factors in determining participation and involvement of professionals in user-involvement strategies. Some services had not managed to progress user-involvement activities beyond conventional satisfaction questionnaires or inviting a 'token' service user to a meeting.

'I don't think there is any ownership of it throughout the organisation ... as I say we tried the telephone way and we tried this way, I've briefly thought about, I mean well we've talked about kind of focus groups as well. But our patient clientele obviously are not well' (palliative care professional).

Concerns were also raised about the challenge user involvement can bring to palliative care staff about their practice. A fear was expressed that it may even threaten their professional power.

'I think there's also a little bit of fear about, if a negative comment does crop up, I often get a sense that you sort of feel well who's fault is it, that kind of blame culture that we're trying to move away from ... So I think that there's an element of resistance from that point of view' (palliative care professional).

DISCUSSION

The main findings of this study were that patients, carers and health professionals reported a number of rewards and barriers to their engagement with user-involvement initiatives in palliative care. The balance between motivations to participate and the barriers to engagement are arguably tipped towards the latter, as most palliative care services reported difficulties in maintaining sufficient enthusiasm from enough patients and carers. It appeared that a few highly motivated individuals, both service users and professionals, were influential in initiating and sustaining user involvement within a few organisations and the loss of such individuals caused user involvement to flounder.

Study limitations

The study participants were a heterogeneous group. They were recruited because they were already contributing to user-involvement activities; therefore, they represent a potentially biased group. We endeavoured to speak with professionals from organisations in the statutory and non-statutory sectors, those predominantly concerned with people affected by cancer and those servicing other disease groups. We specifically sought the experiences of user-involvement initiatives with black and ethnic minority groups. Finally, we collected data from services that had formerly undertaken user-involvement activities but then abandoned them. We do not claim these data are representative in a statistical sense but, in our view, they capture the range of activities that were being undertaken in Britain during 2004. We were overwhelmed by the willingness of people to contribute to our project – we exceeded the anticipated recruitment of people, resulting in a wealth of rich data. Likewise, we had anticipated problems in a poor response to our invitation to a consensus meeting at St Christopher's Hospice, but once again we were pleased that 48 people attended. Therefore, we can conclude that user involvement as a topic is highly salient and one in which people from many backgrounds and sectors wish to engage. However, we were unsuccessful in recruiting people from black and ethnic minority backgrounds despite offers

of interpreting services. Further attention needs to be directed to the needs of these groups of people as language problems alone may not account for their unwillingness to engage in largely 'white' events (19).

The data were collected during interviews, which may mean it was difficult for participants to express concerns or more negative views (20). Data were also collected from participants who were well enough and able to engage. This may have led to an overestimation of the enthusiasm for user-involvement activities. Further investigation of patients and carers who decline involvement are likely to be informative. To reduce the risk of bias in our interpretations of the findings, we invited critical commentary from service users and professionals. Our study focused on involvement in service development rather than research (11).

The findings suggest we need to consider three groups when reviewing the effects of patient involvement in palliative care services: (i) patients participating in the development of services; (ii) family carers; and (iii) healthcare providers and managers. It is assumed that involving patients enhances their self-esteem (by being consulted, being given an opportunity to express choices and participating in democratic decisions) and we found some evidence of this from patients and carers who were currently involved (10). Involvement may also have a negative effect for some people. It may be difficult for some people to contemplate the types of services needed in advanced stages of their condition (7). This leads to concerns about how participants are selected and the 'representativeness' of people who participate in groups and committees. Because of the 'top-down' nature of user involvement, service users that are involved were often contacted and 'selected' by professionals, creating a potential bias. It is important that further work is undertaken on the implicit/explicit criteria used. Is there a 'right type' of patient? These appear to be some implicit characteristics used: well rather than very ill, educated, mobile, English speaking, with access to information technology (e-mail), available in the daytime, have own transport, articulate, knowledgeable and socially skilled, with experience of committee processes. Currently, there are no agreed criteria for when patients and carers stop being regarded as 'service users'. For example, what length of time since their initial treatment episodes are their views no longer regarded as reflecting current practice? This is particularly important for emerging groups such as cancer 'survivors' (21). Involvement may appeal to certain types of people, such as those who are fitter, those who 'recover' (the views of the dead can only be accessed indirectly through bereaved carers) and people who are more assertive, more articulate and more familiar with committee structures and processes. The views of these people may not reflect those of people who are less likely to participate. We found some evidence that patients and carers became disillusioned by the

process of consultation because they felt that their views were neglected or over-ridden, or that the pace of change was too slow. Our study found evidence that there were a few users who had become 'professionalised' and developed 'careers' in user involvement. Their motivation and experiences are worthy of further investigation.

Implications for practice

For palliative care services to develop user involvement successfully, there is a need for each organisation to recognise the different motivational factors and perceived barriers to enable people to become engaged with new initiatives and to prevent user involvement from being undermined. This requires senior managers to consider how far they are prepared to make changes recommended by service users and how open they are to considering ideas and suggestions. It requires an open dialogue and a preparedness to try new things out and to adapt and change. It also requires resources such as the provision of dedicated staff time and money for travel and associated out-of-pocket expenses. Education about user involvement throughout an organisation is essential if it is to be taken up at every level. There also needs to be a feedback process on the outcomes of suggestions and why they have been accepted or rejected. Motivation appears to increase where there is a process of partnership and service users are able to see the benefits of their involvement, or where service users are actively involved in seeking solutions to problems. Reframing these activities as partnership working with fellow citizens may help to achieve a cultural change.

Implications for future research

This study has identified that there may be a role for collaborative research with service users to develop and evaluate creative and novel interventions to involve those who are too ill, too tired or unable to attend meetings. There is a need to develop and analyse relationships between community groups and services, to identify how local voices contribute and shape local services and develop interventions to overcome the exclusion of people with literacy and language problems. Further research, however, is needed to investigate the efficacy, costs and benefits of different models of user involvement in palliative care from the perspectives of patients and carers, professionals, and organisations.

KEY POINTS

- *Patients and carers are increasingly invited to be involved in the development and shaping of services in palliative care.*
- *A few highly motivated individuals, including service users and palliative care professionals, are extremely*

PROGRESS IN PALLIATIVE CARE

influential in starting and maintaining user-involvement initiatives within organisations.

- * *Service users and professionals report intrinsic and extrinsic motivating factors and a number of barriers to their involvement.*
- *Organisations need to engage with, and address, the different motivational factors of staff and service users to prevent user involvement activities being undermined.*

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