

✧ ORIGINAL ARTICLE ✧

Hearing what older consumers say about participation in their care

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Accepted for publication 17 September 2006

Penney W, Wellard S. *International Journal of Nursing Practice* 2007; 13: 61–68
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A study exploring older people's participation in their care in acute hospital settings reveals both consumers' and nurses' views of participation. Using a critical ethnographic design, data were collected through participant observation and interviews from consumers in acute care settings who were over 70 years old and nurses who were caring for them. Thematic analysis identified that older people equated participation with being independent. Importantly, consumers highlighted the complexity of the notion of participation when describing situations where they were unable to participate in their own care. The difficulties in communicating with health professionals and an inability to administer their own medications in inpatient settings were identified as barriers to participation. Understanding what consumers believe participation means provides a starting point for developing meaningful partnerships between health professionals and people receiving care.

Key words: care of older people, consumer participation, critical ethnography, self-medication.

INTRODUCTION

There is considerable demand on health-care services, and therefore the staff they employ, to actively and visibly engage with consumers during episodes of care. Although the genesis of this demand is multifactorial, the consequences for failing to achieve consumer participation are significant, including influencing accreditation¹ and/or a loss of funding. Not surprisingly, many institutions are developing structures to facilitate institutional engagement with consumers, which include consumer/patient advocates employed to support patients in negotiating

care or resolving conflicts and the increasing membership of consumers on various committees. In the Western countries, there have been visible consultative processes with consumers about how their values can be incorporated into health-care reforms.^{2–5} For example, a critique of the National Health Service (UK) as oriented to health professionals rather than its users led to a new emphasis on issues of communication and the subsequent development of Patients' Charters emphasising consumers' rights.⁶ However, there remains little understanding of how consumers can be engaged in active partnership with health-care professionals while admitted as patients in acute care facilities.

There is an extensive international body of literature exploring consumer involvement in human services, yet there remains a lack of consensus about what is meant by

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participation and the use of the term 'consumer'. The terms 'patient' and 'consumer' are often used interchangeably in referring to individuals who have, or potentially have, a relationship with health-care professionals for the purpose of receiving health-care services.⁷ It has been argued elsewhere that the term 'patient' frequently denotes a passive relationship between a 'sick' person and their health-care professional, which is commonly paternalistic.^{8,9} Therefore, we have adopted the term 'consumer' in this work, but acknowledge that there are difficulties associated with its market economy origins. This paper reports on older consumers' views of participation in acute care settings as one aspect of a larger study, and provides a basis for further exploration of mechanisms for developing meaningful consumer participation in health care.

Consumer participation in health care has been adopted from a political perspective with little thought of how to implement the process in practice.¹⁰ There is little evidence that consumers are provided with opportunities to participate in the planning, delivery and evaluation of their health care.^{11–13} Although consumer participation is increasingly embedded in health-care policy, services have had limited success in meeting this goal.^{14,15} Practical processes supporting the implementation of consumer participation in clinical settings are yet to be successfully put into place.^{16,17}

Complex funding structures for the provision of health services work in opposition to improving health care through consumer participation. The diagnostic related groups funding model is based on the number of patients treated, with the dollar value per person dependant on their diagnosis.¹⁸ This system results in pressure to deliver care within a restricted time frame, thus influencing inclusion of patients in planning their own care, with discharge dictated by clinical pathways based on medical diagnosis.¹⁹ In Victoria, a shortage of hospital beds, exacerbated by an acute nursing shortage,²⁰ further increases the pressure for timely discharge.

The principles of consumer participation including autonomy and choice have been overshadowed in the Australian health-care system by fiscal constraints and staff shortages, resulting in an increasing inability to provide quality health care that meets the needs of a changing society.²¹ Illiffe argued that consultative processes between health providers and consumers have broken down, pointing out that governments need to commit to health service reform that focuses on workforce issues.²²

Consumer participation is claimed as central to contemporary nursing practice;^{23,24} yet there is confusion and little evidence to confirm a clear consensus of its meaning.^{25–27} Although there are varying definitions of participation, a consumer's rights to make decisions and be involved in care planning are fundamental aspects.^{25,28,29} Participation is often discussed in the context of caring,²³ is dependant on a model of empowerment³⁰ and is accomplished by taking into account patient individuality.³¹

Within nursing literature, there is a lack of agreement in relation to how consumer participation might be facilitated and concern is raised whether nurses are actually committed or able to implement the concept.³² The few published studies involving direct observation of consumer participation in clinical practice found that nurses spoke of the importance of communication but were seen to only have contact with the people they were caring for when there was a task to complete.^{13,33} Moreover, when nurses did have contact with patients, little conversation took place. Consumers involved in Henderson's study indicated that when they communicated with nurses and got to know them on a personal level, their participation was enhanced,²⁴ supporting the view that mutual trust, rapport and sustained contact are important for successful participation to occur.

Following our previous work, which identified a paucity of research related to participation in acute health care,¹³ we aimed to investigate the characteristics of consumer participation including the identification of barriers during episodes of acute care. Although the research uncovered many aspects related to participation, including nurses' understanding of barriers to partner relationships, this paper reports on findings that describe participation from the consumer perspective.

METHOD

Using a critical ethnographic design, data were collected from two major acute health-care facilities in a large urban centre, one is a public institution and the other a private not-for-profit facility. Critical ethnography³⁴ is adopted as it provides the potential for changing practice and the literature review supported the need for an approach that moved beyond blaming health professionals for poor practice. Participant observation and in-depth interviews with consumers and nurses were the methods used for data collection over a 6 month period in 2003.

Following approval from the university and hospital human research ethics committees, 36 consumers and 31

nurses agreed to participate in the study. Consumers aged ≥ 70 years who had the ability to understand written and spoken English and were not cognitively compromised were recruited. Substantial field work was central to the project and included interviews that provided the depth of detail required for analysis.³⁵ Consumers were interviewed in their own homes within 2–3 weeks following discharge from hospital, and nurses were interviewed away from the ward environment towards the end of the participatory observation period which lasted 8 weeks at each site. A total of 240 h was spent by one of the researchers (WP) observing encounters between nurses and consumers. This involved being immersed in their culture in the clinical setting and writing detailed descriptions of activities.^{34,36,37} Analysis of interview and field note data involved listening and reading transcripts combined with manual and electronic categorization of information into themes and sub-themes. All participants were assigned a pseudonym to maintain confidentiality.

FINDINGS

Consumer interview data were generated in response to the question 'tell me about your recent hospital stay from the perspective of participating in your own care'. Consumers appeared to find the term *participation* hard to define, and initially limited their responses to self-care and being independent. However, an understanding of their views of participation became visible in their numerous stories of what they conveyed as 'not participating'. Their stories were supported by field note data detailing the practices of health professionals and ways that busy environments of the hospitals impacted on consumer involvement in care.

Participation and independence

In the beginning, analysis identified that consumers equated participation in their care with being involved in self-care and being independent. Consumers indicated their desire to be involved in everyday personal activities: to be independent by walking, going to the toilet and showering themselves where possible. Adele reflected this by saying:

I was participating in my own care considerably because I was able to walk around with a walker. . . therefore I was doing everything for myself, showering and not asking for any help from the nurse.

Being independent was directly associated with a desire to return home, a goal all participants aspired to, sadly a reality that not all achieved. Conversations relating to independence illuminated the importance of managing personal care and triggered many stories that reflected determination. Evelyn said:

That's why as soon as I could shower myself that's what I wanted to do because to me doing things for yourself means that you are on the way to getting out again.

Consumers related independence with a desire to return home with some recalling points where they thought they might die. These stories revealed many motivating aspects linked to individual determination to return home, including life experiences and the importance of family support. Barry explained he began to plan to go home the moment he was admitted to hospital. He described how he got dressed everyday in street clothes to demonstrate to staff that he was well enough to be discharged. Barry pointed out that:

. . . if you stay in hospital your memory gets worse because there is nothing to jog it, that's why you've got to get out.

Jack and Nancy told of their fear of dying in hospital, a period of time when they believed they might 'not make it'. Both reflected on the value of family, 'knowing they were there' helped them 'pull through'. Other people's experiences supported the significance of family, clearly articulated by Nola who believed it would be easy to 'give up' without her daughter. She stated:

Life is a battle at the moment, nobody really knows. . . I don't know how long I will go on for, if it wasn't for my daughter I would lie down and die.

Jack went on to explain that memories of his father who ran a farm with one arm and his own early life breaking in horses motivated him not to give up as he was learning to walk again. Field notes describe several times where Jack said: 'I'll be right when I get back home'.

Limited opportunity for participation

Further analysis revealed a more complex notion of participation where consumers discussed situations where they felt denied or unable to participate in their care. Not being listened to, not being given sufficient information,

and medication administration were three areas identified by consumers as examples of 'not participating'. Field note data confirmed situations where consumers perceived limited opportunities for exchange of information. Millie spoke of doctors who would not address her problem with her bowels with diarrhoea that she found more debilitating than the back pain that was being treated. Roy complained that tests had been ordered despite his refusal to have further investigations. Field notes detailed a heated exchange between Ron and nursing staff as he was told he was well enough to go home. Ron believed he knew his own body and expressed he was not well enough. When visited at home post discharge he said:

. . . I didn't make that decision. That decision was made from the doctor, to get out. Not from me. I was not asked whether I want to go out. I was never asked if I'm well enough to go out. I just had to follow up with what he told me. 'You go out, you're well enough.'

Ron was one of several consumers who expressed clearly they were not consulted about their discharge. Three of these people were subsequently readmitted within 24 h and remained hospitalized for another week. Other consumers detailed their experiences of being discharged as late as 18:00 h, a time that was inconvenient especially for those living some distance from the hospital.

Field work data supported consumer reports of confusion and delays in discharge procedures. Consumers spoke of waiting extended periods of time in a transfer lounge for medications to be ready because their beds were needed for others. The frustration associated with an inability to participate in their discharge was frequently exacerbated by limited information and problems with discharge medications, which needed to be resolved at home. Problems reported with discharge medications included omitted drugs or dosages different to what consumers expected. Overall, consumers demonstrated an understanding of resource issues, commenting that it was 'not the hospitals' fault' and attributed problems to a 'mix up' or to staff 'doing their best under difficult circumstances'. One consumer, Frank, stated that compared with other countries, Australian people are cared for well. He said, 'what can you expect money does not fall out of the sky'.

Communication

Situations where insufficient information was provided for people to be active in their care were observed, including

consumers not being clear about their diagnosis and not understanding their current medication and treatment plans. Consumers commented that 'you don't get told much' and 'information does not get passed on'. Consumers suggested that limited communication was a result of staff being too busy, pointing out that nurses were 'marvellous' and did their best. All consumers who participated in this study commented in some way about a lack of time and nurses being too busy. As Ron explained:

. . . they did their duty and I reckon they've got too much work for one person. They can't look after so many things at once . . .

Similarly, Vicki stated:

You know nurses have their jobs to do and it's go, go, go, you know. You never see them standing still and having a chat or doing anything like that.

While identifying a lack of time as a major barrier to consumers being involved in their care, several consumers suggested that their hearing difficulties and communication styles impacted on their ability to receive information. Hearing was made more difficult when health professionals spoke among themselves and did not directly converse with the consumer. This was described by one consumer as 'speaking over the top of you' and was considered 'quite frightening' as only half of the information was heard. Some consumers pointed out that the different accents of health professionals from non-English speaking backgrounds exacerbated their difficulty of receiving information.

Consumers reflected a mixture of acceptance and frustration in their stories. Vicki experienced respiratory difficulties following an anaesthetic; she was annoyed that she was told about the situation by a friend. She explained:

. . . none of the nurses said anything to me, and not even the doctors you know, they didn't say 'oh we had a bit of trouble with you' or 'you were a bit of a pest' not even in a light hearted way. And it was only because my friend happened to be there waiting for me to come back. And of course she got a great fright. I didn't get a fright because I didn't know anything about it.

Some accounts reflecting non-participation through a lack of information impacted on consumers' ability to

manage care at home. Val explained she was discharged home on insulin, a new treatment for her. Her husband, who was also her carer, had recently been diagnosed with cancer and receiving daily radiotherapy as well as a continuous portable infusion of chemotherapy. According to Val, he was only shown once how to give her insulin and she received minimal education relating to her diabetes. She explained during her home interview:

Well I don't think anybody told me what a hypo was, I am sure I wasn't told in there. Only they just said that I had to have sugar, something sweet and to eat food. A diabetic woman [diabetic nurse educator] did come in to see me but she was only filling in these forms to tell me when I can get the diabetes cheap needles . . .

Medication management

People receiving care repeatedly discussed medication management. Consumers spoke of not being able to participate in this aspect of daily care, as well as a desire to be more involved in administering their medications while they were in hospital. They recounted frustrations at having to wait until after breakfast for tablets that needed to be taken with food, not knowing what some medications were for, and of changes to medications that happened without their knowledge. Donald and Larry's comments highlight how many consumers felt about medication administration, an activity that they believed they should be more involved in.

Donald: . . . they do over dramatize the locking up of medications in the hospital. Now as you can see I do my own medication . . . In there I wasn't allowed to even get my patch out the drawer.

Larry: . . . the problem that I have found is trying to get people to sit down with you, I was on up to 24 tablets a day. And there were some that I thought that I didn't need to take, particularly in bed, you know like blood pressure tablets, they did take them off in the end [ceased the drug]. But you know I think I could have helped them a lot more if they had done that and I would have helped myself because I would have understood what the problems were.

Several consumers admitted to arguing with staff about their medications, pointing out that they had been managing their medications for many years; it was part of their daily routine that did not need to be altered while in hospital. Many consumers said that doctors and nurses were

experts who knew best and therefore, they, as patients, should follow their instructions. However, they also indicated the need for more involvement in this process. Medications were considered a daily activity that consumers wanted to maintain independence in.

DISCUSSION

This study reveals that consumers found participation difficult to define because of the multifaceted nature of the concept. Exploration of the term found a breadth of descriptions as consumers referred to involvement with daily hygiene activities, the desire to be listened to, and the need to receive information and be part of discharge planning processes. The meaning of participation for consumers is complex with individuals indicating their belief that health professionals know best juxtaposed with their desire to be more involved in aspects of care. Consumers in this study clearly identified areas of difficulty in participating in their care while in acute hospital settings. By telling stories that illustrate situations where participation did not occur, consumers provided insight into what participation meant from their perspective.

These findings suggest that participation for older people involves engaging in daily activities that support the maintenance of their independence. This includes being actively involved with medication management. Of importance is the opportunity to be listened to, as well as receive clear information about treatment plans. This is consistent with current literature relating to the concept of consumer participation that indicates the need for mutual involvement and a relationship between nurses and consumers which includes communication and information exchange.^{11,23,28,32,38} Development of trust through positive, friendly communication and empathy by nurses has been argued to facilitate consumers participation in their care.^{33,39-42}

Consumers in this study were able to identify qualities that enabled them to participate in their care, but it was apparent that there were many missed opportunities. Non-participation for consumers resulted from not being included, not being listened to, as well as a lack of knowledge due to limited information provided by health professionals. Arguably these issues are not new.^{11,13,43-45} It has been reported that patients, while needing to spend time with nurses to develop participatory relationships, do not expect it as they perceive nurses as busy people.³³ Henderson pointed out that patients were reluctant to participate in medical decisions because of a lack of

knowledge. She reported that health professionals have been criticized for assuming a dominant role due to their expert knowledge.³⁰ These issues were supported by consumers' stories in this study, in particular concerns that busy environments influence health professionals' approaches to care.

Many people involved in this study viewed health professionals as experts and believed, as 'patients', they should do as they were told. They noted exceptions in areas related to medication management and consultation about discharge. Some Australian institutions have attempted to involve individuals in the administration of their own medications while in hospital, but concerns remain regarding duty of care and legal issues.⁴⁶ In Britain, in-hospital self-medication has been implemented with some success⁴⁷ and potentially there are lessons for addressing current Australia concerns. Consumers in this study identified medication management as a self-care activity that they wanted to control and would be expected to manage when discharged home. When visited at home, consumers demonstrated their expertise in managing their medications and an ability to resolve problems associated with their discharge medications. There is a need for further research in safely managing in-hospital self-administered medication. Technological solutions using electronic locks with bar code access for consumers may partially address this problem, freeing staff time and giving consumers greater sense of autonomy in an area they feel competent.

Problems related to communication with consumers are complex and require strategies beyond the all too frequent simplistic suggestion that nurses and doctors should learn to communicate better.⁴⁸⁻⁵¹ Consumers may have been given more information regarding their care than they perceived. Recent research shows that individuals' recall of information while in hospital is related to the timing of information and readiness to learn.^{52,53} However, the consumers in this study highlighted the importance of having knowledge in order to participate actively in care. It is therefore important to develop strategies to ensure that consumers are discharged with adequate knowledge of their condition and treatment. This might mean incorporating multiple methods of communicating information.⁴⁶ Given the increasingly short length of stay in acute care facilities, the use of documented information could serve as a useful adjunct to other educational strategies that consumers can refer to after they are discharged.

The findings of this study reveal that consumers used different approaches to dealing with barriers that prevented their participation in their care. Some consumers were passive, some were assertive, and at times, some were aggressive. Ron openly verbalized his disagreement with the discharge decision made without his involvement. Others, like Val and Larry, appeared to be silent and disempowered while in hospital, unable to voice their point of view in an environment where they presumed experts know best. Barry found voice in a different way as he silently influenced staff to let him go home. Other consumers were not completely silent, choosing to go along with expert knowledge in some aspects of their care but voicing their views in areas such as medication management.

Finding ways to increase working in partnership between consumers and nurses is difficult. Understanding consumer perceptions of practices that they feel create barriers to their participation is one part of a complex problem. This research suggests that many consumers believe that health professionals have expert knowledge and therefore they know best when it comes to care issues. Consumers also revealed that the complex environment of acute care, with significant limitations on resources, presents barriers. Nurses were reported as very busy and consumers assumed passive roles in an attempt to support nurses; they tried to fit in with what was expected of them.

Our goal has been to illuminate consumer views and describe situations where participation was not optimal. Consumers detailed situations where participation was limited, but also indicated a desire to be more involved in these aspects of their care. Understanding consumer perceptions provides a starting point for examining institutional structures and health professional practices that contribute to consumer-perceived barriers to participation. This study found that consumers value their independence and are keen to be involved in their care.

These findings challenge previous findings that older people in hospital generally do not want to participate.¹¹ However, the confusion that consumers have about what participation means, indicates a need to provide information to people entering hospital, detailing opportunities to be involved in their care. Similarly, health professionals need exposure to information that challenges the idea that older people prefer to be passive recipients of care.

Using a critical research methodology facilitated the initiation of change in practice. Nurses participated in

focus groups where they were challenged through hearing views of consumers. This raised their awareness and nurses subsequently contributed to designing professional development to enhance their skills in including consumers. Nurses also suggested the development of preadmission information packs. In one setting changes were made to discharge planning processes and in another further exploration of the feasibility of a patient self-medication system is under investigation.

CONCLUSION

This work contributes to the documentation of older consumers' perceptions of participation in acute care settings in Australia. Consumers clearly associated participation with involvement in activities supporting their independence. Importantly, they also articulated aspects of care where they experienced limitations on their desire to participate in their care. Issues relating to medication management, discharge planning and communication in the acute care setting were the major areas discussed. Creating opportunities to improve relationships between health professionals and consumers is challenging because the current regulation of resources creates structures that inhibit consumer involvement. Exposing these structures and identifying consumer opinion is the first step to promoting changes in both consumers' and health professionals' approach to partnerships in care.

ACKNOWLEDGEMENTS

We acknowledge the financial support of the (Australian Research Council) ARC and industry partners for this project. We are grateful to the consumer and nurse participants for their generous gift of time and for sharing their experiences. The views expressed within the paper do not necessarily represent those of the ARC or the industry partners.

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