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**“It’s my pleasure?”: the views of palliative care patients about being asked to  
participate in research**

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## **Abstract**

Based on a larger pilot study to examine patient satisfaction with hospice care, and using a qualitative interview approach, this paper explores the views of hospice users regarding their motivations for taking part in a study designed to inform the delivery of care and ensuring on-going service improvement. Despite the basic tenet of palliative care provision being patient-centred care, and an increased focus upon the involvement of service users in research, involving patients with a life-limiting illness often raises ethical concerns for researchers. Assumptions are readily made about whether research participation is appropriate for this patient group due to their perceived vulnerability and ‘gatekeeping’ by health professionals is common practice, motivated by concerns that research participation might cause more harm than good. However, there is a paucity of studies that examine the motivations of, and perceived benefits to, hospice users who choose to participate in research studies. This paper addresses this gap in knowledge by drawing upon in-depth interviews conducted with 21 patients under the care of three hospices in the Auckland region of New Zealand. Participants were unanimously agreed that hospice patients should be involved in research. A number of motivations for involvement were discussed, including: the importance of legacy; altruism; and feeling ‘honoured’ to be invited. However, it was also apparent that this patient group do constitute a ‘captive audience’ for researchers, with ethical implications that require consideration by researchers. These findings lend support to the argument that hospice users should be offered the opportunity to participate in research within established ethical frameworks.

## **Keywords**

Palliative care patients; research participation; sensitive; end of life care; hospice

## **Introduction**

According to Small and Sargeant (2011), user and public involvement has always been central to the modern hospice movement, which has frequently instigated changes based on the experiences of its service users. Indeed, patient centred care is a basic tenet of palliative care services and treatment is geared toward individual and family needs and patients' opinions are sought wherever practicable (Kraus, 2003). A number of countries have now expanded this individual focus to develop policy initiatives which stress the need to engage with the general public and service users to shape the delivery and character of palliative care services, characterising such engagement as fundamental to their success (Rumbold, 2011). However, if services are to be truly shaped by the views of service users, their experiences and perspectives need to be central to the research evidence base informing service delivery. It is therefore of concern that the majority of the published literature related to the ethical dimensions of research participation amongst patients with life limiting illness, and particularly those who are in the last few months of life, is informed by 'professional' opinion rather than service users themselves. Indeed, as consumers of health care, the voices of palliative care patients regarding their involvement in, and motivations for taking part in research remain conspicuously absent from the literature. The present study addresses this gap in current knowledge and understandings by exploring motivations for participation in research amongst patients in receipt of hospice care in Auckland, New Zealand.

The ethics and sensitivities involved in conducting research with palliative care patients have been well documented from a health professional perspective (Jordhoy et al, 1999; de Raeve, 1994; Addington-Hall, 2002). Ethical conflicts occur when researchers find themselves in

situations in which they have difficulty distinguishing issues that constitute harm and those that provide benefit. As Pollit and Hungler (1999) have argued, palliative care patients may be at high risk of unintended side effects because of their circumstances. As a consequence, such patients may need to be afforded a higher degree of protection than is afforded to other groups. Concerns have also been raised as to whether palliative care patients derive benefit from participating in research (Janssens and Gordijn, 2000) and it has been argued that research participation may be unethical where no direct benefit is perceived (ibid). For people at the end of life, an ethical challenge that has been recognised is that research participation may inhibit their ability to undertake other activities given the limited time they have available to them (Gott, 2004). Concerns regarding the captive nature of hospice in-patients and the resulting potential for coercion have also been documented in the literature (Raudonis, 1992; Rosenblatt, 1995). It has been argued that they may not give an honest appraisal of their experiences for fear of being 'sent back' to hospital (Raudonis, 1992).

However, Wilkie (1997) points out that individuals living with a life limiting illness do take part in research for various reasons and that, from his clinical experience, participation may be desired even when no immediate benefit may be derived and when symptoms such as fatigue and pain may make this difficult. Reasons for participation have been suggested, including perceptions of benefit to future patients and the desire to leave a 'legacy' (Amenta, 1986; Petrosina, 1986; Coyle, 2006), but these represent professional opinion and are not empirically informed. Indeed, the views of individuals regarding their motivations for taking part in studies designed to inform palliative care service delivery are conspicuously absent from the literature, although it is likely that research which has explored motivation for engagement with user-involvement activities do have some applicability (Gott et al, 2001; Sargeant et al, 2007). A recent UK study identified that reasons for such engagement

included putting something back, feeling of empowerment, sense of being valued for one's skills and knowledge, and improvement of services and facilities (Sargeant et al, 2007: 129). Nevertheless, and in common with palliative care user involvement initiatives more generally, participants in this study were 'well rather than very ill'. Indeed, the views of people at the very end of life regarding motivation for participation in both service user and research engagement are under-explored (Raudonis, 1992; Seymour and Skilbeck 2002).

Exploring the perceptions of palliative care patients in relation to research participation is particularly pertinent at the present time because of concerns raised by researchers that current ethical frameworks governing research conduct in this area are overly restrictive and potentially paternalistic (Addington-Hall, 2000; Ward et al, 2004; Wald, 2004). For example, researchers involved in a recent study conducted with a palliative care population argued that 'the requirements imposed by the ethics committee resulted in a research study where the highest standards of transparency of purpose and informed consent were compromised in the context of a wish to 'do not harm'' (Gardiner et al 2010: p. 471). They identified that the heightened degree of protection and sensitivity afforded to palliative care patients can serve as a source of conflict between researchers, ethics committees and health care practitioners. These are concerns that have been highlighted by other researchers. For example, Seymour and Ingleton (1999) note that research ethics committees are not present in the 'field' and are only recognising the intent of the research. Indeed, ethical standards in most countries state that, if cognitively able to give informed consent, participants have a right to listen to a researcher's explanation of a study and, based on that information, determine if they should participate (Christians, 2000). Casarett and Karlawish (2000) argue that there is no reason to consider palliative care a special case in which the established ethical principles and guidelines do not apply. Those with a life limiting illness are still people, with decision-

making capacity (unless proved otherwise). Nevertheless, the potential to engage in such decision-making is often thought to be compromised by 'gate-keepers' with whom researchers often have to negotiate to make contact with potential participants (Raudonis, 1992). This issue has also been acknowledged by Seymour et al (2005: p.173) who maintain that *'even if they [participants] are identified, gatekeepers (on whom researchers often rely to extend an initial invitation to participate in research) may find this problematic and embarrassing because of the sensitivity of the study subject, or because their priorities lie elsewhere.'*

Drawing upon a larger study to assess the acceptability and usability of two satisfaction questionnaires to guide service development and improvement within hospices across New Zealand, this paper provides an account of the motivations of hospice service users to take part in the research. The paper offers a valuable insight for individuals involved in palliative and end of life care research, as well as those responsible for ethical review.

## **Method**

Qualitative, in depth, semi-structured interviews were conducted with 21 participants recruited via inpatient and community settings (day care services) from three hospices in the Auckland region (Table 1). Participants were purposively selected to ensure representation of men and women and people of different ages and cultural backgrounds. The researchers worked closely with hospice staff to ensure that individuals with diagnoses other than cancer were targeted to achieve as broad a sample as possible.

### **Table 1: Participant characteristics (n=21)**

Male	10 (48%)	
Female	11 (52%)	
Age Group		
40-49	3	
50-59	3	
60-69	5	
70-79	8	
80-89	2	
Ethnic origin (self defined)	NZ/European	17
	English	1
	Dutch	1
	Philipino	1
	Chinese	1
Diagnosis	Cancer	15
	COPD	3
	Motor neurone disease (MND)	1
	Acquired immune deficiency syndrome (AIDS)	1

Ethical approval to conduct the study was obtained from the Northern Y Regional Ethics Committee via the expedited route (reference NTY/10/EXP/051) and written informed consent to interview participants was obtained prior to data collection. All the interviews were conducted by experienced researchers on hospice premises in a private setting. In all cases, an invitation to participate was extended to potential participants via a third party.

These 'gate-keepers' comprised those managers responsible for each area with knowledge of their patients (including their medical condition). Whilst we were concerned that this approach could limit the ability of some patients to participate, we had to balance these concerns with competing ethical demands. In particular, we did not want to approach anyone who, for reasons of cognitive ability, was unable to provide informed consent. Staff members were also not prepared to allow us to invite patients directly for fear of causing distress. This approach fit with the views of Wright et al (2002) who suggest that this method is paramount given the existing relationships that individuals with a life limiting illness hold with their professional carers.

Interviews were audio-recorded and transcribed verbatim. A short background questionnaire containing a number of demographic details was also completed. At the end of each interview, participants were asked a series of questions about their experiences of involvement in the study: their reasons for taking part; their experiences of taking part and their views regarding the involvement of palliative care patients in research.

During the analysis, a framework was first devised following an initial familiarisation with the interview transcripts and a number of themes and subthemes were generated. This involved a structured process of 'sifting, charting and sorting material' according to key issues (Ritchie & Spencer, 1994). Four themes pertinent to this paper were identified and are presented below. Interview excerpts taken from participants' interviews are presented below and are indicative of the nature and diversity of views obtained.

## **Findings**

The reasons articulated by participants regarding their motivations for taking part in this study were varied. The four themes identified were: maintaining a contribution; on being altruistic; being chosen, and ‘the captive audience’.

### **Maintaining a contribution**

It was apparent in participants’ accounts that the knowledge that they were living with a life limiting condition was significant to their decision to take part in the study. Several mentioned that their participation enabled them to make a contribution to others following their death. It was also apparent that speaking to an interviewer provided participants with an opportunity to ‘have their say’, something that the following participant linked to ‘living’:

*‘I’m all for it, I’m all for having a go, saying my piece. That’s what life’s all about.’*

(Michael, In-patient)

Indeed, a belief amongst some participants that being close to death could result in people not being seen as being actively able to contribute to society was evident:

*‘Again, it makes you feel as if you’re actually doing something, that you haven’t been forgotten, your not just put away in a room and forgotten there.’*

(Shaun, Community patient)

It was therefore apparent that research participation was valued by all participants as a means of feeling engaged with the world beyond their illness and reinforcing their understanding of themselves as someone who still had something of value to contribute. There was also a

recognition that people with life limiting illness can provide unique information to inform service developments which cannot be accessed by other means:

*'I think you get it (information) straight from the horse's mouth really.'*

(Lee, In-patient)

### **On being altruistic**

A further factor participants' identified as important to them in making the decision to take part in the study related to altruism. Related to the issues raised above, they wanted to be 'of help' to others who found themselves in a similar position in the future:

*'...hopefully it will [be of] help for other patients out there'*

(Elaine, Community patient)

*'...if on a wider way, if this can help somebody else then that's fine.'* (Susan, In-patient)

Related to this for some participants was a desire to 'give back' to the hospice services which they perceived had been supportive of them during the course of their illness:

*'Because hospice have done so much for me, so, anything I can do in return for them, it's all good.'*

(Marc, Community patient)

In a related manner, the following participant viewed participation in the study as an opportunity to say 'thank you' to the hospice:

*'I was asked [to participate] and I didn't mind. I think it's nice to get the privilege to be able to say how wonderful you think the service is because you don't always get that opportunity to stay, you know? And so when a survey does come up I don't mind doing them*

*at all because it does give you that opportunity to say your thank you's to them, you know, for what they've done and the services they've provided myself and my family, my children. Yeah, I don't mind, didn't hesitate at all.*

(Helen, Community patient)

**Insert concluding sentence here?**

### **Being chosen**

For some participants, the invitation to participate in the study had made them feel 'special':

*'I know that I'm getting interviewed and I was quite excited of being, you know, chosen to come and answer all these questionnaires and all, all these questions from you.'*

(Elaine, Community patient)

*'No, I don't know, I felt pretty honoured really [laughter].'*

(June, Community patient)

**Another concluding sentence here?**

### **The captive audience?**

Finally, it was evident in several participants' accounts that they took part because they were invited to by a known member of staff and, whilst no evidence of coercion was identified, it was apparent that this may have made it difficult for them to refuse. Moreover, while each participant faces a unique list of motivators and pressures when confronted with the informed consent process, the extent to which participants consented to take part in this study to 'please' their carers cannot be overlooked:

*'Well just because [staff member] asked somebody who would be willing to give them [researcher] a few minutes.'* (Jean, Community patient)

*'I don't want to down the hospice because it's a free organisation, it's helped me immensely. So it's hard sometimes to be negative, to think of something negative because it's a service that I would not normally have.'* (Martin, Community patient)

*'Oh well [volunteer] is very persuasive.'* (Shaun, Community patient)

**Concluding sentence here?**

## **Discussion**

Participants in this study were able to provide valuable insights into their motivations for taking part in a study designed to measure satisfaction with the care and treatment they received as hospice patients. The findings of this study resonate with the work of Coyle (2006) and the importance assigned to legacy- the capacity to 'make a difference' so that future patients might benefit from their contribution. Participants who discussed this issue did so in relation to the belief that they had been given the opportunity to create or correct something for others and the wider society. The opportunity to participate in research was intrinsically valuable in the sense that it enabled participants the opportunity to maintain a view of themselves as individuals in control or at least, as someone as desirous of being in control. As a result, the views of participants in this study run counter to the concept of the 'social death' which was first coined in the 1960's in the medical-thanatological literature to describe how individuals withdraw or disengage prior to their biological death (see for example Glaser and Strauss, 1966). Indeed, rather than individuals withdrawing, they expressed a preference to participate as a means of still feeling valued.

**Paragraph here about other themes?**

As researchers, of particular concern is the ‘captive’ nature of the group (Raudonis, 1992). Our findings concur with Rosenblatt (1995) who highlights the potential for coercion as a factor in study participation. This is particularly pertinent when individuals, considered as ‘vulnerable’ are asked to participate in research by members of the care team known to them and they feel pressured into ‘doing the right thing’.

Similar to the experiences of Addington- Hall (2002), our sample was a highly selective sub sample of the total population of eligible patients. In line with Sharkey et al (2010) we surmise that a certain amount of ‘gatekeeping’ took place and only those individuals deemed ‘suitable’ to participate were selected by staff to participate. As a result, we have no way of knowing whether other participants invited to take part in the study might have done so if they had been approached directly by members of the research team. Similar concerns have been raised by Addington-Hall (2002). Whilst we recognise the importance of working with health care providers who play an integral role in facilitating access, this can have the effect of presenting those individuals the ‘opportunity to make autonomous informed decisions about research participation’ (Ibid. p. 222) as well as denying researchers access to potentially rich and valuable data. For similar reasons, the experiences of patients close to death are also unrepresented in this study. **Concluding sentence weighing up the ethical pro’s and con’s?** However, participants were a heterogeneous group with respect to disease type, age and ethnicity and geographical location.

## **Conclusion**

The involvement of patients who use palliative care services in research to guide and improve service delivery is paramount. Whilst there are a number of ethical and methodological issues that we highlight in this paper, our findings lend support to the argument that hospice users should be offered the opportunity to participate in research within established ethical frameworks. **Strengthen conclusion or remove?**

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