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The benefits of hospital admissions from the perspectives of patients with palliative care needs

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Background

Palliative care need in the hospital setting is well described in the literature. Indeed, studies have shown that up to 30% of inpatients are likely to be in the last year of their lives,¹ and most people in developed countries will die in a hospital setting.² Moreover, factors such as the global ageing population and the increasing use of hospital based technology in palliative care are predicted to impact significantly on demand for hospital care in the short to medium term.³ This potential rise in hospital usage at the end of life, when viewed within the context of the global economic recession and a dominant societal view of a “good death” occurring at home, has resulted in policy recommendations to reduce hospitalisations at the end of life in a number of countries.^{4,5}

However, identifying avoidable hospital admissions for those with palliative care needs is difficult,⁶ and the factors that contribute to these admissions are not well understood. Studies showing that inadequate symptom management and unmet care needs at home may result in a hospital admission^{7,8} underpin the argument that increasing community based resources could prevent a component of these admissions.⁶ However, there is also evidence that even when community based services are involved and healthcare providers advise against a hospital admission, patients will still present to hospital.⁹

Whilst studies of the general population have shown that the majority of people would prefer to be cared for and die at home rather than in hospital,¹⁰ preferences for place of care may change as the illness progresses.¹¹ Moreover, evidence suggests that some patients would rather be cared for in a hospital or hospice setting.¹²⁻¹⁴ With the advent of specialist palliative care units, designed to care for those with the most complex needs, meeting patient preference is becoming less likely, indeed very few people die in a hospice setting in developed countries and most people die in hospital.³

However, a recent review of the literature identified that little is known about patients’ experience of using hospitals at the end of life.¹⁵ Moreover, whilst the negative aspects associated with a hospital admission have been previously examined, no studies were identified which explored benefits associated with a hospitalisation from the patient perspective. Given a policy drive to reduce hospital admissions amongst patients with palliative care needs in many countries, it is important to fill this gap in the existing research literature. Understanding patient experience,

including the benefits of hospitalisation, will contribute to a more balanced understanding of the role hospitals play in the provision of palliative care and why patients seek care in a hospital setting.

The aim of this paper is to explore the benefits of hospitalization for **patients with palliative care needs** from their perspective.

Design

Given the exploratory nature of the research, a qualitative approach was adopted. Critical realism¹⁶ was used as a theoretical framework to guide study design. **Critical realism acknowledges “the empirical (that which is experienced and perceived), the actual events that occur (whether perceived or not) and the real underlying structures that can cause changes in those events.”¹⁷**

Longitudinal semi-structured face-to-face interviews were used to elicit the views of patients with palliative care needs admitted to one large urban hospital in New Zealand. Serial interviewing provides opportunities for rich and contextualised accounts of individual experiences over time.¹⁸

Study setting

Auckland City Hospital (ACH) is the largest public hospital in New Zealand and provides care for a socio-demographically diverse population.¹⁹ Ethics approval was obtained from the University of Auckland’s Human Ethics Committee (No: UAHPEC 9499).

Study population

The sample comprised patients admitted between July 2013 and March 2014 who met one of the Gold Standard Framework Prognostic Indicators (GSF-PIG) for palliative care need. The GSF-PIG has been successfully used in research settings to identify hospital in-patients in the last year of life.^{20,21}

Sampling

Participants were recruited from general medicine, oncology (medical and radiation), urology and surgery. According to ACH admission data, 30.8% of admissions were for patients with a GSF diagnoses (unpublished data, December 2012). A daily list of hospital admissions to these services

was reviewed. Past and current clinical notes were screened to assess patients' eligibility including whether they met one or more of the GSF prognostic indicators (see Table 1 for inclusion criteria). The interviewer (JR) also worked as a nurse with the ACH palliative care team. To avoid a conflict of interest as a result of dual roles, any patients that had been referred to the palliative care team were excluded from the study. No participants recruited to the study were referred to the service.

Table 1 here

Eligible patients were approached by the ward nurse. JR was contacted directly by the nurse if the patient agreed to take part. Written consent was obtained from all participants and family who the participant requested to be present.

A purposeful approach to sampling was adopted.²² Sample characteristics were not pre-determined; however, factors identified from the literature known to influence experiences of hospitalization such as age, diagnosis and ethnicity²³⁻²⁵ were taken into account during the recruitment phase.

Participants were selected to ensure a range of ages, diagnoses and ethnic groups were achieved.

As data were analysed, additional characteristics such as prognosis and current treatment were considered and guided the subsequent selection of participants.

Data collection

Participants were interviewed twice. Interviews were conducted between July 2013 and March 2014. Expectation is considered to be a major determinant of satisfaction and is related to an individual's perceptions of the benefits of care and the extent to which these meet their expectations.²⁶ Therefore the purpose of the first interview was to understand participant's expectations of hospitalisation and explore the circumstances that brought them into hospital. This interview occurred within 48 hours of admission, was conducted on the ward and lasted 20-30 minutes. The second interview occurred within one week of discharge and lasted 45-90 minutes. The purpose of the second interview was to explore the participant's experiences of having been in hospital.

A number of pre-determined open ended questions were used to guide the interviews. Interview guides for both the first and second interview were informed by a systematic review of the relevant literature.¹⁵ The interview guides were designed to elicit participant views regarding the expected

and actual benefits associated with being in hospital. The interviewer (JR) used an unstructured approach to interviewing which allowed for the emergence of themes that were relevant to the study aim.²⁷ Two pilot interviews were carried out to test the questions for clarity and understanding. As no changes were required, data from these interviews were included in the final analysis.

Data Analysis

All interviews were audio recorded and transcribed verbatim. The software programme *NVivo* was used to categorise data. A process of thematic analysis as described by Braun and Clark²⁸ was used to analyse the interview data. This involved a process of coding across the entire data set and then collating the codes into themes. Themes from within the data were identified using an inductive approach. There was no predetermined coding frame, instead this was developed as the data were coded and was subsequently applied to all transcripts. JR conducted and transcribed all interviews. CG and JR reviewed two transcripts independently to ensure consistency in coding and to clarify coding decisions. **All coding was done by JR with consensus regarding theme development reached during regular meetings with MG, CG and JR.**

Findings

A total of 14 participants were recruited. Twelve participants completed both interviews; two died prior to the second interview. Family were allowed to be present during the interviews if requested by participants. During seven interviews participant's family was present; however, the extent of participation varied.

Although participants were not directly questioned about their prognosis for ethical reasons, all appeared to understand that their illness was incurable and that over time it would progress. Participants were at varying stages of their illness (see table 2) and **the reasons for admission included symptom management, management of treatment side effects, investigations of new symptoms and exacerbations of non-malignant conditions (see table 3).**

Table 2 and 3 here

Participant's expectations of the benefits of being in hospital were based on unmet need prior to the admission. Most participants had their expectations met during the hospital admission. However,

many experienced additional benefits that were not identified by participants during the first interview.

Participants described a range of benefits related to their hospital admission and reported on their preferences for place of care. The benefits of being in hospital were reported to extend beyond the treatments they received, and all but one participant reported a preference on this occasion for hospital care, even if they had been able to access the care they received in hospital at home.

Four themes related to the benefits of being in hospital were identified from data collected from both interviews:

- Being cared for and feeling safe
- Getting help to manage at home
- Relief for family
- 'Getting and/or feeling better'

1. Being cared for and feeling safe

Most participants reported they felt relieved about being admitted to hospital. Not knowing why they were feeling unwell or why new symptoms had developed contributed to a sense of feeling unsafe at home. Furthermore staying at home came with a risk of becoming more unwell:

You are sitting at home on the side of the bed huffing and puffing and coming here knowing that. I had the nebuliser and I was doing all this but I mean if I got to the stage where I was breathing my last at least here is somebody there to do whatever it is. (89 year old woman with COPD)

Having knowledge about their symptoms, what was causing them and how they could be managed, was reported by some participants as a relief. Understanding the cause of the symptoms required investigations that could only be accessed in a hospital setting:

I knew there was something wrong with me and I needed my stomach drained. I didn't know that I needed that but they couldn't have done that at home but intuitively I knew because my own little health regime had broken down. (57 year old woman with cancer)

Knowing that the hospital staff were doing everything they could to understand the cause of their symptoms was reassuring for participants and contributed to a sense of being cared for:

This is what she said: this time whilst you are here we can't let anything get past us so either today or tomorrow or sometime I'm having a CT scan just of my head so they are going to look into that as well. (83 year old woman with cancer)

Hospital staff were seen as the 'experts' in managing illness. Some participants reported that coming to hospital provided them with an opportunity to access this expertise in a timely manner and to 'solve the problems' they were experiencing:

I suppose I learn things like what type of treatment I have. So if the doctor is managing me I don't have such knowledge to solve this problem to find out those questions, those answers so it is good, very good. Therefore the nurse and the doctor they got more information about my sickness. (60 year old man with cancer)

In addition, the ongoing observation and monitoring that are features of hospital care, as well as the expert help that is readily available, contributed to a feeling of being safe:

I feel safe here because I can press the buzzer three times and know that somebody is going to come running whereas I can't do that at home. (57 year old woman with cancer)

2. Getting help to manage at home

Many participants reported that they had received input from the multidisciplinary team including physiotherapists, occupational therapists and dieticians. Access to equipment to maintain their independence at home was facilitated during their hospital stay:

The hospital have been marvellous like in respect of helping me to stay at home. They have given me a hospital bed and they have helped me with things around the home to make my life easier like raise my chairs and rails. (77 year old man with cardiac disease)

Participants reported that they received education and support from staff to manage their care needs at home. Improving their mobility and independence was considered an essential component in preparing to manage at home for some participants:

Before I was twisting around but now I can just pop my legs behind me and then stand up and there's no pain on my legs, no stress on my back. All those things that before I was twisting and turning. So they may seem like little things but I think even as you get more debilitated they become more important. Before it was the bigger things, now it is the little things that make my life more manageable. (57 year old woman with cancer)

Another participant received input from the dietician who provided her with special foods and supplements that she felt would help her to remain physically strong. This advice was provided in conjunction with management of nausea and vomiting which had left the participant feeling frail:

They did the job I was there for which was to control the nausea and get me eating. They made very good suggestions for high health foods and to continue them at home that was very good. Big leaflets and lots of ideas for high health foods and managing the nausea. I am getting stronger. I got very weak with not eating but I am getting stronger. (83 year old woman with cancer)

3. Relief for family

Participants reported that their families felt relieved when they were admitted to hospital. This was seen as relief from the responsibility of decision making associated with caring for someone with a serious illness. One participant reported that his family **panicked** when he became unwell at home:

Being in the hospital is the best place because that way you know you are going to get looked after properly and at home, like all my family they don't know what to do and they just panic. (47 year old man with cancer)

Some participants expressed concerns for their family and were aware of the strain their illness placed on them. The benefit of being in hospital was related to relieving the burden on family having to care for someone at home who was unwell:

I was absolutely relieved. I thought there was no good me going home to my daughter. My daughter has been marvellous, absolutely marvellous looking after me but then she has started a big, new job today and she's working and got four children. (83 year old woman with cancer)

Some family present during the interviews reported that they felt relieved when the decision was finally made for their family member to go to hospital:

"It would have been on our conscience if we had...while she was at home not knowing what to do. We got her to hospital and she came out better." (Husband of 75 year old woman with cancer)

Participants also felt that their family were relieved when they saw them finally getting the treatment they needed which was only accessible in the hospital setting:

She's relieved that I'm getting some treatment. She's hoping that I will get well enough to start eating and hoping that I will get well enough to put some weight on and get strong. (83 year old woman with cancer)

4. 'Getting and/or feeling better'

Receiving care in the form of symptom management, investigations and treatment resulted in most participants 'feeling better'. Although some could not describe specifically what treatment they had received or how it had contributed to their improvement, all participants felt that they left hospital feeling better than when they had arrived:

I always feel like I'm really, really great when I come out of hospital and it makes me sort of feel like when I come out I know what I have got to do to make me feel better. (69 year old woman with cancer)

Moreover for some participants 'getting better' was the only way they could describe the benefits of being in hospital. Going to hospital was simply something they did when they felt unwell, and if they didn't go to hospital, some participants believed there was a risk they might die:

What do you think might happen if you don't go to hospital? (Interviewer)

If I don't go to hospital something might happen. I might die. (79 year old man with cardiac disease)

The fear of staying at home while unwell combined with previous experiences of 'feeling better' as a result of having been in hospital, influenced participants preferences for care. Almost all participants reported a preference to return to hospital if they became unwell again:

They give me treatment and then I recover and they send me home and then I come [to hospital] again ready for the challenge coming. (61 year old man with cancer)

'Getting better' was measured using clinical indicators and body language cues by some participants. For example one participant used laboratory results and the facial expressions of her doctor to understand the seriousness of her illness and whether she was getting better or not:

They say that the creatinine was at 230 which apparently is excessive and then some...from the expression on the man's face. It's now 200 and that's an improvement in the right direction but he said I am not prepared to let you go until its further down. (80 year old woman with cardiac disease)

Discussion

This is thought to be the first study to explore the benefits of hospitalizations from the perspective of patients with palliative care needs. Participants identified a number of benefits associated with the admission including being cared for and feeling safe, receiving care to manage at home, relief for family and 'getting better and/or feeling better'.

Whilst the concept of feeling safe has been defined for general hospital admissions,²⁹ within a palliative care context little is known about how feelings of safety influence preferences for place of care. Our findings suggest that a sense of feeling safe in hospital is associated with patients being cared for by staff who have expert knowledge and who are readily available should their condition change. Moreover a sense that staff were monitoring their condition contributed to their sense of security. Most studies examining patient experiences of feeling safe in hospital have been conducted in intensive care or emergency settings where staff have specialised technical knowledge and the level of monitoring and observation of patients is high.^{30,31} **Participants in this study were situated across the hospital which suggests that patient perceptions of 'expertise' are more pervasive and may relate to not just technical skill but also to a sense of competence and confidence patients feel in the staff caring for them.**

If a consequence of being in hospital is that patients 'feel safe', it may be logical to assume that being at home may feel 'less safe' at certain times. This was supported in our study by participants expressing anxiety about remaining at home when symptoms occurred that were unexplained or worsening. Furthermore the relief experienced by families when the hospital admission finally occurred indicated a level of anxiety for caregivers. Unexplained symptoms and sudden changes in the patient's condition can cause patients and families considerable fear and anxiety.³² Indeed, one study has described patients' experiences of palliative care at home as "uncertain safety". Anxieties about remaining at home when problems, such as unbearable pain, occur can leave patients feeling frightened and insecure.³²

When patients' needs are changing at home, community services are challenged to respond in a timely manner in order to ensure patients feel safe. Most participants in this study stated a preference to be in hospital rather than remain at home even if what had been provided in hospital could have been accessed at home. This suggests there is something unique about being in hospital

that might be difficult to replicate in the home setting. A recent study by Beernaert et al³³ explored barriers and facilitators to the early identification by general practitioners of palliative care needs. They found that patients often viewed their hospital physicians as being more capable than their general practitioner when dealing with specific manifestations of their illness. The authors found that general practitioners are less likely to be involved in patient care when they are receiving curative or life prolonging treatment and find it easier to identify palliative care needs in the last weeks of life when prognosis is clearer.³³ These factors can make it difficult for general practitioners to be involved in clinical decision making during a period of sudden deterioration or change in symptoms particularly when there is uncertainty about prognosis.

Caring for someone at home with a life limiting illness can be challenging for family caregivers.³⁴ The findings from our study suggested a level of burden for family that was associated with the responsibility of caregiving particularly when the patient was becoming unwell at home. A study by Skilbeck³⁵ found that carers were burdened not only by the physical work associated with caregiving but also the constant need to assess and monitor the patient for complications and changes in their condition. A study by Stajduhar et al³⁶ suggests carers feel frightened when unexpected changes in the patient's condition occur, and rely on services being responsive with ready access to health professionals to feel secure in their role as caregiver. Our study supports these findings and indicates that the presence of such expertise in hospital may be an important factor in reducing carer burden.

A sense of 'getting better' and 'feeling better' as a result of having been in hospital was a common theme throughout this study. These concepts in relation to people with a life limiting illness are poorly understood in the literature. A study by Beaton et al.³⁷ found that the underlying meaning of 'being better' for patients with musculoskeletal injuries reflected not just a resolution in the underlying disorder but were influenced by a person's experience of the illness, their coping styles and the comparators used to define health and illness, all of which can influence the experience of "being better".³⁷ In our study some participants used the concept of 'feeling better' as a way of articulating the benefits of having been in hospital. **Similar to Beaton's³⁷ study, the factors that contributed to participants 'feeling better' were not only associated with an improvement in the physiological parameters of their illness or a resolution of their symptoms.**

Strengths and limitations

To the best of our knowledge this is the first study to explore the benefits of hospitalization from the perspective of patients with palliative care needs. Purposive sampling was used to achieve wider resonance and maximise the diversity of the sample of patients with palliative care needs. A mix of age, diagnoses and ethnicities were captured within the selected sample. Furthermore participants represented a range of prognoses with 64% of participants having died within 12 months of being interviewed. By using longitudinal, semi-structured interviewing participants were able to speak freely about their experiences providing opportunities for rich and contextualised accounts of individual experiences over time.

However, some limitations must be acknowledged. Recruitment was limited to one urban hospital in New Zealand and four admitting services; therefore the findings may not have the same resonance in other countries or services. Participants were questioned about their experiences of one particular admission to hospital and assumptions cannot be made that they had similar experiences during other admissions. Nevertheless, many participants drew upon past experiences of having been in hospital during the interviews.

Conclusions

Perceptions of the appropriate role of the acute hospital in palliative care are predicated upon a number of factors including perceived preference for place of care, patient burden and cost. By exploring the benefits associated with hospitalisation from the perspectives of patients with palliative care needs, this research provides a unique contribution to the literature. Findings suggest that the benefits associated with being in hospital extend beyond the treatment patients receive to encompass feelings of safety and 'feeling and/or getting better'. Furthermore, hospitalisation enabled patients to access the help they needed to manage at home and relieved family of responsibilities of caregiving. These findings challenge current assumptions regarding the role of the acute hospital in palliative care provision in developed countries. Further research is needed to explore the apparent dissonance between the policy view of the appropriate role of hospitals within a palliative care context and the experiences and opinions of patients themselves.

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Conflict of interest

The authors declare that there is no conflict of interest.

Underlying research materials related to his paper including copies of interview schedules may be accessed by contacting the leading author.

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