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A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs

Robinson J, Gott M, Gardiner C and Ingleton C, Palliative Medicine, 2015

Introduction

The acute hospital continues to play a significant role in caring for people with a life limiting illness. Evidence shows that at any one time 13-36% of hospital inpatients meet the criteria for palliative care need (1-3) and approximately 30% of patients admitted to acute hospitals are likely to be in their last year of their life (4). Furthermore in developed countries most people will die in a hospital setting. Indeed, a comparison of institutional deaths across 45 countries concluded that, for half of those countries, more than 54% of deaths occur in the hospital (5).

People with a life limiting illness also spend a significant amount of time in a hospital setting in the last year of life (6, 7). Hospitals are where patients with exacerbations of chronic disease such as chronic obstructive pulmonary disease and heart failure will receive life prolonging therapies often over many years (8). It is also the setting where patients receive interventions such as imaging, intravenous antibiotics and surgery, all of which are increasingly used in palliative care to manage symptoms, improve quality of life and in some instances extend life (9). Furthermore as more people with cancer receive palliative chemotherapy and radiotherapy, hospital care is often needed to manage treatment complications such as pain and infection (10).

At a policy level there is an increasing interest in how hospitals are being used by patients with a life limiting illness. The UK End of Life Strategy (11) identifies hospital admissions as a key element of expenditure and suggests that the additional costs needed to support patient's preferences to be cared for and die at home, could be offset by a reduction in hospitalisations and length of stay. Hospitalization represents the principal component of cost in the last year of life (12) and research has concluded that avoiding hospital admissions could result in significant cost savings (13, 14). A systematic review of the literature exploring experiences of palliative care in a hospital setting identified that hospital admissions can be burdensome for patients and families (15). For example, studies have reported that patients can experience inadequate management of symptoms and the environment can be noisy and busy with little opportunity for privacy and quiet. Furthermore being involved in decision making can be difficult for patients and families (15).

Whilst the experience of hospital admissions for patients with palliative care needs has been extensively explored in the literature what is known is limited to discrete aspects of care (15). Moreover research to date has focused exclusively upon the negative aspects of hospitalisation. Currently there is nothing known about the benefits of hospital admissions for patients with palliative care needs. Understanding all aspects of the care experience including the benefits of being in hospital will contribute to a more balanced understanding of the role of the hospital for this cohort of patients. The aim of this qualitative study was to explore the benefits of hospital admissions, from the perspectives of patients with palliative care needs.

Design

Given the exploratory nature of the research, a qualitative study design was adopted. Longitudinal semi structured interviews were used to elicit the views of patients with palliative care needs admitted to hospital in one large urban acute hospital in New Zealand. The use of serial interviewing is considered to be a useful method of data collection, providing opportunities for rich and contextualised accounts of individual experiences over time. Furthermore the evolving researcher-participant relationships can create an environment of trust, enabling the participant to share a more personal account of their experience (16).

Study setting

Auckland City Hospital (ACH) is the largest public hospital in New Zealand and provides care for a socio-demographically diverse population (17). Ethics approval was obtained from the University of Auckland's Human Ethics Committee.

Study population

The study population consisted of patients admitted to ACH between July 2013 and March 2014 who met one of the Gold Standard Framework Prognostic Indicators (GSF-PIG) for palliative care need. Whilst primarily developed for the primary health setting, the GSF-PIG has been successfully used in research settings to identify hospital in-patients with palliative care needs (3, 18). A census study at ACH identified a 70% mortality after 12 months in patients identified as having palliative care needs in an acute hospital setting using the GSF-PIG (18).

Sampling

Participants were recruited from four admitting services – general medicine, oncology (medical and radiation), urology and general surgery. These services were chosen because they account for 30.8% of admissions for patients with a GSF diagnoses (unpublished data). A daily list of hospital admissions to these services was reviewed and past and current clinical notes were screened to assess patients eligibility (see table 1 for inclusion criteria). The interviewer (JR) also worked as a Nurse Practitioner with the ACH palliative care team. To avoid a conflict of interest as a result of the dual roles, participants that had been referred to the palliative care team were excluded from the study.

Table 1: Inclusion Criteria

Inclusion criteria
Admitted less > 48 hours ago
Speaks English
Not referred to hospital palliative care team
Meets one or more of the GSF PI's
Aged >18 years old

Eligible patients were approached by the ward nurse. The researcher was contacted directly by the nurse if the patient agreed to take part in the study. Written consent was obtained from all participants and any family who the participant requested to participate in the interview.

In order to maintain flexibility sample characteristics were not pre-determined, however factors identified from the literature known to influence experiences of hospital admissions such as age, diagnosis and ethnicity (19-21) (see table 2) were taken into account during the initial sampling process. This sequential, theoretical approach to sampling assists in highlighting variation and identify gaps in the data that require further exploration (22). A process of constant comparison analysis was used to inform the selection of subsequent participants (23).

Table 2: Participant characteristics (n=14)

Characteristics	n=14
Mean Age	69.8 years
Gender	
Male	7 (50%)
Female	7 (50%)
Ethnicity	
NZ European	6 (42.9%)
Maori	3 (21.5%)
Pacific	2 (14.3%)
Indian	1 (7.1%)
Chinese	1 (7.1%)
Other	1 (7.1%)
Diagnosis	
Cancer	9 (64.3%)
Non cancer	5 (35.7%)
Age	
18 – 39 years	0 (0%)
40 – 49 years	2 (14.3%)
50– 59 years	1 (7.1%)
60 – 69 years	3 (21.5%)
70 – 79 years	4 (28.6%)
80 – 89 years	4 (28.6%)
>90 years	0 (0%)
Admitting Service	
General Medicine	5 (35.7%)
Oncology	8 (57.1%)
Urology	1 (7.1%)
General Surgery	0 (0%)
Known to hospice	
Yes	8 (57.1%)
No	6 (42.9%)
Survival after interview	
< 6 months	5 (35.7%)
6 - 12 months	4 (28.6%)
> 12 months	5 (35.7%)

Data collection

Participants were interviewed twice. Expectation is considered to be a major determinant of satisfaction and is largely related to an individual's perceptions of the benefits of care and the extent to which these meet their expectations (24). 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 took place within 48 hours of admission, was conducted on the ward and lasted 20-30 minutes.

The second interview took place within one week of discharge from hospital and lasted 45-90 minutes. The purpose of the second interview was to explore fully participant's experiences of having been in hospital. Participants were given a choice of where this interview took place

A number of pre-determined open ended questions were used to guide the interviews. Two interview guides were developed after a review of literature related to patients experiences of hospital admissions in palliative care (15). Participants were asked about their perceptions of the expected and actual benefits and burdens associated with being in hospital. The data on burden is reported separately. The interviewer used a relatively unstructured approach to interviewing which allowed for the emergence of new themes that were relevant to the overall study aim (25).

Data Analysis

All interviews were audio recorded and transcribed verbatim. The software programme N-Vivo was used to aid categorisation of the data. A process of thematic analysis as described by Braun and Clark (26) 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 or patterns 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. Regular meetings were held with MG, CG and JR to review coding decisions and the development of themes.

Results

A total of 14 participants were recruited to the study. Twelve participants completed both interviews, two participants died prior to the second interview. Family were allowed to be present during the interviews if requested by participants. During seven interviews a member of the participant's family was present, but their participation in the narrative varied.

Although not asked directly all participants appeared to understand that their illness was not curable and that over time it would progress. Participants were at varying stages of their illness (see table 2).

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

Five themes related to the benefits of being in hospital were identified from the data, these will be discussed below:

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

1. Being cared for and feeling safe

Most participants reported that 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 not feeling safe at home. Furthermore staying at home was felt to come 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 and treatment 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 participant’s illness. Some participants reported that coming to hospital provided them with an opportunity to access this expertise in a timely manner if their condition was to worsen 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 is a feature of hospital care, alongside the ‘expert’ help that is readily available in the hospital setting, all 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

During their stay in hospital many participants reported that they had received input from other members of 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 hospital staff to manage their own care needs at home. Improving their mobility and increasing their 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 medical management of intractable nausea and vomiting which had left the participant feeling frail and tired.

“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 in terms of relief from the responsibility of decision making that was associated with caring for someone with a serious illness. One participant reported that their family experienced anxiety and panicked when he became unwell or developed new symptoms 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 the they just panic” (69 year old woman with cancer)

Some participants expressed concerns for their family and were aware of the strain their illness placed on them. For these participants the benefit of being admitted to hospital was related to relieving the burden on family of having to be cared for at home while they were so 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 better' and '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 feeling unwell combined with previous experiences of ‘feeling better’ as a result of having been in hospital, influenced participants preferences for care in the future. 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 the first study to explore the benefits of hospital admissions, from the perspectives of patients with palliative care needs who have experienced such an admission. Participants identified a number of benefits of having been in hospital including being cared for and feeling safe, receiving care to manage at home, relief for family and ‘getting better’.

Whilst the concept of feeling safe has been relatively well defined for general hospital admissions (27), within a palliative care context little 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 and observing 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 usually high (28, 29). Participants in this study were situated across the hospital in general medical and oncology wards suggesting that perceptions of 'expertise' are more pervasive and relate not just to technical skill, but also to a sense of competence and confidence in the staff caring for them.

If a consequence of being in hospital is that patients "feel safe", it is 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. Worsening and unexplained symptoms and sudden changes in the patient's condition can cause patients and families considerable fear and anxiety (30), 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 (31).

At times when patient's 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 al (31) 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 when patient 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 (31). 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 (ref). 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 Skilbeck (32) 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 al (33) 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 health and wellness for people with a life limiting illness are poorly understood in the literature. However, a study exploring the underlying meaning of 'being better' for patients with musculo-skeletal injuries reflected not just a resolution in the underlying disorder. Responses to "being better" were highly individual and 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"(34).

In our study some participants used the concept of 'feeling better' as a way of articulating the benefits of having been in hospital. The factors that contributed to participants 'feeling better' were not only associated with an improvement in the physiological parameters of their illness which in turn may improve the severity of their symptoms, but it was also associated with the benefits of being in hospital that extended beyond the treatment they received. This included a sense of being cared for and feeling safe during the admission, receiving the help they needed to maintain independence at home and the relief their families experienced when they received the care they need to become 'well' again.

The benefits of being in hospital reported by participants in this study may be difficult if not impossible to replicate in the community setting. Studies have shown that in order for people to spend time at home during the last days and weeks of life, improved service co-ordination including access to equipment, effective discharge planning and timely access to medical support is required (35). Our findings suggest that the hospital setting provides a unique set of circumstances that benefits the patient beyond just the treatment they receive.

Limitations

Recruitment was limited to one urban hospital in New Zealand and recruitment was limited to four specialty services therefore the findings may not be generalizable to 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 previous or subsequent

admissions, however many participants drew upon past experiences of having been in hospital during the interviews.

Conclusions

The role of the acute hospital is predicated upon patient preferences, but also upon a number of assumptions regarding the appropriateness of hospital care for patients with palliative care needs.. Hospitals provide life prolonging treatments that are also orientated towards improving symptom control and quality of life for patients with a life limiting illness. This research contributes to a greater understanding of the benefits associated with hospitalisation for patients with palliative care needs. The findings from our study suggest that the benefits associated with being in hospital extend beyond the treatment they receive. The perceived benefits of being in hospital are likely to influence patient's preference for place of care at certain times during their illness trajectory. Further research exploring the assumptions associated with the role of the hospital in palliative care and whether these assumptions are congruent with patient preferences for care at the end of life is required.

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