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Predictors of patient related benefit, burden and feeling safe in relation to hospital admissions in palliative care: a cross sectional survey

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What is already known about the topic?

- Hospital is rarely chosen as the preferred place of care or place of death.
- Palliative care policy internationally has 'problematised' the provision of palliative care in the hospital setting.
- Inadequacies in the hospital's physical surrounding and the cultural milieu of the hospital have been shown to impact negatively on patient's experiences of hospitalisation
- Recent qualitative research has identified that patients with palliative care needs experience benefits from hospitalisation such as feeling safe, relief for family, and receiving help to manage at home.

What this paper adds?

- Age, ethnicity, diagnosis and deprivation influence patient experiences of benefit and burden being in hospital in palliative care.
- 'Feeling safe' in hospital is a significant predictor of a preference to return to hospital during a period of acute illness in palliative care.

Implications for practice, theory or policy?

- Further research is needed to explore the factors that contribute to a sense of safety for patients in hospital particularly for those from non-Western cultures and those with a non-malignant illness.
- Understanding how "feeling safe" can be can be extended to other care settings may influence patient's preferences to return to hospital and contribute to a reduction in hospital admissions in palliative care.

- There needs to be recognition at a policy level that patients with palliative care needs do experience a benefit of being in hospital particularly those who are living in more deprived areas.

Predictors of patient related benefit, burden and feeling safe in relation to hospital admissions in palliative care: a cross-sectional survey."

Introduction

Hospital use within palliative care is under increasing scrutiny is given attempts to curtail rising healthcare costs.[1] Palliative care policy internationally has 'problematised' the provision of palliative care in the inpatient hospital setting, focusing instead on reducing hospital admissions and supporting patient's assumed preference to be cared for at home.[2] Inadequacies in the hospital's physical surrounding and the cultural milieu of the hospital have been shown to impact negatively on patient's experiences of hospitalisation[3,4] and are cited as support for the argument that those with palliative care needs should avoid a hospital admission. However, a recent systematic review of in-patient's experiences of palliative care in an acute hospital setting suggests that current evidence is limited to the negative aspects of care, with little attention paid to potential benefits of hospital admissions.[5]

Little is known about the preference for place of care for patients with palliative care needs during a period of acute illness. Furthermore, although hospital is rarely chosen as a preferred place of death[6,7] and despite an increasing support for community-based palliative care in many countries, patients return to hospital frequently during the last year of life.[8] It may be assumed that patients present to hospital for inpatient care for on treatment of their illness and that the benefits they experience are related to that treatment. However, recent qualitative research has shown that the benefits of being in hospital extend beyond the treatment received,[9] and these benefits appear to influence patients' preferences to return to hospita. Within this context, the aim of this research is to identify predictors of perceived benefit and burden of hospitalisation and how these experiences influence patient's preferences to return to hospital.

Methods

Study setting/recruitment

The study was set in a large tertiary hospital in urban New Zealand.[10] A previous study identified one fifth of the hospital's inpatient population were likely to be in the last year of life.[11] This data was used to guide recruitment and ensure the current study's population reflected that of the hospital. Recruitment took place in one oncology ward, four general medical wards and a respiratory ward. Participants were approached by ward nurses for consent.

Eligibility criteria

To be eligible participants had to be a hospital inpatient, aged > 18 years and able to speak English. In addition they had to meet at least one of the Gold Standards Framework prognostic indicators, indicating they were likely to be in their last year of life.[12]

Data collection

JR carried out the surveys directly with participants. Information regarding functional status was collected using the Karnofsky Performance Status (KPS).[13] Measures of deprivation were collected using the New Zealand Index of Deprivation (NZ Dep2013).[14]

Using the findings from an integrative literature review,[5] policy analysis[2] and qualitative research,[3,15] the variables benefit, burden and feeling safe were developed. Each variable consisted of several items (see supplementary information for a copy of the questionnaire). Feeling safe was found to be a significant factor in patient experiences of benefit in a previous study [15] therefore 'feeling safe' was developed as a separate variable. A fourth variable 'preferences to return to hospital' was also included. Using a five point, Likert scale participants were asked to score each item from within the variable as 1 "strongly agree" to 5 "strongly disagree".

Variables were tested for internal reliability. Given the small number of items for the fourth variable "benefits", an inter item correlation was used to test the internal reliability (0.20 with a range of between 0.082 and 0.67) suggesting that the items within the 'benefits' variable related well to each other.

Data Analysis

Statistical analysis was carried out in consultation with a statistician. Comparative group analysis was completed for gender, age, ethnicity, deprivation, diagnosis (cancer or non-malignant), functional score and living arrangements. Descriptive and inferential statistics appropriate to the level of measurement were utilised in the analyses. Statistically significant results using one way between subjects ANOVA are reported against 3 conditions; degrees of freedom (df), the F value (F) and the Sig. value (p value).

Analysis of variance (ANOVA) tests the effect of a categorical predictor variable (independent variable) on a continuous dependent variable. The ANOVA result is reported as an F-statistic (ratio of between-group variance/within-group variance) and its associated degrees of freedom (the number of values that are free to vary) and p-value. Because p is less than .05, the result is statistically significant, meaning that there is a consistent pattern that is unlikely due to chance. Statistical significance is impossible if F is less than 1.

Multivariate regression was undertaken to assess whether benefits, burdens and feeling safe in hospital significantly predicted a preference to return to hospital. Beta co-efficients were calculated to identify predictors of a preference to return to hospital. All data were coded into SPSS 20.

Results

One hundred sixty-three people were invited to be part of the study, 45 declined. One hundred and eighteen patients consented; two were unable to complete the survey due to fatigue. The final sample size was 116 (see table 1).

Place table 1 here

Results

Benefits

There was no statistical significance found in mean benefit scores for groups based on gender, age, ethnicity, diagnosis, functional scores or living arrangements. However, a statistically significant difference was found between deprivation groups (F (4, 109) = 3.15, p=.017). Post hoc testing revealed a statistical difference between deprivation index areas 3-4 and areas 7-8 (p=0.04) with those living in more deprived areas experiencing more benefit being in the hospital.

Feeling safe

No statistically significant difference was found between mean 'feeling safe' scores in the groups by gender, ethnicity, deprivation, functional level and living arrangements. There was a statistically significant ($p < .05$) difference between diagnostic groups with those who had a non-malignant diagnosis feeling less safe in hospital (p=.04) There was also a statistically significant difference between age groups (F (2, 113) = 3.36, p=.03). The main effects of age (F (2, 114) = 4.50, p=.01) and diagnosis (F (1, 111) = 5.6, p=.01) on feeling safe were significant. Younger people felt safer compared to older people.

Burden

There was no statistical difference between mean burden scores in groups based on gender, deprivation, diagnosis, level of function and living arrangements. However, a statistically significant difference in burden scores was found between age groups (*F* (2, 111) =7.78, *p*=.000) and ethnicity (*F* (4, 109)=4.44, *p*=.00). Pacific ($\bar{x}$ =39.42, SD=5.85) and Asian people ($\bar{x}$ =43.33, SD=5.68) experienced significantly more burden being in hospital (MD=7.64, MD=11.55; p=.00).

An interaction effect was found between living alone and ethnicity (F(1, 100)=3.50, *p=.03*); the effect size was small (partial eta squared = .06). Post hoc testing revealed differences between ethnic groups with Pacifica ($\bar{x}$ -41.16, SD=3.97) and Asian groups ($\bar{x}$ =43.33, SD=5.68) who were living with others experiencing significantly more burden compared to NZ European who were living with others ($\bar{x}$ =32.73, SD=6.58).

Preferences to return to hospital

The model benefits, burdens and feeling safe was significant (p=0.02). When comparing the unique contribution of each independent variable, 'feeling safe' had the largest beta coefficient indicating a statistically significant (*B*=0.14, *p*=0.03) contribution to the dependent variable 'preferences to return to hospital' (see table 2).

Table 2 here

Discussion

This study adds new information about the benefits associated with hospitalisation for patients with palliative care needs. The findings showed those living in more deprived areas experienced greater 'benefit' being in hospital. Experience of benefit being in hospital may lead to more frequent use of the hospital as a place of care. This is consistent with a recent study by Macfarlane and Carduff[16] showing that those experiencing greater deprivation are more likely to die in hospital and less likely to die in a hospice setting, even if they are known to specialist palliative care services.

We also found that those with a non-malignant illness felt less safe in hospital compared to those with cancer. Feeling safe as a concept has been related to the gaining of knowledge by patients about their health status.[17] However, for those with palliative care needs, knowledge about a limited prognosis cannot be assumed. A study by Gardiner et. al[18] showed that patients with COPD expressed concerns about the manner in which they would die, however none of the patients' had discussed their fears with a health professional. This lack of knowledge about the nature of their illness may lead to increased feelings of being unsafe in hospital.

In this study, New Zealand European participants experienced significantly less burden being in the hospital compared to Asian and Pacific participants. This is perhaps unsurprising given that Western cultural ideals underpin the delivery of care in hospitals. For example, Asian and Pacific cultures are known to place value on a community or collective approach to decisions regarding their health.[19,20] However, within a Western framework individual autonomy and support for patient preferences are central to clinical decision making.[20] This difference creates problems for both staff[21] and patients.[22]

A preference to be cared for outside the hospital setting for those with palliative care needs has been well documented in the literature.[6,7,23] However indicating a preference for a 'home" death may be "premised on a mutual, culturally normative, assumption that the most 'natural' place to prefer to die would be the home."[7] As this research demonstrates, this preference cannot be viewed in the abstract. Rather as circumstances change, preferences may also change. 'Feeling safe' during the current hospital admission was found to be the greatest predictor for a preference to return to hospital in this research. This suggests that hospitals can assume a 'home-like' aspect for some people, given that feelings of safety are central to notions of 'home'.[24]

Strengths and limitations

Surveying participants as they neared the end of the admission meant that participants were drawing upon very recent experiences of being in hospital.[25] However, recruitment was limited to one hospital in New Zealand and three specialty services; therefore the findings may not have the same resonance in other countries or services. In addition, the standardisation of questionnaires means that participants were forced to give set answers to questions that may not truly reflect their individual experiences. Finally, it is unclear whether the non-participant group was the same demographically as those who agreed to participate in the study. This may have influenced the interpretation of the findings.

Recommendations for policy, practice and research

Further research is needed to understand the factors that contribute to a sense of safety for patients with palliative care needs across different care settings thereby ensuring that hospitals are not the 'default care provider' when patients feel unsafe at home. Using a qualitative approach to data collection could provide rich contextualised data regarding experiences of feeling safe.[26] The policy focus on reducing hospital admissions in palliative care[2] should include evidence of the benefits of hospitalisation in order to identify appropriate strategies that will ensure hospitals are used wisely in palliative care. In addition, understanding the meaning of 'feeling safe' for patients and identifying occasions when patients may not feel safe, is an important addition to how clinicians might support patients preferences for place of care not just at the end of life but throughout the illness trajectory.

Conclusion

This study demonstrates that deprivation, diagnosis, age and ethnicity influence patient experiences of benefit and burden in hospital within a palliative care context. Furthermore, feeling safe (a substantial benefit of being in hospital) was identified as a significant predictor for a preference to return to hospital. Patients experiences of benefit and burden related to hospitalisation will influence their preferences for place of care at different times of their illness trajectory.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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References

1. Simoens S, Kutten B, Keirse E, et al. The costs of treating terminal patients. *J Pain Symptom Manage* 2010; 40: 436-48.
2. Robinson J, Gott M, Gardiner C, et al. The ‘problematisation’ of palliative care in hospital: an exploratory review of international palliative care policy in five countries. 2016; 15.
3. Robinson J, Gott M, Ingleton C, et al. The impact of the environment on experiences of hospital admissions from the perspectives of patients with palliative care needs. 2015; *Under review*.
4. Gardiner C, Cobb M, Gott M, et al. Barriers to providing palliative care for older people in acute hospitals. *Age Ageing* 2010; 40: 233-38.
5. Robinson J, Gott M and Ingleton C. Patient and family experiences of palliative care in hospital: What do we know? An integrative review. *Palliat Med* 2014; 28: 18-33.
6. Arnold E, Finucane A and Oxenham D. Preferred place of death for patients referred to a specialist palliative care service. 2013; 13.
7. Thomas C, Morris S and Clark D. Place of death: preferences among cancer patients and their carers. *Soc Sci Med* 2004; 58: 2431–44.
8. Goldsbury DE, O'Connell DL, Girgis A, et al. Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: a populaton-based retrospective cohort study. 2015.
9. Robinson J. Are there any benefits to hospital admissions for people with palliative care needs? In: Care EAoP, (ed.). 2015.
10. Auckland District Health Board. About the Auckland DHB. 2014.
11. Gott M, Frey R, Raphael D, et al. Palliative care need and management in the acute hospital setting: a census of one New Zealand Hospital. *BMC Palliat Care* 2012; 12.
12. Gold Standards Framework. p. http://www.goldstandardsframework.nhs.uk.
13. Peus D, Newcomb N and Hofer S. Appraisal of the Karnofksy Performance Status and proposal of a simple algorithmic system for its evaluation. *BMC Med Inform Decis Mak* 2013; 13.
14. *NZDep2013 Index of Deprivation*. University of Otago, Wellington, New Zealand, 2014.
15. Robinson J, Gott M, Gardiner C, et al. A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliat Med* 2015; 29: 703-10.
16. Macfarlane M and Carduff E. Does place of death vary by deprivation for patients known to specialist palliative care services? 2016.
17. Stenwall E. J, M.E. J, J. S, et al. The older patient’s experience of encountering professional carers and close relatives during an acute confusional state: an interview study. 2008; 45.
18. Gardiner C, Gott M, Small N, et al. Living with advanced chronic obstructive pulmonary disease: patients concerns regarding death and dying. *Palliat Med* 2009; 23: 691-7.
19. McLaughlin L and Braun KL. Asian and Pacific Islander cultural values. *Health Soc Work* 1998; 23: 116-26.
20. Tsai F-C. Personhood and autonomy in multicultural health care settings. 2008; 10: 171-6.
21. Gott M, Ingleton C, Bennett MI, et al. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ Support Palliat Care* 2011: 42-8.
22. Kagawa-Singer M and Blackhall LJ. Negotiating Cross-Cultural Issues at the End of Life. “You Got to Go Where He Lives”. 2001; 286: 2993-3001.
23. Stajduhar K, Allan D, Cohen S, et al. Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers. *Palliat Med* 2008; 22: 85-8.
24. Williams AM. Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. 2002; 55: 141-51.

25. Bhandari A and Wagner T. Self-reported utlization of health care services: improving measurement and accuracy. 2006; 63: 217-35.
26. Collier A, Phillips JL and Iedema R. The meaning of home at the end of life: a video reflexive ethnography study. *Palliat Med* 2015; 29: 695-702.