Exploring why some terminally ill people die in hospital when home was their preferred choice

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Disclaimer

One of the authors completed the study as part of her Masters program at Murdoch University, and was an employee of the Port Pirie Palliative Care Service, Country Health SA Local Health Network.

KEY WORDS

Palliative Care, home death, hospital death, preferred site of death, rural

ABSTRACT

Objective

This small study was designed to gain a better understanding of issues that led to hospital admission of palliative care clients who had a preference for home death, but died in hospital.

Design

A mixed method approach was chosen for the study using descriptive analysis of routinely collected client demographic and clinical data, and conventional content analysis of case note entries.

Setting

The study was undertaken in two community based palliative care services located in rural South Australia.

Subjects

The case notes of fourteen deceased adults registered with the Northern Yorke Peninsula and Port Pirie Palliative Care Services, with a recorded preferred site of death (PSD) of home and who died in hospital were studied.

Main outcome measure

Understanding of issues that may have led to hospital admission of palliative care clients who had a preference for home death but who died in hospital.

Results

The findings reported here focus only on the qualitative aspect of the study. Issues that may lead to hospital admission include: unstable symptoms, deteriorating condition, client/caregiver decision making, lack of services over twenty four hours and the caregiver's ability to manage client care.

Conclusion

Services can now consider these findings and develop local strategies to improve support for clients with a preference to die at home, and in particular, those that focus on improving caregiver training and information.

INTRODUCTION

It is well documented that many terminally ill people, given the choice, would prefer to die at home (Van den Block et al 2007; Beccare et al 2006; Foreman et al 2006), however many still continue to die in hospital (Bell et al 2010; Bruera et al 2002). The Northern Yorke Peninsula and Port Pirie Palliative Care Services (referred to below as the Palliative Care Services) are located in rural South Australia, as part of the state government Country Health SA Local Health Network (CHSALHN) hospital and health services system. The Palliative Care Services are coordinated by nurses working in partnership with local medical practitioners, generalist community nurses and allied health staff to support terminally ill people in the community. Palliative care medical specialist support is available from the city of Adelaide (over 150 kilometres away) via telemedicine facilities and occasional rural service visits, there are no hospices located in the service areas. The home death rate for people referred to the Port Pirie Palliative Care Service in 2012 was 12.5 %. This percentage is low when compared with what has been written in the literature regarding terminally ill people’s preference to die at home. An understanding of what led people with a recorded preference for home death to be admitted to hospital where they then died was needed to enable palliative care services to develop strategies to support people with their choice.

LITERATURE REVIEW

A literature review was conducted to source information on previous studies that explored preferred site of death for palliative care clients and indicators for hospital admission. The review of research literature revealed a focus on quantitative methods of data collection and analysis (Howat et al 2007; Van den Block et al 2007; Beccare et al 2006; Chvetzoff et al 2005; Bruera et al 2002; Tang 2002). Studies conducted in Australia and specifically in a regional area were limited (King and Fischer 2010; Howat et al 2007; Foreman et al 2006). No papers were found that specifically described exploratory or descriptive patient experience study designs. The gaps identified in the literature relate firstly to studies conducted in the context of rural Australia and secondly to qualitative studies describing the study design as an exploration, description or reporting on themes within this particular area of care.

AIMS

The study had two aims, firstly to develop an understanding of issues that led to hospital admission of palliative care clients who had a preference for home death but who died in hospital. Secondly, identification of factors that could identify risk of hospital admission for clients with a preference for home death. The specific research questions were: (1) What factors can be identified that lead to hospital admission of people who die in hospital, with a recorded preference for home death? (2) Are there any other considerations which influence a decision to enter hospital for patients with a recorded preference for home death but die in hospital?

METHODOLOGY

A mixed method approach using both qualitative and quantitative retrospective data collection was chosen for the study. The analysis of quantitative data provides a method for examining some readily available variables from patient records; however an exploration of client and caregivers experience was also needed to understand the issues that could not be identified through quantitative data analysis alone. Descriptive analysis was conducted on demographic and clinical data, and conventional content analysis was used to explore deceased client case note entries which were more qualitative in nature. Ethics approval was obtained from the SA Health Human Research and Murdoch University ethics committees; this included one amendment following initial data collection. This paper reports on the qualitative research findings only. A copy of the report can be obtained by contacting the authors.

Sample Selection

Case notes of deceased adults registered with the Palliative Care Services with a recorded preferred site of death (PSD) of home and who died in a CHSALHN hospital were the focus of the study.

A report identifying the total number of client deaths (N=182) between the dates of 1 February 2011 to 1 June 2013 was extracted from the data management system used by both Palliative Care Services. The PSD code, located in the data systems' palliative care episode information, was used to identify client PSD which was recorded for 46 (25.27%) clients and not recorded for 136 clients (74.73 %). The case notes of deceased clients with a recorded PSD of home (N=14) were included in the study.

Qualitative Data Collection and Analysis

Photocopied case note entries in the four weeks prior to the hospital admission date that ended in death for the 14 deceased people in the study sample were de-identified, relabelled and provided to the researcher. The period of four weeks was chosen to enable exploration of the client and caregiver experience leading up to the hospital admission, without focussing solely on the immediate reason for which the person was admitted. The case note entries were written by allied health clinicians, specialist palliative care and generalist nursing staff, and captured the complexity of some individual cases, experiences and perceptions of clients and their caregivers in the home environment.

Conventional content analysis was chosen to explore the case notes (Hsieh and Shannon 2005). This method required the researcher to read the de-identified case notes several times, identifying keywords that could provide some understanding of what may have led to a person with a preference to die at home to be admitted to hospital where they died (Hsieh and Shannon 2005).

FINDINGS

Through the process of conventional content analysis 144 level 1 codes were identified. Examples of level 1 codes were 'client scared', 'hopes to die soon' and 'client fear of losing bodily functions' which were grouped to form the level 2 category of client psychological distress. The level 2 categories were then clustered together to create level 3 category clusters. The level 3 category clusters led to the development of the level 4 category themes. Four main study themes were generated describing the experiences of the study population as recorded in the case notes (see figure 1).

Theme 1: Services to support end of life care at home

Service issues identified included hospital attendance, out of hours support needed, delay in service provision and support not available. Of note was the advice of nurses to caregiver's to bring the client to hospital if symptoms were unmanaged or the caregiver was unable to cope. It is likely that if the client presents to hospital in an unstable condition, or if the caregiver has stated they are unable to cope, that the client will be admitted to hospital for terminal care.

Theme 2: Caregivers' role in providing end of life care

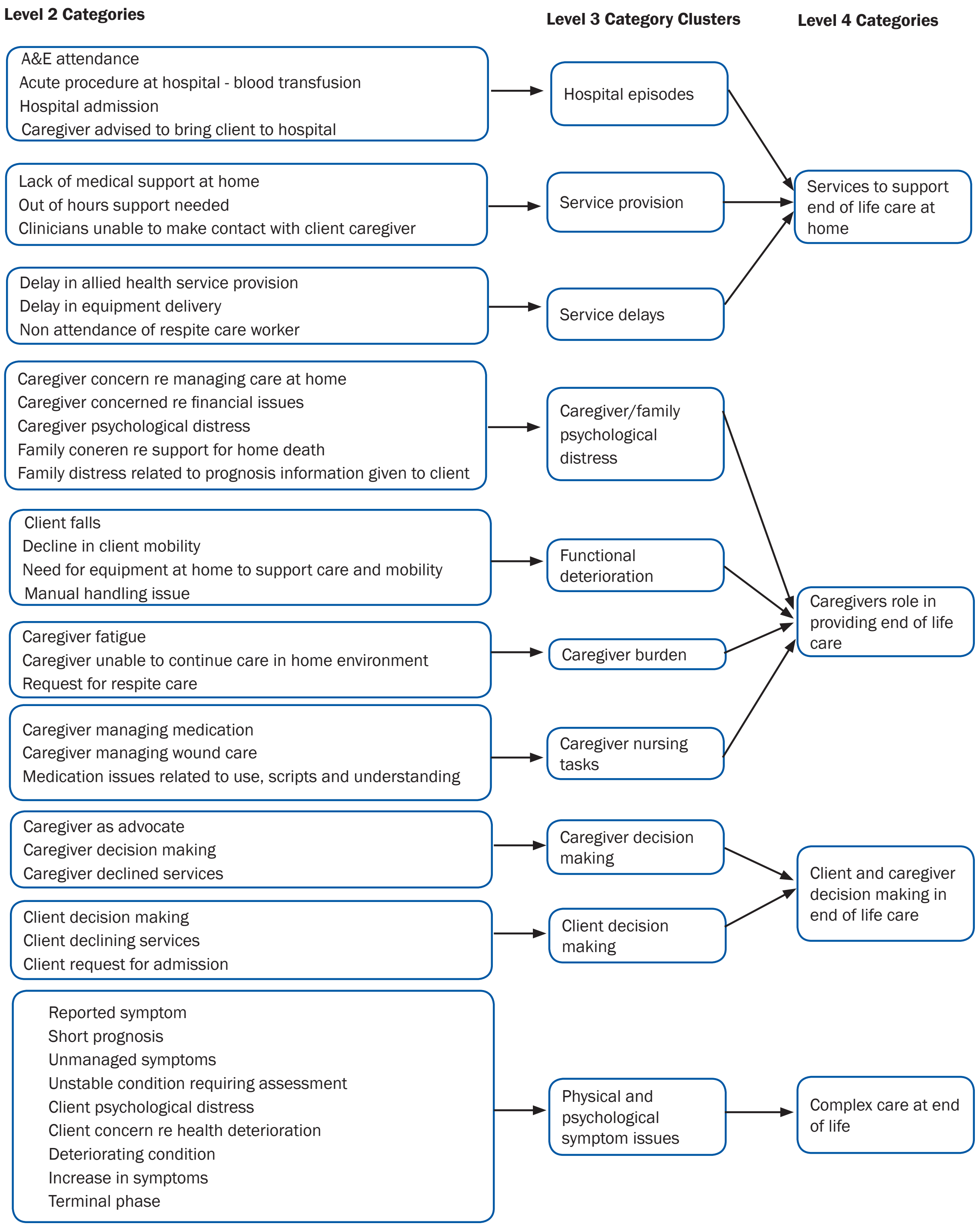
Caregiver issues identified included practical nursing tasks, caregiver burden and psychological distress. Medication management and manual handling were identified as the most commonly occurring caregiver nursing tasks.

Medication management

Medication codes were used when the case note entries described caregivers having responsibility for management or administration of medications. This was identified on eleven occasions for three clients.

Of note was the complexity of individual cases, with caregivers required to understand which medication to give

Figure 1: Level 2 categories, level 3 category clusters and level 4 categories (themes)



for which symptom, administer injectable drugs and on one occasion change the syringe in a syringe pump.

The following are examples of case note entries:

'…visited on weekend and inserted Intima T s/c line and showed caregiver how to administer s/c medications.'

'husband said he would give client "what she likes" and gave her Tramadol 50mg tablet.'

If medication use and administration are not fully understood by the client or caregiver there is potential for poor symptom control and errors leading to further problems. The responsibility of managing complex medication regimes can lead to significant burden for the caregiver (Tamayo et al 2010).

Manual handling

Manual handling issues included the need for equipment, caregiver and client statements of difficulty moving and mobility issues. If caregivers are unable to provide basic care due to difficulties in moving clients they may be inclined to request hospital admission where they know staff are trained to manage this. The following text was taken from individual client case notes:

> *'…he is a dead weight", and "I can't move him."'*
>
> *'client having difficulty getting out of bed and to toilet on time'*

Theme 3: Client and caregiver decision making in end of life care

Decision making by both the caregiver and client was commonly identified throughout the case notes. Decision making related to; service provision, health professional advice, use of equipment, activities of daily living, medications and site of care. While client/caregiver choice is supported, decisions made influence the outcomes of care. A number of examples from the client case notes demonstrate how client/caregivers decisions could lead to hospital admission:

> *'GP reported client not taking prescribed tablets and did not want to follow his advice.'*
>
> *'GP visiting later today but carer unsure if client could wait this long. Declined attending the GP surgery earlier if an appointment were available.'*
>
> *'Discussed electric bed option and explained benefit of air mattress for pressure relief but clients husband saying they will have to think about it and didn't feel client needed'*

Worsening or unstable client symptoms from non-compliance of medication regimes, development of pressure injuries and the decision not to access medical support early could all lead to hospital admission if the client becomes distressed or the caregiver feels that they are not able to provide adequate care (Topf et al 2013).

Theme 4: Complex care at end of life

Complex care issues were identified: these included client physical and psychological issues. The physical issues related to newly reported, unmanaged or increase in symptoms, deteriorating condition and terminal phase. Psychological distress related to client concern for themselves and their caregivers, anxiety, fear, desire to die statements and crying. The following are examples of care issues that could lead to a hospital admission if they remain unmanaged or increase in severity:

> *'Large necrotic area to both buttocks observed.'*
>
> *'Carer reports client is "anxious and at times this exacerbates her breathlessness"'*

DISCUSSION

Caregivers and clients are expected to make many decisions relating to their care at end of life. There are times when the decisions made can differ from the advice given by health professionals, with the outcome sometimes resulting in hospital admission. Caregivers and clients require accurate information so they are fully informed and understand the consequences of the decisions they make in relation to facilitating a home death. It is a reality that home death for some clients is not possible and this too should be discussed (Topf et al 2013).

Caregivers are fundamental in supporting people with end of life care in the home environment, undertaking many tasks day and night for which they may have had no previous experience or training (Tamayo et al 2010; Rabow et al 2004). This role may include, but not be limited to manual handling, medication management and care decision making. Assessment of caregiver capability, their expectations of the caring role and provision of training in areas needed to support them in their role is therefore needed (Topf et al 2013; Tamayo et al 2010; Bee et al 2009). There were few entries in the case notes that indicated this had occurred but it is also possible that health professionals do not record all relevant information in case notes and this too can be problematic.

Unstable symptoms and deteriorating condition were frequently identified in the case note entries. Symptom assessment and medication management are skills nurses obtain through formal training and experience. Carers are often expected to complete these tasks 24 hours a day and at times with limited access to services (Topf et al 2013; Tamayo et al 2010; Thomas et al 2010). The alternative is to bring the dying person to hospital for help with care. Many caregivers will attempt to honour the client's preference to die at home, and only when the unstable symptoms become too difficult for the caregiver to manage or the client to tolerate, will they transfer them to hospital (Topf et al 2013). Admission to hospital at end of life is likely to result in the client dying in hospital (Van den Block et al 2007). Lack of services in rural areas to support caregivers and clients to remain in the community when needed, and an automatic reliance on the hospital as the only alternative plan, will lead to more hospital deaths and less people dying at home.

LIMITATIONS

This was a small pilot study and could not be considered representative of the population. The study was reliant on the quality of the note makers and many busy staff will be less inclined to make detailed notes about weighing up the pros and cons of particular care options, personal reflections and decision-making. What they recorded will inevitably be an approximation of the clients' and caregivers' account and their own professional assessment of needs. In addition, the study used the recorded PSD however, details of when this had been recorded and if it was still the client's preference at end of life could not be determined.

CONCLUSION

Understanding reasons why people with a preference for home death are admitted to hospital where they then die is important if services are to support people with their choice. Issues that could have led to people being admitted to hospital when they had a preference to die at home include: deteriorating client condition and unstable symptoms, client/caregiver decision making, caregiver ability to manage care and lack of services over twenty four hours. Caregivers and the issues they encountered while caring for a terminally ill person in the last four weeks of life were identified in all four study themes. The development of strategies to support caregivers in their role would therefore seem paramount to improving the likelihood of people dying at home, and in particular, those that focus on improving caregiver training and information.

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