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# Families and caregivers of older people: Expectations, communication and care decisions



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## KEYWORDS

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**Summary** While family caregivers may temporarily relinquish responsibility for daily care to health professionals for the period of hospitalization, new expectations and demands are placed upon them. Family caregivers can be asked to commit to new relationships with health professionals, contribute to care decisions and discharge planning. For the caregivers of older patients these new expectations may be challenging, and contribute to feelings of burden and increased stress. The aim of this qualitative descriptive study was to explore the experience of family caregivers when their relative is an inpatient in this outer Melbourne geriatric evaluation and management facility. This study found that the burden associated with the experience of caregiving continued despite the hospitalization of their relative. The challenges faced by families included communicating with health professionals, and being asked to contribute to care decisions, in particular those regarding discharge planning, and managing conflict. In conclusion, the issues and challenges faced by family caregivers needs to be acknowledged and considered as an extension of patient care planning.

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## Introduction

There is a growing focus on improving the way that Australian health services communicate and consult with families and caregivers. This is reflected in the Victorian government initiative 'Best care for older people everywhere' toolkit (Department of Health, 2011) which is a key deliverable in the strategic plan of the health service in which this study is set. Family caregivers can experience a high level of

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anxiety when their relative goes into hospital, and caregiver resilience and support are important predictors of successful discharge planning (Bauer, Fitzgerald, Koch, & King, 2011; Cox, 1996; Efraimsson, Sandman, Hyden & Rasmussen, 2006; Haesler, Bauer, & Nay, 2007) – one of many reasons that this is essential to maintain. In the case of older people, especially those with dementia, the processes used by hospitals to prepare families to receive them back into the community are vital to a successful discharge. Failure to consult and adequately communicate with the families results in a greater risk of re-admission (Fitzgerald, Bauer, Koch, & King, 2011; Haesler, Bauer, & Nay, 2008; Hennings, Froggatt, & Keady, 2010).

Family caregivers are frequently called on to participate in decision-making on behalf of their relatives. This responsibility can be accompanied by feelings of burden and anxiety and it is important to ensure that adequate support is provided to them to avoid rushed decision-making and poor outcomes, both of which may lead to dissatisfaction with care (Hines et al., 2011). It is particularly necessary when the decisions are about life-sustaining treatment, as the burden of making these decisions can have on-going psychological consequences for the decision-maker (Hansen, Archbold, Stewart, Westfall, & Ganzini, 2005). Family caregivers can feel overwhelmed by the healthcare system about which they have little knowledge and this can lead to a feeling of powerlessness and the inability to influence the decisions advocated by the clinical team (Efraimsson et al., 2006). When communication is used effectively, better outcomes ensue for the patient and their families, and importantly the compassion of the staff is evident.

Many of the family caregivers of people in sub-acute care may need considerable support to navigate their way through the health system and to ensure that they are able to continue as caregiver once their relative is discharged, as they are often older and may have health issues themselves (Haesler et al., 2008). There is a danger that vulnerable family caregivers can feel disempowered by the health care system, as a result of their exclusion from decision-making and the lack of recognition for their 'expertise' in the care of their relative (Bauer, Fitzgerald, Haesler & Manfrin, 2009; Douglas-Dunbar & Gardiner, 2007; Haesler, Bauer, & Nay, 2010). In many instances older people are likely to defer to the opinion of the health professional rather than contribute to decision-making (Stewart, Meredith, Brown, & Galajda, 2000). The stress and anxiety felt by family caregivers when their relative is an inpatient cannot be underestimated. Excluding them from discussions is counterproductive as the success of discharge is dependent on the capabilities of the family to manage the care of the person at home. Their input into discharge planning is therefore fundamental.

The health service in which this study was set has an interdisciplinary care programme, which aims to promote a cohesive interdisciplinary team approach which is focused on person centred goals and outcomes and facilitates patient and carer involvement in care (Peninsula Health, 2013). This focus on person centred goals and outcomes underpins the delivery of care to the sub-acute inpatients. The main principles include a person-centred approach which is delivered by an interdisciplinary team supported by best practice evidence (Bourke & Edis, 2011). Person-centred care in this facility is defined as 'treatment and care ... that places the

person at the centre of their own care and considers the needs of the older person's carer' (Victorian Government Department of Human Services, 2003). In this model the perspectives of the patients and family are central to the planning and delivery of care, and the clinical team need to get to know the person and their circumstances beyond the diagnosis. Effective information sharing between the clinicians, the patients and families is essential to enable informed choices which are incorporated and respected by the team. To facilitate this communication, each patient and family is assigned a clinician as 'key contact person' (KCP) whose role is to liaise between the patient/family and the team, and advocate for the patient in team discussions. Due to the nature of shift work, nurses are less likely to undertake the KCP role compared to allied health professionals who are consistently available on weekdays.

No Australian studies were found which examine the actual success of communication with families in sub-acute care; hence this study was undertaken in a 60-bed geriatric evaluation and management (GEM) facility in outer Melbourne.

## Research questions

- How do family caregivers perceive the communication with health professionals while their relative is an inpatient in this facility?
- What is the family caregivers' experience of their involvement in discharge planning and decision-making for their relative?
- What are the opportunities for improvement in communication with families as seen through their eyes?

## Aim

The aim of the research is to better understand the experience of the family carers when their relative is an inpatient in the sub-acute facility, particularly regarding communication with the clinical team and involvement in care decisions.

## Setting

The setting for this study was a 60-bed geriatric evaluation and management facility which is part of an outer Melbourne Australia health network. The majority of the patients are admitted from the nearby acute hospital where they have been treated for an acute illness or injury, and many of them have multiple co-morbidities and chronic illnesses. Orthopaedic or neurological conditions, cardiovascular disease including stroke, respiratory diseases and malignancies are frequent presenting diagnoses, and the complicating issues of dementia, diabetes and obesity are common. The busy, noisy and unfamiliar hospital environment can exacerbate spatial disorientation and anxiety in the person with dementia, subsequently leading to unsettled or aggressive behaviour (Marquandt, 2011) adding additional challenges to care. The average age of the patients is 85 and the average length of stay (LOS) is 23 days, with approximately one third being discharged to residential

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