



Outcomes for family carers of a nurse-delivered hospital discharge intervention for older people (the Further Enabling Care at Home Program): Single blind randomised controlled trial



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ABSTRACT

Background: Hospital discharge of older people receiving care at home offers a salient opportunity to identify and address their family caregivers' self-identified support needs.

Objectives: This study tested the hypothesis that the extent to which family caregivers of older people discharged home from hospital felt prepared to provide care at home would be positively influenced by their inclusion in the new Further Enabling Care at Home program.

Design: This single-blind randomised controlled trial compared outcomes from usual care alone with those from usual care plus the new program. The program, delivered by a specially trained nurse over the telephone, included: support to facilitate understanding of the patient's discharge letter; caregiver support needs assessment; caregiver prioritisation of urgent needs; and collaborative guidance, from the nurse, regarding accessing supports.

Setting and participants: Dyads were recruited from the medical assessment unit of a Western Australian metropolitan public hospital. Each dyad comprised a patient aged 70 years or older plus an English speaking family caregiver.

Methods: The primary outcome was the caregiver's self-reported preparedness to provide care for the patient. Data collection time points were designated as: Time 1, within four days of discharge; Time 2, 15–21 days after discharge; Time 3, six weeks after discharge. Other measures included caregivers' ratings of: their health, patients' symptoms and independence, caregiver strain, family well-being, caregiver stress, and positive appraisals of caregiving. Data were collected by telephone.

Results: Complete data sets were obtained from 62 intervention group caregivers and 79 controls. Groups were equivalent at baseline. Needs prioritised most often by caregivers were: to know whom to contact and what to expect in the future and to access practical help at home. Support guidance included how to: access help, information, and resources; develop crisis plans; obtain referrals and services; and organise legal requirements.

Compared to controls, preparedness to care improved in the intervention group from Time 1 to Time 2 (effect size = 0.52; $p = 0.006$) and from Time 1 to Time 3 (effect size = 0.43; $p = 0.019$). These improvements corresponded to a change of approximately 2 points on the Preparedness for Caregiving instrument. Small but significant positive impacts were also observed in other outcomes, including caregiver strain.

Conclusions: These unequivocal findings provide a basis for considering the Furthering Enabling Care at Home program's implementation in this and other similar settings. Further testing is required to determine the generalisability of results.

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What is already known about the topic?

- Numerous studies have investigated older peoples' outcomes from interventions instigated at the point of their hospital discharge.
- By comparison, there has been a limited focus on outcomes for their family caregivers at discharge.

What this paper adds

- Improvements in family caregivers' self-reported preparedness for caregiving were found when a specially trained nurse implemented the Further Enabling Care at Home program upon the hospital discharge of the older person receiving care.
- Positive impacts were also observed in these caregivers' levels of self-reported distress and strain and in their ratings of the care recipients' symptoms.

1. Background

Old age is associated with the increased prevalence of health issues, including cardiovascular disease, dementia, and multi-morbidity and all countries are expected to experience population ageing within the next 15 years (Bloom et al., 2015). Therefore, care for older people in poor health is a global priority. As this priority is realised, home care provided by family and friends (family caregiving) is increasingly recognised as a vital health care component.

A recent systematic review of support interventions for caregivers of frail older people living at home determined impacts to be small and inconsistent (Lopez-Hartmann et al., 2012). Conclusions were that the dynamic and individual nature of caregivers' situations warrants support needs assessment to address caregivers' priorities, contexts, and existing resources; also that multiple services are often required to provide a suitably tailored response. One opportunity to address this issue is when a health care crisis for the older person results in hospital admission, triggering a nexus between formal and informal caregiving at a time when the patients' needs are clearly evident.

1.1. Caregivers of older people in hospital

The evidence indicates, however, that the importance of the older person's family caregiver may not always be fully recognised within the hospital context. A systematic review of qualitative studies (Bridges et al., 2010) found that hospital admissions challenged the extent to which both older people and their supporting families felt recognised, valued, and included in decision making about the future. Similarly, a more recent study in the United Kingdom showed that family caregivers of hospitalised older people felt relegated to 'outsider' status, excluded and unrecognised for their caregiving role and expertise, and experienced frustration and anger (Lowson et al., 2013). From a more practical perspective, an integrative review (Morrow and Nicholson, 2016) and a recent Australian study (Slatyer et al., 2013) have both drawn attention to the limited opportunity for the hospital staff to liaise with family caregivers regarding discharge in the scarce time available.

Hospital discharge provides a particularly salient focus because of the expectation that family caregivers will resume their caregiving roles and may also need to extend these following the patient's illness. There has been substantial research into hospital discharges for older people, and the family caregiver is generally included, in some way, in the interventions tested. However, as illustrated in three recent systematic reviews (Allen et al., 2014; Fox et al., 2013; Shepperd et al., 2013), the focus of research in this area is resoundingly on outcomes for the patient

and the health care system with minimal, if any, reporting of caregiver outcomes. By this omission, caregivers, who are often fundamental to the success or failure of the discharge, are treated as a resource rather than as individuals who merit consideration in their own right.

The most recent of these three systematic reviews included 12 randomised controlled trials evaluating interventions to support discharge home for older hospital patients (Allen et al., 2014). Interventions were described as promoting the "safe and timely transfers of patients" (p. 2). Preparation of the family caregiver for the transition was an intervention component and a variety of models were included (for example, case management, medical practitioner and primary nurse model, discharge protocol plus advanced practice nurse) (Allen et al., 2014). Although a variety of benefits for patients resulted, family caregiver outcomes were seldom addressed, with caregiver burden measured in just two studies (Allen et al., 2014).

Another of these reviews was of randomised controlled trials testing hospital-to-home discharge planning (Shepperd et al., 2013). Sixteen studies included older people with a medical (as opposed to a surgical or psychiatric) condition. Studies showed that impacts included cost savings, a reduction in readmissions within three months, and positive effects for discrete patient groups (for example, those with heart failure and those who had experienced a stroke). Although there was family caregiver involvement in discharge planning, the only caregiver outcome considered by the reviewers was satisfaction. However, this outcome was not found to have been evaluated in any of the included studies (Shepperd et al., 2013).

The third review included nine trials testing early discharge planning for ill or injured older patients (Fox et al., 2013). Again, this review showed impacts for patients, including fewer hospital readmissions and shorter lengths of stay. Yet, although families were sometimes involved in planning, no caregiver outcomes were examined. The authors note a need to evaluate caregivers' quality of life and satisfaction in future work.

Three critical points are clear. First, family caregivers of older hospital patients sometimes feel excluded and unrecognised during the admission and the time for the hospital staff to liaise with them prior to the discharge can be very limited. Second, hospital discharge interventions do tend to include the caregiver, however, the research focus is on patient, rather than caregiver, outcomes. Third, such a patient centred focus tends to ignore the necessity of sustainable home-based caregiving post-discharge. Preparation for the caregiving role, and especially empowering caregivers to identify their own support needs and adopt strategies to address them, is clearly a necessary focus for current investigation.

1.2. Developing a caregiver focussed hospital discharge intervention

In recognition of this need for a new focus, the study reported here drew upon work conducted in the United Kingdom, within the context of palliative home care, to develop a caregiver focussed hospital discharge intervention. In the British work, a person-centred approach was designed to assess and address the needs of caregivers of palliative care patients (Ewing et al., 2015). This approach incorporated the Carer Support Needs Assessment Tool, which was developed from interviews with 75 bereaved caregivers and validated with 225 current caregivers (Ewing et al., 2013; Ewing and Grande, 2013). The approach is systematic, having five sequential stages: Introduction of the Assessment Tool, Carer's Consideration of Needs, Assessment Conversation, Shared Action Plan, and Shared Review (Ewing et al., 2015). The approach is also caregiver-led, in that the assessment tool is first introduced so that the caregiver has time to reflect upon the included items, and the

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