

Outcomes for family caregivers from inclusion in the Further Enabling Care at Home program when older people are discharged home from hospital: A single blind randomised controlled trial

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Keywords: Aged, community health care, family caregivers, hospitals, patient discharge.

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 to 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.

Keywords

Aged, community health care, family caregivers, hospitals, patient discharge.

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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.

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.

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 assessment conversation supports the caregiver to identify the relevance and importance of each one. Shared action plan development and review can then help the caregiver to take the steps they see as appropriate to address their needs (Ewing et al., 2015).

This approach was recently implemented in a Western Australian stepped wedge cluster trial in palliative home care (Aoun et al., 2015a, Aoun et al., 2015b, Aoun et al., 2015c). The trial showed substantial benefits with a significant positive impact upon caregiver strain (Aoun et al., 2015c). Nurses perceived benefits in terms of prompt and targeted caregiver support provision (Aoun et al., 2015b). Caregivers also reported that, although reflection on the caregiving situation could be confronting, the process resulted in feelings of empowerment from recognising ways in which to better manage the caregiving role (Aoun et al., 2015a). The same approach has since been piloted by the community care staff providing services for people living at home with motor neurone disease (Aoun et al., 2016). In this instance too, positive feedback about the intervention was provided by both the family caregivers and the staff.

For the study reported here, an adapted version of the approach was used as a hospital outreach caregiver support intervention titled the Further Enabling Care at Home program. This program is for caregivers of older people discharged home from hospital. To ensure the feasibility of program delivery at the time of hospital discharge, the mode of delivery was designated to be over the telephone. In the recent study involving caregivers of people with motor neurone disease, the Carer Support Needs Assessment Tool was successfully administered via the telephone on 21% to 54% of occasions (Aoun et al., 2016).

Using the telephone for caregiver support

Overall, telephone support interventions for family caregivers have been widely investigated, particularly for caregivers of people living with dementia. One systematic review found 13 studies that focussed specifically on telephone support for caregivers of people living at home with dementia. Outcomes examined were mainly depression, burden, self-efficacy, stress, and bother. Interventions included psycho-education, psychotherapy, support assessments, or various multicomponent combinations and many had positive impacts (Jackson et al., 2016).

The literature documenting trials of telephone interventions incorporating self-assessment of needs plus supportive responses is more meagre, especially at the time of hospital discharge. However, one randomised controlled trial was identified, which examined post discharge

caregiving for stroke patients. The intervention focussed on caregivers identifying their needs and concerns and then participating in a psychoeducation and skill development program (Bakas et al., 2015). Some written materials were provided but most of the program was delivered over the telephone by a specially trained nurse. The comparison condition included provision of the written materials, referrals, plus telephone calls involving only active listening. The main finding was that caregivers with mild to severe depressive symptoms experienced a greater reduction in depressive symptoms when they received the intervention (Bakas et al., 2015). Overall, therefore, there is a growing argument that programs for caregivers delivered over the telephone can be successful.

The role of the specially trained nurse in the new program

The new Further Enabling Care at Home program was also delivered by a nurse. However, whereas the patient's usual nurse embedded implementation of the Carer Support Needs Assessment Tool in their practice in the recent palliative home care trial (Aoun et al., 2015a, Aoun et al., 2015b, Aoun et al., 2015c), the new program involved a dedicated role for a nurse with acute care knowledge relevant to the care of older people in poor health, knowledge of how to access local services, understanding of the family caregiver role, the capacity to work flexible hours to fit in with caregivers' needs, and the skills to support the caregiver during the process of reflection and self-assessment.

Training for this nurse incorporated two components. The first component comprised the principles of the approach to be used and the administration of the tool, which are presented within the context of palliative care in a toolkit developed by Austin and colleagues (2015). The second component was the use of a previously developed resource manual that helped to guide access to supports for caregivers.

Tailoring of the intervention for delivery outside of the usual care team was undertaken because of the extremely rapid hospital discharge process and resultant constraints upon the existing staff's time. Overall cost consequences for the hospital system from this program will be reported elsewhere.

Aim and hypothesis

The aim of this study was to determine how implementing the Further Enabling Care at Home program - immediately after the older patient's discharge from an acute hospital's medical assessment unit – influenced outcomes for patients' caregivers, the patients themselves, and the healthcare system. The full study protocol is published elsewhere (reference removed for blinding).

This paper reports the testing of the following hypothesis:

The extent to which family caregivers of older people discharged home from a hospital in-patient medical assessment unit feel prepared to provide care at home, as measured by the Preparedness for Caregiving Scale from the Family Care Inventory (Archbold et al., 1990), will be positively influenced by their inclusion in the Further Enabling Care at Home program.

Methods

Design and participants

In this parallel group, single blind, randomised controlled trial, patient-caregiver dyads were recruited in the hospital at the time of the discharge from the medical assessment unit. This unit had 36 beds, all for adult general medical patients, and was situated within a metropolitan tertiary hospital in Western Australia with over 600 beds. The majority of the unit's patients were aged 65 or older and the usual pathway into this setting was via the emergency department. Patients remained under the care of the unit's physicians for up to 72 hours, after which time they were either discharged or transferred to the care of another inpatient team. Such a transfer involved physical relocation of the patient as soon as a bed became available.

Inclusion criteria for dyads were that they each comprised a patient aged 70 years or older being discharged to their home or the home of their family caregiver, plus a family caregiver who could speak and read English. We defined a family caregiver as: "a family member or friend who provides unpaid personal care, support and assistance" (Aggar et al., 2011, p. 672). Included caregivers all provided written informed consent to study participation and provided study data via telephone interviews. The study received approval from the Human Research Ethics Committees

of WA Health plus the partnering hospital and university; it was also registered in the Australian and New Zealand Clinical Trial Registry (number removed for blinding).

Intervention and control conditions

The intervention comprised usual discharge care plus the Further Enabling Care at Home program. Usual discharge care included providing the patient with a copy of the letter from the hospital doctor to the patient's regular medical practitioner plus any required medications, prescriptions, referrals, or outpatient appointments. 'At risk' patients and/or caregivers, as prioritised by the social work team at that team's discretion, received whatever social work services were deemed to be appropriate based upon the issues presented; other patients and their caregivers received no such services. Information packs from 'Carers Australia' were available and home care programs were instigated or already in place for some patients.

The Further Enabling Care at Home program involved the implementation of a strict telephone protocol by the specially trained nurse, using the Carer Support Needs Assessment Tool, which has fourteen items covering: (a) support that enables the caregiver to care for the patient at home, and (b) support for the caregiver in their caring role (Ewing and Grande, 2013). There were three, sequential, telephone contacts. Planned dates for contacts were sometimes delayed because of caregivers' limited availability

- Contact 1 was planned to take place within a week post-discharge. This contact allowed the nurse to provide an introduction, schedule appointments for future contacts, and supply the Carer Support Needs Assessment Tool to the caregiver for consideration prior to Contact 2.
- Contact 2 was designated to occur from 7 to 10 days post-discharge. This contact was to: (a) explore the caregivers' understanding of the patient discharge letter and determine how caregivers could obtain answers to their related queries and (b) conduct the assessment and work with the caregiver to support them as they developed an action plan to address up to three prioritised needs, guiding them to access any services required.

- Contact 3 was planned to follow within 14 days of the discharge. This contact was to collaboratively review the action plan, check that the required service access had been achieved, and provide further advice regarding access if needed.

Outcome variables

Designated *data collection* time points at Time 1, Time 2, and Time 3 for outcome measures were as follows: Time 1, within four days of discharge; Time 2, 15 to 21 days after discharge; and Time 3, six weeks after discharge. As was the case for the intervention contacts, these data collection time points were sometimes later than anticipated because of the caregivers' availability.

The primary outcome variable for caregivers was their preparedness to provide care (at home) for the patient, measured by the Preparedness for Caregiving Scale from the Family Care Inventory (Archbold et al., 1990). This outcome was assessed at all three data collection time points. Other (secondary) outcome variables measured at the same three time points were:

- caregiver rated patient Symptom Assessment Scale scores (Aoun et al., 2011);
- caregivers' evaluations of the independence of the patient in ten activities, using the Barthel Activities of Daily Living Index (Yeo et al., 1995);
- caregiver strain, family well-being, caregiver stress, and positive appraisals of caregiving, using the Family Appraisal of Caregiving Questionnaire (Cooper et al., 2006);and
- caregiver ratings of their own health and well-being using the SF-12v2™ © Health Survey (1994, 2003).

These secondary outcomes were selected because they could provide additional information about caregivers' perceptions of the caregiving situation. Caregiver resilience, an important caregiver characteristic, was measured at Time 1 using the Connor-Davidson Resilience Scale (Connor and Davidson, 2003) so that the equivalence of the intervention and control groups could be more comprehensively determined. Also at Time 1, demographic details for caregivers were collected along with additional information about the caring situation. A summary of instrumentation is in Table 1.

Table 1: Instrumentation

Name	Author	Purpose	Subscales	Items	Item scores	Range	Validity and Reliability
Preparedness for Caregiving Scale	Archbold et al. (1990)	Shows changes over time in caregiving preparedness (3 time points)	None	8	0=not at all to 4=very well prepared	0-32	Satisfactory internal consistency, reliability and stability, and unidimensionality (Archbold et al., 1990, Henriksson et al., 2012)
Connor-Davidson Resilience Scale	Connor and Davidson (2003)	Shows resilience in caregivers as a characteristic as it may be protective (baseline)	None	25	0=not true at all to 4=true nearly all the time	0-100	Reliability and validity of this tool is established when used with older people (Gulbrandsen, 2016)
Symptom Assessment Scale	Aoun et al. (2011)	Shows changes over time in patients' symptom severity, rated by caregivers (3 time points)	None	7	0=no distress to 10=worst possible	0-70	Internal consistency reliability 0.64–0.92, (Cronbach's alpha) test-retest reliability (0.84–0.92) (Aoun et al., 2011)
Barthel	Yeo et al.	Shows changes over		10	0=completely	0-100	Inter-rater reliability and predictive

Name	Author	Purpose	Subscales	Items	Item scores	Range	Validity and Reliability
Activities of Daily Living Index	(1995)	time in patients' level of independence as rated by caregivers (3 time points)		activities	dependent Some items scored up to 10, some to 15		validity established; also suitable for per phone administration (Yeo et al., 1995)
SF12v2 (Phone version)	SF-12v2™ Health Survey (1994, 2003)	Shows changes over time in caregivers' physical and mental health (3 time points)	Physical and Mental Health scores	12 in total	According to scoring guide	0-100 for each domain	Construct validity established, at least adequate test-retest reliability, excellent internal consistency reliability (Hussey, 2014)
Family Appraisal of Caregiving Questionnaire- Palliative Care	Cooper et al. (2006)	Shows changes over time in caregivers' impacts from caregiving (3 time points)	Strain Positive Appraisals Distress Family Well-Being	8 7 5 6	1=strongly agree to 5=strongly disagree	4-130	At least acceptable internal consistency reliability and construct validity (Cooper et al., 2006)

Power

A change in the total score of Archbold et al.'s (1990) Preparedness for Caregiving Scale of two points was considered to be clinically meaningful, given that this would mean a change such as from 'Not at all prepared' to 'Somewhat well prepared' in one item or from 'Pretty well prepared' to 'Very well prepared' in two. To detect such a change (the equivalent of a change of 0.25 in the mean score per item, since the scale is based on eight items), with 80% power and a 5% significance level, required the inclusion of 63 caregivers per group. This calculation was based on an estimated standard deviation of the mean score of 0.5 (Archbold et al., 1990). We anticipated loss to follow-up of 30%, and therefore aimed to recruit 180 dyads, planning to cease recruitment when complete data sets had been obtained from 63 caregivers in each group. As confirmed by Holm and colleagues (2015), no clinically meaningful differences in scores had previously been established for the Preparedness for Caregiving Scale, therefore our assessment of a meaningful change was based upon consideration of the intended outcomes from the intervention and how these related to the items in the questionnaire. Nonetheless, our sample size was comparable to that used in recent studies using this scale: a medium effect size was detected in one recent study with 58 intervention group participants and 30 in the control arm (Henriksson et al., 2013), and a small effect size was detected in another study with 82 in each arm (Holm et al., 2015).

Randomisation

Each dyad was randomly allocated to either the intervention or control condition. A computer generated list of random allocations was prepared prior to the study commencing. The list was prepared using a permuted random blocks strategy, so that patients would accumulate to each arm of the study at an approximately equal rate. More details have been published elsewhere (Toye et al., 2015).

Blinding

All researchers involved in participant recruitment and quantitative data collection were blinded to the allocation schedule and actual group assignments. Three strategies were implemented to support blinding:

1. The allocation schedule was held by a researcher who was not involved in recruitment.
2. At Time 2 and Time 3, data collectors routinely reminded participants not to mention to them any calls they had received from other research team members (including the Further Enabling Care at Home nurse).
3. If Time 2 data collection for intervention group members needed to be delayed because of a longer than anticipated intervention period, the required delay to Time 2 data collection was managed by the researcher holding the allocation schedule. This researcher delayed data collection from several participants due to be recontacted at around the same time so that the intervention group member was not identified.

To facilitate an evaluation of the extent to which blinding to group assignment was successful, the researcher holding the list of allocations asked the data collectors to 'estimate' participants' group membership immediately after Time 3 outcome data collection. Estimates were undertaken whenever the researcher was able to access the data collection team at the appropriate time. Findings from these estimates are provided in the results section.

Statistical methods

Descriptive statistics (frequencies and percentages for categorical variables; means, standard deviations, and ranges for variables measured on a continuous scale) were used to describe the participants in the study. The Chi-square test or t-test were used, as appropriate, to compare the profile of participants between the intervention and control groups and determine the extent to which the groups were well-balanced with respect to baseline (ie, Time 1) characteristics. Changes over time in the primary and secondary outcomes (scores measured on a continuous scale) were compared between the two groups using a random effects regression model. This model was used

so that correlation between the repeated measurements made on the same participant could be taken into account. The statistical significance of the pairwise changes in outcomes over the three time points was obtained from the model. Statistical analyses were performed using SPSS software (IBM Corp, Released 2013). A p-value of <0.05 was taken to indicate statistical significance in all tests.

In addition, to identify the needs most often addressed during the intervention, the score for each need identified using the Carer Support Needs Assessment Tool (Ewing et al., 2015) was assembled as a weighted sum of the three priorities of needs recorded by each caregiver. Top priority needs were allocated three points, second priority needs were given two points, and third priority needs were allocated one point.

The extent to which data collectors were accurate in their estimates of participants' assignment to group was established by determining the percentage of correct estimates and comparing this with the extent to which correct estimates would occur by chance. It was assumed that estimates would ordinarily be correct 50% of the time.

Results

Participants and recruitment

Recruitment commenced in April 2015 and ended in November of the same year, when numbers appeared adequate to meet the pre-planned target. During the study, the only variation from the planned intervention was a change to timing of nurse contacts: Contact 1 was implemented within up to 9 (instead of 7) days of the discharge, Contact 2 within 24 (instead of 10) days, and Contact 3 within 40 (instead of 14) days. These changes were required to fit in with the multiple, and often unpredictable, commitments of the family caregivers. This variation, plus limited caregiver availability for data collection across the sample, also resulted in changes in *data collection* time points. However, there was no significant difference between the groups when mean time periods between data collection time points were compared (see Supplementary Table 1).

Figure 1 shows the flow of dyads through the study. Overall, 363 eligible dyads were approached and 193 (53.2%) provided consent to study participation, the main reasons for declining being 'too busy' or 'too overwhelmed'. From these 193 dyads, 11 (5.7%) withdrew prior to randomisation, mainly without providing a reason, and seven more (3.6%) became ineligible because the patient was unexpectedly transferred to another hospital unit (n=6) or died (n=1).

Attrition reported in Figure 1 is derived from a 'baseline' at the time of randomisation of 175 participants and was 13.5% overall; 19.5% in the intervention group and 8.1% in the control group. From the 12 dyads withdrawing after randomisation without providing data, most failed to provide a reason but three caregivers had concerns about, or difficulties with, the planned telephone data collection and one experienced a bereavement. Reasons for loss to follow-up in the intervention group included: caregiver too busy (n=5), caregiver stressed because the patient was readmitted to hospital (n=3), caregiver stressed because the patient's condition declined and care became palliative (n=1), and caregiver preferred not to think of a future deterioration in the patient's condition (n=1). Three caregivers did not respond to the intervention contacts, and one caregiver completed the intervention but preferred not to receive the remaining data collection phone calls. Reasons for loss to follow-up in the control group included: caregiver admitted to hospital (n=2), caregiver stressed when the patient's condition declined and care became palliative (n=1), and caregiver feeling overwhelmed at the prospect of the patient moving into residential aged care (n=1). One caregiver did not provide a reason for withdrawing.

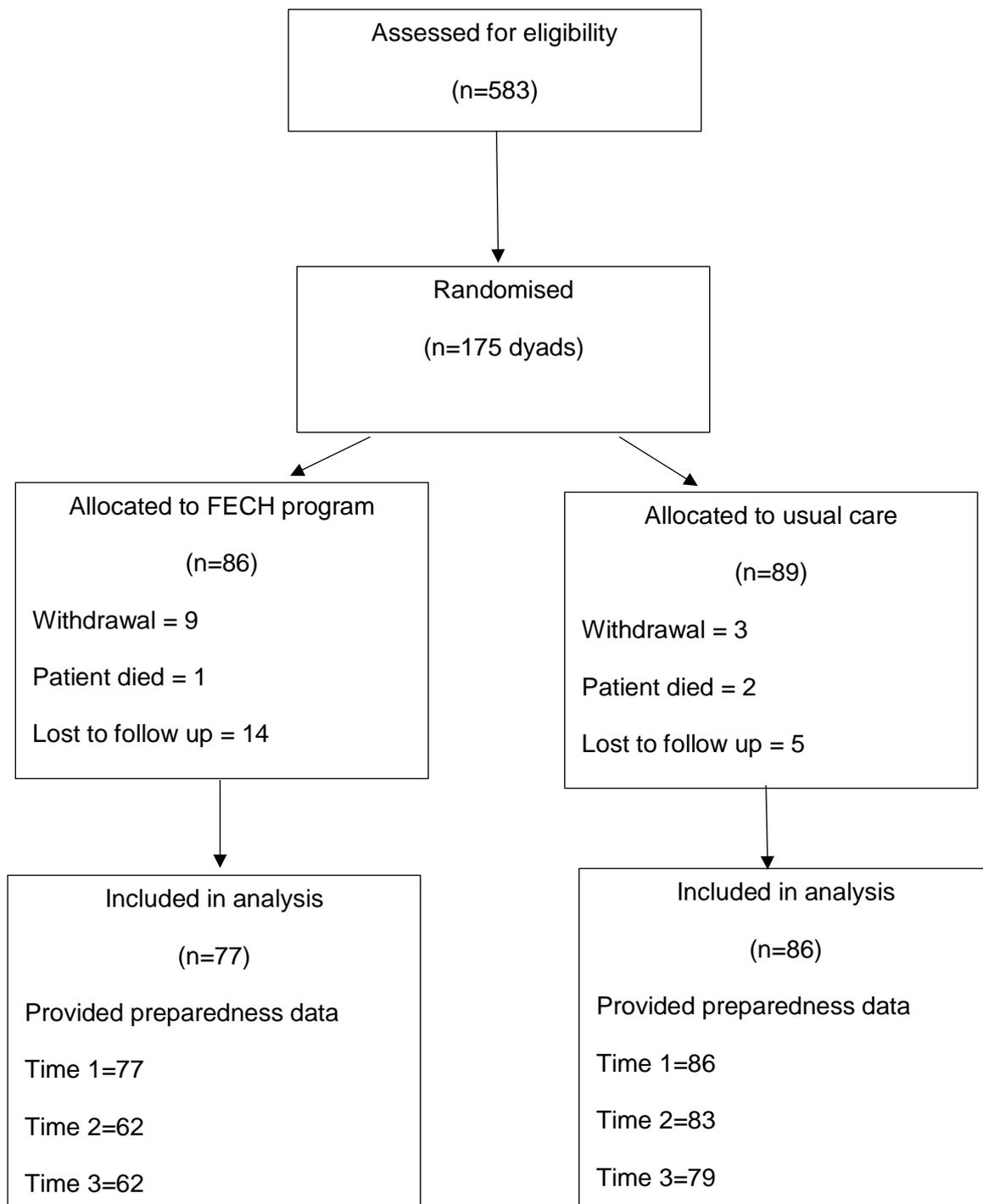


Figure 1. Consort diagram

Note: All withdrawals prior to Time 1, all deaths and loss to follow up after Time 1

Baseline data

Table 2 and Supplementary Table 2 show the baseline characteristics of the caregivers who contributed data at all three time points. There was no significant difference in these caregiver characteristics between the groups. Close to one third of the caregivers had received a tertiary education and more than a quarter worked, or had worked, in professional or managerial roles. Consistent with the mean age of over 60 years, close to half of this caregiver group had retired from paid employment. Patients receiving care did not differ significantly by group in terms of gender, age, or location of residence (see Supplementary Table 3). At baseline, there was also no statistical difference between the groups in resilience or any of the outcome variables (Table 3).

Caregivers' needs addressed by the intervention

Supplementary Table 4 displays total scores attached to each need prioritised during carer assessment. 'Knowing who to contact' was the need that gained the highest score (47 points), while 'Caregiver knowing what to expect in the future' (43 points) and 'Practical help in the home' (35 points) were second and third in the list. Therefore, these were the predominant needs addressed during the intervention. This table also summarises the most common examples of the action plan components implemented in response to the three most frequently prioritised needs.

Blinding

When comparing the estimates of the data collectors regarding participants' group assignment to actual assignments, the research staff had been correct in 43 from 63 instances (68.3%). Blinding, therefore, was considered to be moderately – but not completely – successful.

Table 2: Main caregiver characteristics for each group

Description	Group		p-value (Chi Square)
	Intervention	Control	
	(n = 62) n (%)	(n = 79) n (%)	
Caregiver relationship to patient			0.088
Husband	4 (6.5)	9 (11.4)	
Wife	18 (29)	11 (13.9)	
Son	11 (17.7)	12 (15.2)	
Daughter	22 (35.5)	40 (50.6)	
Other	7 (11.3)	7 (8.9)	
Caregiver Gender - Female	47 (75.8)	57 (72.2)	0.767
Caregiver age - mean [SD]*	63.1 [12.6]	61.3 [13.4]	0.417**
Caregiver born in Australia	39 (62.9)	54 (68.4)	0.618
Caregiver years/Australia – mean [SD]	42.4 [16.5]	43.5 [16.2]	0.885*
Providing care > 24 months	39 (62.9)	60 (75.9)	0.243
Caregiver living with patient	35 (56.5)	39 (49.4)	0.505
Caregiver known medical conditions	43 (69.4)	54 (68.4)	0.881
Type of caregiver support provided			
Patient Physical Care	29 (46.8)	29 (36.7)	0.301
Patient Emotional Care	62 (100.0)	76 (96.2)	0.256
Patient Instrumental Care	59 (95.1)	77 (97.5)	0.654
Patient Social Support/Advocacy	39 (62.9)	56 (70.9)	0.411
At least daily contact by caregiver	51 (82.3)	66 (83.5)	0.381
Previous caring education	10 (16.1)	6 (7.6)	0.187

*Standard Deviation (SD) **Independent samples T-Test

Table 3: Baseline (Time 1) measures completed by the caregivers in each group

Outcome/	Group		95% Confidence		P - Value*
	Intervention	Control	Interval of the		
	(n = 62)	(n = 79)	Difference		
	Mean (SD)	Mean (SD)	Lower	Upper	
Preparedness for Caregiving Scale (0-4 scale, response options 0=not at all to 4=very well prepared)					
<i>For physical care</i>	2.66 (0.87)	2.51 (1.12)	-0.176	0.486	0.356
<i>For emotional care</i>	2.63 (0.89)	2.63 (0.96)	-0.317	0.309	0.980
<i>For service finding/set up</i>	2.52 (1.00)	2.70 (1.15)	-0.545	0.185	0.331
<i>For stress of caregiving</i>	2.42 (0.98)	2.25 (0.98)	-0.163	0.496	0.320
<i>To make caregiving pleasant</i>	2.73 (0.87)	2.73 (0.96)	-0.317	0.300	0.957
<i>To handle emergencies</i>	3.06 (0.72)	3.09 (0.83)	-0.288	0.240	0.857
<i>To get support from the system</i>	2.48 (0.97)	2.43 (1.03)	-0.284	0.391	0.755
<i>How prepared overall</i>	2.89 (0.73)	2.75 (0.93)	-0.135	0.416	0.315
Mean item score from total	2.67 (0.57)	2.64 (0.64)	-0.167	0.242	0.719
Connor- Davidson Resilience Scale (higher score=more resilient)					
	31.39 (5.48)	30.34 (5.17)	-0.734	2.825	0.248
Symptom Assessment Scale - patients' symptoms (0-10 scale, 0=no symptom to 10=worst possible)					
<i>Insomnia</i>	2.95 (3.03)	3.09 (3.44)	-1.378	0.595	0.805
<i>Appetite</i>	2.71 (2.65)	3.10 (3.15)	-1.370	0.252	0.434
<i>Nausea</i>	1.05 (2.17)	1.61 (2.70)	-1.275	0.878	0.175
<i>Bowel</i>	2.55 (3.15)	2.75 (3.26)	-1.461	0.523	0.716
<i>Breathing</i>	2.47 (3.01)	2.94 (2.92)	-1.690	0.193	0.352
<i>Fatigue</i>	4.76 (2.94)	5.51 (2.70)	-1.240	0.867	0.118
<i>Pain</i>	3.02 (3.01)	3.2 (3.24)	-0.969	0.200	0.727
Mean item score from total	2.79 (1.77)	3.17 (1.72)	-2.579	12.132	0.196

Barthel Activities of Daily Living Index – patients’ independence (higher score, more independent)

80.73 (18.35) 75.95 (25.77) -3.472 2.077 0.201

SF12v2 (physical health) (higher score= better health)

51.68 (9.26) 51.77 (9.06) -0.370 0.163 0.951

SF12v2 (mental health) (higher score= better health)

48.43 (7.59) 48.20 (9.78) -0.091 0.269 0.878

Family Appraisal of Caregiving Questionnaire – Palliative Care**Caregiver Strain** (higher score= more strain)

2.44 (0.78) 2.54 (0.81) -0.097 0.350 0.445

Positive Caregiving Appraisals (higher score= more positive)

4.10 (0.49) 4.01 (0.57) -0.734 2.825 0.329

Caregiver Distress (higher score= more distress)

2.78 (0.65) 2.89 (0.76) -0.167 0.242 0.362

Family Well-Being (higher score=better well-being)

3.76 (0.70) 3.64 (0.64) -1.233 0.959 0.265

**Independent samples T-Test*Primary outcome

As shown in Table 4, preparedness to care improved significantly in the intervention group when compared to the control group in 5 items from Time 1 to Time 2, also in the total score (from all 8 items). From Time 1 to Time 3 there were similar improvements for 3 items and the total score. Effect sizes were moderate for ‘How well prepared do you think you are to find out about and set up services for him/her?’ from Time 1 to Time 2 and from Time 1 to Time 3; also for the (mean item) total score from Time 1 to Time 2. Otherwise the effect sizes were small. However, the (mean item) total score difference between the groups exceeded 0.25 from Time 1 to Time 2, meeting our pre-set criterion for the minimum clinically important difference.

Table 4: Significant differences between groups in preparedness changes Time 1 to Time 2 and Time 1 to Time 3

	Change Time 1 – Time 2						Change Time 1 – Time 3					
	Group		95% Confidence		p*	Effect size (Cohen's d)	Group		95% Confidence		p*	Effect size (Cohen's d)
	Intervention (n = 62) Mean (SD)	Control (n = 79) Mean (SD)	Lower Bound	Upper Bound			Intervention (n = 62) Mean (SD)	Control (n = 79) Mean (SD)	Lower Bound	Upper Bound		
Preparedness for Caregiving												
For physical care	0.15 (0.90)	-0.04 (1.19)	0.006	0.669	0.046	0.180						
For service finding/set up	0.40 (1.05)	-0.15 (1.11)	0.044	0.705	0.026	0.509	0.55 (1.05)	-0.03 (1.12)	0.063	0.724	0.020	0.534
For stress of caregiving	0.19 (0.92)	-0.13 (0.99)	0.160	0.812	0.004	0.335	0.15 (1.01)	-0.05 (1.04)	0.036	0.688	0.030	0.195
To get support from system	0.39 (1.18)	0.01 (1.10)	0.095	0.761	0.012	0.333	0.52 (1.04)	0.13 (1.02)	0.110	0.776	0.009	0.379
How prepared overall	0.02 (0.71)	-0.18 (0.86)	0.047	0.619	0.022	0.254						
Mean item score from total	0.16 (0.49)	-0.10 (0.51)	0.088	0.519	0.006	0.520	0.20 (0.51)	-0.02 (0.51)	0.043	0.473	0.019	0.431

* P value computed after adjustment for the repeated measures/person - Mixed Regression Model

Other outcomes

When comparing changes from Time 1 to Time 2 and from Time 1 to Time 3 for the remaining caregiver outcomes, there were also statistically significant differences in change over time between the groups for caregivers' ratings of patients' symptoms, caregivers' distress, and caregivers' strain. Effect sizes were all small. First, when administering the Symptom Assessment Scale (Aoun et al., 2011), patients in the intervention group were rated by their caregivers as experiencing a greater improvement in overall symptoms (mean = -0.70, SD = 1.56) at Time 2 than patients in the control group (mean = -0.16, SD = 1.74; $p=0.002$, $d= -0.327$). Also, this difference persisted at Time 3 (intervention group Time 1-Time 3: mean = -0.38, SD = 1.73; control group mean = -0.01, SD = 1.96; $p=0.011$, $d= -0.200$). Second, caregivers in the intervention group had a greater decrease from Time 1 to Time 2 in caregiver distress (mean = -0.24, SD = 0.46) than those in the control group (mean = -0.09, SD = 0.64; $p=0.036$, $d= -0.269$). However, this difference was not sustained at Time 3. Third, although there was no difference between the groups in changes in caregiving strain from Time 1 to Time 2, strain reduced significantly in the intervention group from Time 1 to Time 3 compared with a stable level in the control group (intervention group mean = -0.15, SD = 0.55; control group mean = 0.04, SD = 0.65; $p=0.040$, $d= -0.316$).

Discussion

This study determined that the Further Enabling Care at Home program improved the (self-reported) preparedness to care of family caregivers of older people discharged home from a medical assessment unit. Although this finding adds to the body of literature showing successful outcomes from the approach developed by Ewen and colleagues (2015), the intervention was tailored for a different population and delivered in a different way. Also preparedness for caregiving was not evaluated in that previous work and was the primary outcome variable in the current study. Of interest is that carer strain was also reduced. Whether this impact occurred as a direct result of the support provided, or

because caregivers felt better prepared for their caregiving role, is unclear. However, preparedness for caregiving was previously found to predict lower levels of role strain (Archbold et al., 1990).

Recent published studies investigating caregivers' preparedness for their caregiving role are mainly found in the palliative care literature. Henriksson and Arestedt's (2013) work in three palliative care units and one haematology unit found that preparedness was associated with greater hope and reward and less anxiety. However, based upon findings from Hendrix and colleagues (2016), sustaining a sense of preparedness from a single intervention can be problematic. These authors implemented an in-hospital education program for caregivers of oncology patients that addressed management of caregivers' stress and patients' symptoms. Preparedness to care increased immediately post-intervention but was not sustained at two or four weeks post-discharge. In the current study, the improvement in preparedness was sustained beyond this one-month period, perhaps because ongoing links with support sources had been initiated. The effect size for this improvement was moderate from Time 1 to Time 2 and only slightly smaller from Time 1 to Time 3. A systematic review and meta-analysis examining impacts from interventions with family caregivers of cancer patients (Northouse et al., 2010) found that most interventions had small to medium effects yet provided significant beneficial outcomes for caregivers.

Better preparing caregivers to sustain their caregiving role is pivotal to the success of home care for an ageing population. Furthermore, in contrast to support programs that need continued input from health care professionals, the Further Enabling Care at Home program facilitated self-assessment of support needs and access to existing services. In addition, the use of the telephone to deliver the intervention was less costly than home visits, allowed more flexibility with regard to contact times, and meant that distance was not an issue. To an extent, the program was similar to that trialled with caregivers of stroke patients by Bakas and colleagues (2015), in that it was a telephone intervention designed to identify caregivers'

self-perceived support needs and improve caregiving capacity. However, the Further Enabling Care at Home program addressed the care of patients with a wide variety of health conditions, meaning that caregivers' needs relating directly to patient care were diverse. Therefore, a key element of the caregiving support provided was related to navigating the healthcare system. Importantly, the support needs identified could all be met within the context of existing resources and there was no indication from caregivers that a lengthier program was needed.

A limitation of this study is that it was conducted in a single medical assessment unit. Also, participating family caregivers were generally well-educated and may, therefore, have had fewer informational support needs and/or a greater capacity to address their needs when guided to do so. The caregivers in most need of support may also have been less likely to participate because of their time limitations or stress levels. The higher rate of attrition in the intervention group was almost certainly due, at least in part, to the heavy demands upon caregivers' time when providing data at three time points plus receiving the intervention. However, the study design meant that this cannot be confirmed as there was no study arm in which similar numbers of telephone calls were implemented without including the intervention. A further limitation was that our team was unable to access data regarding the identification of 'at risk' patients by the social work team and so could not compare the two groups at study baseline with regard to this variable. In addition, the extent to which each social worker responded to the need for services in an identical way could not be established.

Although this study may be regarded as preliminary to a larger trial, several methodological challenges were successfully addressed within this context. First, given the extensive and often unpredictable demands of the caregiving role, flexibility in the timing of recruitment, data collection, and intervention contacts was critical. Second, recruitment across every day, including weekends, was essential to avoid biasing the sample by missing weekend

discharges that might be associated with particular support needs. Third, recruitment was sometimes difficult within the unit itself, given that moves out of the ward often occurred extremely rapidly, once discharge home was decided upon. Therefore, the researchers often finalised this process in the hospital's discharge ward. Overall, the demands upon the research team were considerable and compounded by emotional stress from encountering patients and carers who were experiencing significant crises in their lives. During such a study, the significant support requirements within the study team should not be underestimated.

Minimising the length of hospital stays is increasingly advocated for older people to avoid negative outcomes such as deconditioning, meaning that units such as that included in the current study are becoming increasingly common (Slatyer et al., 2013). The unequivocal findings from this study provide a basis for considering the program's implementation in this and other similar settings. However, a cluster randomised controlled trial across multiple sites is required to determine the generalisability of results. In addition, the feasibility of adding this outreach program to the existing hospital service profile needs to be considered with particular reference to an economic evaluation of cost incurred versus potential cost savings from improved home caregiving sustainability.

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Supplementary Table 1: Time between data collection time points

Time difference in days	Group		95% Confidence Interval of the Difference		P – Value*
	Intervention	Control	Lower	Upper	
	Mean (Standard Error)	Mean (Standard Error)			
Time 1 to Time 2	19.2 (0.83)	17.3 (0.73)	-0.20	4.15	0.075
Time 1 to Time 3	37.4 (0.83)	37.2 (0.73)	-2.00	2.35	0.877
Time 2 to Time 3	19.2 (0.85)	20.6 (0.75)	-3.59	0.87	0.230

* P value computed after adjustment for repeated measures/ person, Mixed Regression Model

Supplementary Table 2: Further caregiver characteristics

Description	Group		p-value (Chi Square)
	Intervention	Control	
	(n = 62) n (%)	(n = 79) n (%)	
Previous/current occupation*			0.864
Retired	26 (42.6)	37 (48.7)	
Current Occupation	29 (47.5)	35 (46.1)	
Homemaker/volunteer/other	6 (9.8)	4 (5.2)	
Caregiver previous and current occupation**			0.490
Management/professional	25 (45.4)	28 (38.9)	
Tradespersons/clerical/service	21 (38.2)	35 (48.6)	
Labourers/junior clerical or service	9 (16.4)	9 (12.5)	
Caregiver Education			0.654
Primary	3 (4.8)	3 (3.8)	
Secondary	23 (37.1)	37 (46.8)	
Trade qualification	17 (27.4)	16 (20.3)	
Tertiary	19 (30.7)	23 (29.1)	

*Missing data (n=1, intervention group; n=3, controls) ** Australian Standard Classification of Occupation(Australian Bureau of Statistics, 2016)

Supplementary Table 3: Patient characteristics*

Description	Group		P value (Chi Square)
	Intervention N (%)	Control N (%)	
Gender			0.158
Male	31 (50.0)	29 (36.7)	
Female	31 (50.0)	50 (63.3)	
Age Mean [SD]	84.7 [6.9]	84.3 [5.5]	0.706**
Location of residence			0.688
Metropolitan area	61 (98.4)	77 (98.7)	
Regional Western Australia	1 (1.6)	0 (0.0)	
Metropolitan area (temporarily before returning overseas)	0 (0.0)	1 (1.3)	

**The three main categories of medical conditions of patients, as reported by caregivers and classified according to the International Statistical Classification of Diseases and Related Health Problems (World Health Organization, 2016) were Diseases of the circulatory system; Diseases of the musculoskeletal system and connective tissue; and Endocrine, nutritional and metabolic diseases.*

***Independent T-Test*

Supplementary Table 4: Prioritised caregivers' needs and 'top 3' action plan components

Need	Score	Key action plan components*
g) knowing who to contact	47	Guidance to: access help in an emergency and after hours; access informal support; obtain a personal alarm for the patient; develop a documented plan to implement in a crisis; access resources.
m) knowing what to expect in the future	43	Guidance to: access information from health professionals, including information on symptom management; obtain referrals; prepare questions for appointments; determine how aged care services might be accessed; organise legal requirements such as advance care plans; access carer support options.
l) practical help in the home	35	Guidance to: access domestic assistance and home care packages.
a) understanding relative's illness	19	
d) financial, legal or work issues	14	
n) getting a break from caring overnight	14	
e) providing personal care for relative	12	
c) managing relative's symptoms	9	
k) talking with relative about his or her illness	8	
b) having time for them in the day	6	
f) dealing with feeling and worries	5	
h) looking after own physical health	4	
i) equipment to help care for relative	4	
j) beliefs or spiritual concerns	0	

Note: Examples provided only for the top three priorities