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Distance education methods are useful for delivering education to palliative caregivers: A single arm trial of an education package (PrECEPt). *Palliative Medicine.*

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Abstract

Background: Face-to-face/group education for palliative caregivers is successful, but relies on caregivers travelling, being absent from the patient, and rigid timings. This presents inequities for those in rural locations.

Aim: To design and test an innovative distance-learning educational package (PrECEPt: PalliativE Caregivers Education Package).

Design: Single-arm mixed method feasibility proof of concept trial (ACTRN12616000601437). The primary outcome was carer self-efficacy, with secondary outcomes focused on caregiver preparedness and carer tasks/needs. Analysis focused on three outcome measures (taken at baseline and six-weeks), and feasibility/acceptability qualitative data.

Setting and participants: A single specialist palliative care service. Eligible informal caregivers were those of patients registered with the outpatient or community service, where the patient had a prognosis of ≥12 weeks, supporting someone with nutrition/hydration and/or pain management needs, proficient in English and no major mental health diagnosis.

Results: Two modules were developed and tested (nutrition/hydration and pain management) with eighteen caregivers. The materials did not have a statistically significant impact on carer self-efficacy. However, statistically significant improvements were observed on the two subsidiary measures of (i) caregiving tasks, consequences, and needs (p=0.03, CI: 0.72, 9.4), and (ii) caregiver preparedness (p=0.001, CI: -1.22, -0.46). The study determined that distance learning is acceptable and feasible for both caregivers and healthcare professionals.

Conclusions: Distance education improves caregiver preparedness, and is a feasible and acceptable approach. A two-arm trial would determine whether the materials benefitted caregivers and patients compared to a control group not receiving the materials. Additional modules could be fruitfully developed and offered.

Key statements

What is already known about the topic?

- Informal caregivers need information and support to aid them in their role.
- Face-to-face/group education is successful, but relies on caregivers travelling to a central venue to receive education, taking time away from the patient and fitting with the education-provider's timetable.

What this paper adds?

- This article presents data indicating that a distance education approach to supporting informal caregivers is both acceptable and feasible.
- Caregivers report feeling more prepared for their role, and being more able to conduct caregiver tasks.
- Caregivers appreciated being able to engage with the education in their own time and speed.

Implications for practice, theory or policy

- Distance learning can be used to support caregivers.
- The modules can easily be used nationally and internationally addressing the burden of geographical constraints which hamper face-to-face delivery of education.
- Further modules can be developed to meet other informational/educational needs.

Background

Practical educational interventions for palliative caregivers are needed.[1] Evidence from palliative care demonstrates that one-to-one and group psycho-education is effective in gaining support and knowledge,[2] preparedness for caring, competence and having information needs met.[3, 4] While it is recognised that accessible, brief and easily delivered education needs to be available,[5] a substantial gap remains around determining how high-quality relevant information can be delivered at a national level, using educational methods which are acceptable to caregivers in palliative care. Although distance learning is used widely in health care professional education,[6-8] it has not been widely explored for caregivers, despite some early results in the dementia field[9, 10] and palliative care[11-14] which offer promising results. Distance learning approaches address inequities created through the provision of support which requires physical attendance at a time/location determined by the palliative care services, and consequently time away from the person receiving palliative care.

Aim

To develop and test the delivery of a distance learning intervention for informal caregivers in palliative care, to determine (a) the acceptability and feasibility of the approach to caregivers and healthcare professionals, and (b) the processes involved in delivery of the key components including: recruitment processes for a full-scale study, data collection procedures/completion rates, and queries directed to the palliative care team from caregivers involved in the feasibility work.

Primary research question: What should a carer distance learning resource contain and how should it be delivered?
Secondary research question: Do the learning modules impact (i) carer self-efficacy, (ii) carer perceptions of their tasks and needs, or (iii) preparedness for caregiving?

Methods

Design

This was an embedded mixed-method feasibility and acceptability study involving an un-blinded one arm pilot test, with embedded qualitative interviews which were used to inform the assessment of the intervention's acceptability and feasibility.[15]

Informal caregivers of people currently receiving palliative care were invited to feasibility test PrECEPt (PalliativE Caregivers Education Package). PrECEPt consisted of two modules identified as priorities in the palliative literature on caregiver needs: nutrition/hydration[16-18] and pain management.[19-23] The package was delivered in hard-copy (handbooks and DVDs, not online). Informal caregivers and patients continued to receive usual care from the palliative care team.
The study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12616000601437).

Setting, sample and recruitment

Recruitment proceeded through the specialist palliative care service in Canberra, Australia, which provides in-patient, outpatient and community services to residents across the Australian Capital Territory. Inclusion criteria for caregivers are described in Table 1. Recruitment commenced in July 2016 with enrolment in August 2016.

Table 1: Inclusion criteria

Inclusion criteria for caregivers
(i) Recognised as the main caregiver for a patient receiving specialist palliative care
(ii) Supporting someone with nutrition/hydration and/or pain management needs
(iii) The patient resides at home (not in residential care or a hospice inpatient)
(iv) Aged over 18 years and able to give informed consent
(v) No formal diagnosis of a major psychiatric disorder
(vi) Patient's life expectancy >12 weeks
(vii) Proficient in English language

Recruitment of Participants

A list of current patients was generated from the electronic medical records system, to identify caregivers meeting the eligibility criteria. Caregivers received a recruitment pack including a letter of invitation and a participant information sheet.

All trial participants were invited to interview; all consenting caregivers were interviewed.

Data collection

Data were collected on the percentage of caregivers who met the eligibility criteria, reasons for exclusion, and reasons for declining involvement where this information was offered by caregivers. Outcome measures were gathered at two time points (pre-intervention and six-weeks after receiving the modules).

- Self-efficacy, measured using the CaSES tool.[24]
- Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN).[25]
- The Preparedness for Caregiving Scale.[26-28]

Qualitative interviews were conducted with caregivers and healthcare staff to elicit appraisals of the intervention's feasibility and acceptability. Caregivers were interviewed at a location of their choice (their home n=4; at the palliative care service n=3). Staff were interviewed at the palliative care service (n=4). All interviews were conducted by an experienced qualitative health researcher, or a research assistant (who is also a palliative care nurse) who had been provided with research training.

Intervention description

The pedagogical approach taken within the distance learning modules have been described.[15] Written materials, incorporating anatomy/physiology, psychological support and hints/tips, were pitched at a reading level of grade 6-7 (equivalent of a reading age of 11-12 years).[29] The pain module was 42 pages, and the nutrition/hydration was 35 pages.

In addition to written materials, six videos were developed illustrating caregiving scenarios, practical illustrations of problems and potential solutions. The films varied in length from 2-6 minutes and were presented on DVDs. Both modules had embedded levels of increasing complexity, so that carers could chose to engage with basic to more detailed materials, to fit their learning needs. All materials were posted to participants, with no face-to-face component. Table 2 provides illustrative content for each module.

Table 2: Example content of distance learning materials

Managing Pain	**Nutrition/Hydration**
Pain assessment; the psychology of pain	The psychology of eating/drinking
Over the counter medicines; types of pain medicines; Non-medical treatments	Feeling less hungry; Feeling sick
Injections for pain relief.	Mouth care for nausea or dry/sore mouth
Video clip: giving subcutaneous injections	Video clip: mouth care when the person is unconscious

Analysis

Formal power calculations and hypothesis testing are not appropriate in pilot work[30] as the study was not designed to formally test for difference. Data from the primary and subsidiary outcome measures were analysed using descriptive statistics and paired t-tests.

Qualitative interviews were digitally recorded, transcribed and managed using NVivo (version 10). Data were analysed thematically.[31] Analysis was conducted by the chief investigator (an experienced healthcare researcher), nurse researchers and a social science research assistant. Caregiver and health professional data were analysed separately and then synthesized to identify overlapping, complementary and discordant themes.

Collectively, data were analysed to guide the refinement of the modules, and inform methodological parameters for a later scaled-up fully powered trial and provide an assessment of the feasibility and acceptability of the approach.

Ethical permissions

Calvary Public Hospital and Australian Catholic University provided approval (ref: 2-2016 and 2016-85R respectively). Data have been anonymised to preserve confidentiality.

Findings

Recruitment and participant flow

Table 3: Recruitment

Round	Patients screened	Eligible carers / Excluded (%)	Carers Invited	Carers Recruited (%)	Carers Enrolled	Baseline Returned	Follow-up Returned (%)

1	132	73/59	73	11	10	9	6
2	23	12/11	12	5	5	5	4
3	100	36/64	36	10	10	9	8
Total	**255**	**121/134** **(47%)**	**121**	**26** **(21%)**	**25**	**23**	**18** **(69%)**

Participant timelines and flow through the study are illustrated in Figure 1. Participants are described in Table 4, illustrating a heterogeneous group.

Table 4: Participant characteristics

		Baseline (% 23)	**Follow-up (% 18)**
Sex	Female	15 (65)	12 (67)
	Male	8 (35)	6 (33)
Caring for	Spouse	21 (91)	18 (100)
	Parent	2 (9)	0 (0)
Occupation	Retired	13 (56)	11 (61)
	Full time work	3 (13)	3 (17)
	Part time work	4 (17)	3 (17)
	Other	3 (13)	1 (5)
Age	31-49	2 (9)	1 (5)
	50-69	13 (56)	10 (56)
	70+	8 (35)	7 (39)
Education	High school	8 (35)	6 (33)
	University/College	6 (26)	4 (22)
	Professional higher degree	9 (39)	8 (44)
Patient diagnosis	Cancer	13 (56)	10 (56)
	MND	4 (17)	3 (17)
	Lung disease	2 (9)	2 (11)
	Renal disease	2 (9)	1 (6)
	Other	2 (9)	2 (11)
Total		**23**	**18**

Impact on self-efficacy, caregiving tasks and preparedness

There was an improvement in (i) perception of being able to conduct caregiver tasks/improved consequences/decreased needs (CaTCoN), and (ii) caregiver preparedness, but a slight reduction in self-efficacy (CaSES) (Table 5).

Table 5: Mean scores, standard deviations and ranges of scores on primary and secondary outcome measures at study time-points

	Baseline (n=23) Mean raw score (SD) Range	**Follow-up (n-18)** Mean raw score (SD) Range	**Paired t-test** (SD)	**Significance (CI)**
CaSES - Self efficacy (higher scores indicate *better* self-efficacy)	Mean: 2.99 (0.831) Range: 1-4	Mean: 2.93 (0.808) Range: 1-4	Mean (T1): 2.95 (0.564) Mean (T2): 2.94 (0.513)	P= 0.86 (CI: -0.17, 0.2)
CaTCoN - Cancer Caregiving Tasks, Consequences and Needs (higher scores indicate *worse* functioning)	Raw mean: 42.33 (9.9) Range: 0-3	Raw mean: 37.3 (14.7) Range: 0-3	Mean (T1): 42.56 (9.89) Mean (T2): 37.5 (14.71)	P= 0.03 (CI: 0.72, 9.4)
Preparedness for caregiving (higher scores indicate the carer feels *better* prepared)	Mean: 2.35 (0.57) Range: 0-4	Mean: 3.24 (0.70) Range: 0-4	Mean (T1): 2.29 (0.59) Mean (T2): 3.19 (0.60)	P=0.001 (CI:-1.22, -0.46

The qualitative data indicated that the modules gave carers greater understanding of what the patient was experiencing, and how to communicate more effectively:

> I went back over little bits and so it helped me rephrase how I was saying things and understanding why he was doing that. And also there was a bit there when he was denying being in pain but you could see that he was. So going back, yeah, and reading over those [...] it helped me understand where he was coming from and also to understand how I should react to his reaction. (C4, carer of person with cancer)

When asked if she thought having the modules had helped manage symptoms at home she said:

> It does but it also helps us when we go to see the GP, or when we go to see the oncologist. […] It means that we're prepared and we can ask them questions as opposed to going on the internet and trying to find information from there. (C4, caregiver of a person with cancer)

Thus the data indicate that carers felt more prepared and effective in their role.

Feasibility

Eligibility (reported in Table 1) compared favourably with comparable group education.[32] Recruitment was slightly less favourable than other published studies [2, 32] [3] Retention for this study was high, at 69%.

Both staff and caregivers felt that approaches to recruitment (via post, in clinic and face-to-face) were appropriate.

Staff queried the feasibility of requiring a life expectancy greater than 12 weeks:

> I'm a bit unsure about this 12 week criteria. I think it has to be more of a case by case basis and you have to look at whether families are dealing with particular things at the time of their approach for recruitment. (Staff 1)

Some caregivers felt that it would be a useful resource to have soon after being made aware that the diagnosis would result in a shortened life-span:

> I might have got more out of it if I'd received it when we were told he was stage 4 terminal rather than wait until the 'end of days' (C3, carer of a patient with cancer)

Content and presentation of modules

Caregivers indicated that although the modules were long, they were presented appropriately, were useful and should be recommended for other caregivers. They appreciated the staged approach to presenting information, progressing from simple to more complex ideas and scenarios.

Carers identified gaining insight into their own coping. One carer said that the materials helped her recognise that she would find caring for her husband very hard at end of life:

> I didn't realise how much nursing was involved. Well, I didn't realise, I had no idea. All I knew was that it wasn't me, that I couldn't do it. (C3, carer of person with cancer)

The layout and design of the materials enabled engagement with it:

> I went to the written word first because that’s just my preferred option, that’s what I usually do. But then after I’d done that I put the DVDs in and watched those. (C7, carer of a person with cancer).

Regarding the DVDs, one carer reported:

> I thought that was brilliant. A picture’s worth a thousand words. It’s all very well to read it but what does that actually mean? I thought that was really good. I learned quite a lot from that. (C1, carer of person with lung disease)

Carers appreciated being able to engage with the package in their own time and speed:

> When I first received it I sort of skimmed through it all, went through bits and pieces of it and sort of filed that away, and then when I had time I would sit down and decide that this chapter is what I’m going to read and then when I had time I would go through it all. (C4, carer of person with cancer).

Discussion

This innovative approach used distance learning to overcome the shortcomings of face-to-face delivery. Without relying on internet access or travel to group sessions the approach offers equitable learning opportunities which can be used by carers wherever they live. The approach enabled caregivers to feel more prepared for their role. Distance learning was both feasible and acceptable.

The modules were based upon a well-articulated theory, which informed the design of the intervention and outcome measures. Self-efficacy was chosen because it had been identified in carer education studies as a modifiable factor, and as related to management of pain for someone at end of life.[33] The limited change in self-efficacy in this study may reflect the small sample size, the acuity of patients' illness (and consequently carer burden) or indeed be an accurate reflection of the inability of the approach to impact self-efficacy. Preparedness for caregiving did demonstrate a statistically significant change, and consequently is recommended for subsequent use.[26]

The eligibility rates for this study can be used to inform likely national pool of palliative caregivers who may benefit from this learning approach. Extrapolating from this study's recruitment figures, 14,963 caregivers across Australia would be eligible to participate in the study, and therefore gain benefit from using the materials.

A scaled-up trial would be strengthened through recruitment primarily through out-patient clinics, where patients typically have a prognosis greater than 12 weeks and when receiving information has potential to be most helpful.

Unlike many other palliative caregiver educational interventions, the sample in this study was not heavily weighted toward caregivers of people with a cancer diagnosis.[2, 34] The heterogeneous sample indicates that the acceptability and feasibility aspects transfer to the broad palliative care population not solely those affected by cancer.

Limitations

This study recruited from only Canberra, Australia, which has a relatively affluent/educated population who are geographically close to a specialist palliative care service. Consequently, the data on recruitment process and participation rates may not be directly transferable. Future studies could determine impacts of the intervention beyond the caregiver. For example, patient data could be collected focusing on their perceptions of care provided,[35] or to examine dyadic adjustment. It would also be prudent to examine in more detail whether the materials help caregivers to support their relative to die at home, or to identify earlier on the likely need for inpatient care of caregivers who may struggle.

This study reported only six-week follow-up data, and longer term impact would be valuable. Carer education interventions typically report short-term impacts, such as two weeks.[4] Of the 18 caregivers who completed follow-up measures, only seven opted into an interview. The majority of these interviewees were supporting patients in the earlier stages of their palliative phase; that is without significant symptom burden or symptoms that were well controlled. At the end of the study period all seven patients were still alive, meaning that the interviewees were not representative of the illness burden of patients associated with the study.

Clinical implications

This study has for the first time, developed detailed modules for informal caregivers of people receiving palliative care. The package indicates a positive impact on caregivers feeling prepared for their role, and enables them to engage in learning without need to travel, be absent from the patient, or adhere to rigid timings. Since the evaluation did not identify any implementation problems of note, the study design and content met feasibility criteria.

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