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The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients

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ABSTRACT

Background A key component of palliative care is support for family caregivers. Although some family caregivers identify positive aspects, the impact is typically burdensome; they are prone to physical and psychological morbidity, financial disadvantage and social isolation. Outcomes of systematic reviews have highlighted the importance of investment in family caregiver intervention research.

Purpose To provide an overview of the development, evaluation and outcomes arising from a programme of research (The Melbourne Family Support Program (FSP)), which focused on reducing the psychosocial burden of family caregivers.

Methods Developmental work involved a systematic literature review; focus groups with family caregivers and health professionals; and identification of a conceptual framework. Following a pilot randomised controlled trial (RCT), a programme of psychoeducational intervention studies was developed and tested; one via RCT, the others via prepost test.

Results Four psychoeducational interventions, incorporating one-to-one and group format delivery, conducted in both the home and inpatient hospital/hospice were evaluated. Statistically significant outcomes included improvements in family caregivers' preparedness, competence, positive emotions, more favourable levels of psychological wellbeing and a reduction in unmet needs. Internationally endorsed guidelines for the psychosocial support of family caregivers were produced and several resources were constructed. Fifteen publications in international peer-reviewed journals have arisen from this programme.

Conclusions The interventions and resources from the Melbourne FSP provide several evidenced-based and clinically relevant approaches that focus on reducing the

psychosocial burden of the caregiving role. In several instances, however, more rigorous methodological testing is advocated.

INTRODUCTION

Palliative care focuses on supporting patients diagnosed with advanced, incurable disease; it is 'family centred', with the patient and their family (the unit of care) being core to all its functions.¹ Given the significant burden associated with caring for a dying relative, WHO advocates that healthcare services focus on enhancing family members' quality of life during caregiving and bereavement.² Accordingly, many nations have established standards and policies for palliative care provision which focus on assessing and responding to the psychosocial needs of family caregivers.¹

Although some family caregivers identify positive aspects associated with their role,³ the impact of caring can be considerable. The role is typically burdensome; family caregivers are often prone to physical and psychological morbidity, financial disadvantage and social isolation.⁴ Some caregivers take on the role because of a sense of obligation, perceiving they have little choice.⁵ Caregiving can extend for several years; it can be equivalent to a full-time job.⁶

A life-threatening diagnosis can have a greater negative psychological impact on the family members than the patients.⁷ Depression rates of between 12% and 59%,⁴ and anxiety rates of between 30% and 50%^{4, 8} in caregivers have been reported. A recent study involving caregivers (n=300) soon after referral to specialist palliative care, identified that approximately 50% met criteria for

psychological distress (based on a validated screening instrument).⁹ Unfortunately, these high rates of psychological distress are typically under-recognised and, consequently, not addressed.¹⁰

Irrespective of a requirement for healthcare professionals to support family caregivers, the reality is that in many instances this support is less than optimal.¹ Family caregivers' psychosocial needs are frequently considered either secondary to those of the patient, or overlooked; there is neither consistency nor a systematic approach to assessing needs.¹¹ Furthermore, caregivers are often not aware of available support, they usually have limited prior exposure to death and dying, and feel excluded from information and care planning.¹² Health professionals acknowledge that providing psychosocial support to family members, as well as patients, presents an enormous challenge, and they may not be resourced or have the required skills to provide such support.¹³

Systematic reviews of interventions for family caregivers reveal that effective support is in its infancy.^{14 15} Results from an international survey¹⁶ concluded that interventions focused on improving family caregiver psychosocial support were a priority. According to a recent review,¹ interventions to improve family caregiver support are important for numerous reasons which are outlined in the Box 1.

The following reflection exemplifies the experience for many caregivers who feel underprepared for their role:

I just had no idea what I was in for. If I had known maybe I wouldn't have been so forthcoming about making the promise to look after him at home. It all sounds so nice when we first talked about; 'Oh yes, it would be nice to have him at home, that's so much better, so peaceful'. And when its really happening you think, oh my God, this is horrendous. It's not at all what I expected.¹⁷

In summary, there are clinical, academic and policy reasons for developing a programme of intervention research focused on improving the psychosocial well-being of family caregivers; without such research, the field will continue to fall short of meeting standards of palliative care provision.¹ This paper outlines the rationale, pilot work, conceptual framework for such a programme and provides an overview of several interventions and resources primarily developed and/or led by the Centre for Palliative Care (St Vincent's Hospital and Collaborative Centre of The University of Melbourne, Australia). Accordingly, this suite of strategies and resources has been labelled: the Melbourne Family Support Program (FSP).

METHODOLOGICAL AND THEORETICAL FRAMEWORK AND PILOT WORK

Methodological framework

In order to develop the interventions tested as part of the Melbourne FSP, a theoretical framework was

Box 1 Reasons why interventions to improve family caregiver support are required*

Interventions to improve family caregiver support are required because caregivers:

- ▶ should receive evidence-based support from health professionals as per national and international policies and standards
- ▶ are receiving support which is neither systematic nor fully evidence based
- ▶ are prone to physical and psychological morbidity
- ▶ are responsible for numerous tasks, such as symptom management
- ▶ are financially disadvantaged
- ▶ become socially isolated
- ▶ report unmet needs (typically aligned with lack of information about their role)
- ▶ have needs equal to and/or greater than the patients' needs
- ▶ have very limited first-hand exposure to death and dying
- ▶ are often excluded from information and care planning and, consequently, feel underprepared for their role
- ▶ have the potential (with suitable support) to gain positive outcomes from their experience.
- ▶ are pivotal to achieving 'successful' home care (where most people prefer to die)
- ▶ make a substantial economic contribution to healthcare
- ▶ may significantly enhance the patients' well-being when their role is well supported.

*Adapted from Hudson and Payne.¹

sourced and pilot work undertaken. This strategy is commensurate with the Medical Research Council, UK's approach for the development and evaluation of complex interventions to improve health.¹⁸

Theoretical framework

The theoretical framework for guiding the Melbourne FSP was based on a transactional model of stress and coping.¹⁹ Proponents of this framework argue that the diversity of responses related to end-of-life issues from patients and family caregivers can be understood from a psychological perspective based on a transactional model of coping in which caregivers make cognitive appraisals to determine the possible impact of a potentially stressful event. The more prepared and capable the caregiver is, or the greater the number of resources at their disposal to manage an event, the more likely the individual will display adaptive behaviours. Such resources include having adequate information to prepare them for their role, fewer unmet needs and focusing on positive aspects in order to

minimise psychological distress. Hence, strategies that targeted these domains were core to the Melbourne FSP.¹⁹

Pilot work

Four approaches, summarised below, were undertaken to help inform the development of the Melbourne FSP.

1. The first study sought insights (through focus groups) from palliative care nurses and family caregivers to inform intervention development.²⁰ Results identified what caregivers need to prepare them for their role, the key information that should be routinely offered and the best way to present the information. Based on these data, a guidebook on preparing family caregivers for the role of supporting a relative/friend with a palliative care diagnosis was also produced.²⁰
2. A critical literature review of supportive interventions for family caregivers²¹ confirmed the need for new supportive care strategies for families to be developed. Psychoeducational interventions evaluated via randomised controlled trials (RCT) were considered a priority.
3. Successful interventions need to be developed in a pragmatic way; accordingly, the challenges faced by healthcare professionals associated with providing support to family caregivers were considered.¹³ The supportive care challenges fell into three broad categories: family related challenges, health system barriers and communication barriers. Identifying these obstacles influenced the development of a FSP focused on these 'coal face' issues.
4. Based on the aforementioned work, a pilot RCT; a home-based one-to-one (nurse to caregiver) psychoeducational intervention focused on preparing family caregivers (n=106) for the role of supporting a dying relative at home was undertaken.²² Data were collected at three time points: upon commencement of home-based palliative care (Time 1), 5 weeks later (Time 2), and then 8 weeks following patient death (Time 3). No intervention effects were identified with respect to preparedness to care, self-efficacy, competence and anxiety. However, participants who received the intervention reported a significantly more positive caregiver experience than those who received standard care at both Times 2 and 3. A larger follow-up trial was recommended.

Melbourne FSP: aim and objectives

The Melbourne FSP's focus was on insights from the theoretical framework and pilot work. The Melbourne FSP's purpose was to develop evidence-based strategies (and associated resources) that focus on promoting the psychosocial well-being of primary family caregivers of patients receiving palliative care. Specific elements of the programme included developing healthcare-led psycho-educational mechanisms to: (1) increase family caregivers' sense of preparedness for their role; (2) bolster their positive emotions; (3) reduce their unmet needs; (4) reduce their psychological distress.

Particular emphasis on preparedness was considered important. Family caregivers consistently report that communication and information related to end-of-life care is inadequate; they want to be better prepared for their role.¹² Inadequate family caregiver preparedness for death has been shown to be associated with depression, anxiety and complicated grief.²³⁻²⁴ Furthermore, the concept of preparedness fits neatly with the chosen theoretical framework.

Overview of Melbourne FSP strategies and resources

Over a decade, five main strategies (and associated resources) have been developed and evaluated; these are outlined in table 1. A comprehensive account of the objectives, evaluation methods and outcomes of each of the strategies can be found in the publications arising from each specific study. As outlined, four of the interventions (1–4) involved healthcare professional-led, direct interaction with family caregivers in both one-to-one and group formats, conducted in either the home or inpatient/hospice setting. The interventions were primarily tested via prepost design with one examined via a RCT. All interventions showed statistically beneficial outcomes in at least one of four outcome variables: preparedness, unmet needs, positive emotions and psychological distress. The final strategy involved the development of guidelines for the evidence-based psychosocial and bereavement support of family caregivers, endorsed by several key national and international organisations.

DISCUSSION

The need for more research to underpin support for family caregivers related to palliative care has been acknowledged by an international assembly of senior researchers,³⁴ and was the rationale for the inception of the International Palliative Care Family Caregiver Research Collaboration.³⁵ The results of several published reviews¹⁻¹⁴⁻¹⁶⁻³⁶⁻³⁷ also advocate for major investment in intervention research in this area.

The Melbourne FSP has produced several interventions showing statistically significant outcomes for family caregivers, including increased sense of preparedness, competence, rewards, more favourable levels of psychological well-being and a reduction in unmet needs. Several resources have also been developed, including clinical practice guidelines endorsed by key international institutions (see table 1). Fifteen publications in international peer-reviewed journals have arisen from the Melbourne FSP.

Research limitations and implications

Several research implications and limitations arise from this programme. A 'pilot' RCT formed the foundation of the research²² with an additional follow-up phase III RCT.⁹ The remaining interventions, however, were evaluated via pretest/post-test designs which have noteworthy limitations, including

Table 1 Summary of Melbourne Family Support Program (FSP) interventions and resources

Strategy/ intervention	Setting	Research design/ methods	Outcome variables	# Of participants	Results	Resources	Publications arising
<i>Melbourne FSP #1.</i> One-to-one home-based psychoeducation programme. Delivered by nurse to primary family caregiver	Family caregivers of patients enrolled in home-based/ community specialist palliative care services - 4 sites, 3 states of Australia	Randomised controlled trial. T1 (baseline commencement of palliative care), T2 (2 weeks >intervention), T3 (2 mths >patient death)	Preparedness, competence, rewards, unmet needs, psychological distress	300	Statistically significant improvement in preparedness and competence @ T2. Significantly less rise (worsening) in psychological distress @ T3 in the intervention group.	Caregiver guidebook ²⁰	(T2) ^{9 11} (T3) ²⁵
<i>Melbourne FSP #2.</i> Group home-based psychoeducation programme. Delivered by health professional to group of primary family caregivers. Face-to-face sessions x 3 @ local hospice	Family caregivers of patients enrolled in home based/ community specialist palliative care services - 6 sites, Victoria Australia	Pretest post-test. T1 (baseline commencement of palliative care), T2 (2 weeks > intervention)	Preparedness, competence, rewards, and unmet needs	156 (30 programmes)	Statistically significant improvement in preparedness, competence, rewards, and needs met	Caregiver guidebook ²⁰ DVD for health professionals (http://www.centreforallcare.org)	26 27
<i>Melbourne FSP #3.</i> Group hospital. Delivered by health professional to group of primary family caregivers. Face-to-face sessions x 1 @ hospital palliative care unit/hospice	Family caregivers of patients admitted to hospital palliative care units/hospices - 3 states, 4 sites in Australia	Pretest post-test. T1 (prior to commencement), T2 (3 days >) intervention	Preparedness, competence, psychological unmet needs and psychological distress	125 (52 programmes)	Statistically significant increases in preparedness, competence and needs met.	Web guidebook (http://www.centreforallcare.org)	28 29
<i>Melbourne FSP #4.</i> Evaluation of guidelines for conducting family meetings	Family caregivers of patients admitted to hospital palliative care units/hospices in one site, Melbourne Australia	T 1 (pre-FM), T 2 (post-FM); T3 (2 days later) Plus qualitative	Unmet needs	22 family meetings	Statistically significant increases in needs met	30	30–32
<i>Melbourne FSP #5.</i> Guidelines for psychosocial and bereavement support of family caregivers	Designed for healthcare professionals involved in palliative care across settings	Literature review. Focus groups. Semistructured interviews. Delphi survey. Endorsement by key palliative care organisations	Not applicable	Not applicable	Officially endorsed by several institutions including: St Christopher's Hospice (UK); Palliative Care Australia; International Observatory of End of Life Care UK	Complete version of guidelines (http://www.centreforallcare.org)	33

DVD, digital video disk.

potential selection bias, and 'regression to the mean' issues.³⁸ Hence, these interventions should undergo evaluation via more rigorous experimental methods. Although two of the studies involved a bereavement data-collection point, the remainder did not; future work should consider incorporating these longer-term

endpoints. Other methodological challenges and strategies associated with family caregiver intervention research have been described elsewhere.^{1 37 38}

Future work should also attempt to clarify primary endpoints for psychoeducational interventions of the kind undertaken via the Melbourne FSP. In theory, the

primary outcome should link to the main objective of the intervention. However, although the Melbourne FSP interventions had similar aims and ingredients, it was difficult to determine, in some circumstances, which primary outcome should be measured. For example, we debated whether or not reducing caregiver psychological distress was more preferable, as a primary outcome, than reducing their unmet needs or increasing their sense of preparedness. Based on the theoretical framework underpinning the Melbourne FSP, it seemed logical to propose that if preparedness improves and family caregivers have their needs met, then it followed that their psychological well-being may be more optimal. Thus, psychological status would appear to be a justifiable primary endpoint. Intervention #1 identified that by 2 months after the patients' deaths, the caregivers in the intervention groups had significantly less increase in psychological distress than the control group.²⁵ Future empirical inquiry should examine this further, including clarifying the relationship between the variables outlined within the theoretical framework. It would be useful, for example, to know if preparedness and competence were highly correlated. Consideration should also be given to emerging methodological ideas surrounding examination of multiple endpoints.³⁹

The results arising from the Melbourne FSP seem to justify the ongoing use of the transactional model of stress and coping as a means to guide interpretation of the caregiver experience and interventions to ameliorate negative outcomes.¹⁹ For example, positive aspects of the caregiver role were bolstered by one intervention, and preparedness improved in several interventions. Schumaker and colleagues⁴⁰ found that negative reactions to the family caregiver experience can be buffered when caregivers are better prepared for their role. Despite these favourable findings, more empirical work is needed to determine the relationship between variables.²³

Clinical implications

It is difficult at present to assess the clinical significance of the Melbourne FSP interventions and resources. Despite dissemination via peer review, international journal publications (see table 1) and conference presentations arising from each of the Melbourne FSP initiatives, and formal endorsement for the clinical guidelines from major institutions, the extent of implementation is unclear. The utility of each intervention was partially examined as the evaluation incorporated some level of exploration of applicability, affordability and accessibility (outlined in the publications arising from each individual study). Some of the pragmatic issues discussed in detail in the publications arising from each intervention include factors, such as attracting enough family caregivers to warrant resourcing a group education session; given that some family caregivers are reluctant to leave their home to attend such programmes. Issues related to

optimal dose and frequency of interventions are also outlined.

The Melbourne FSP has incorporated a variety of face-to-face delivery methods, including one-to-one (health professional: family caregiver) group programmes, and conducted in the home-based and hospital palliative care setting, complemented by resources for family caregivers and health professionals. The rationale for this approach was that there is no 'one size fits all' for family caregiving in the context of end-of-life care. Family caregivers will most likely desire some information/guidance on how to provide support to their friend/relative. For some, a resource such as a guidebook may suffice. Others may benefit from structured face-to-face psychoeducational interaction; either one-to-one or via a group approach supported by written resources. Future work should focus on web-based initiatives. It is also important to expand these initiatives to other populations, for example, family caregivers of patients with end-stage neurological or organ failure, and to caregivers of children/young adults.¹

The Melbourne FSP has deliberately focused on the primary family caregiver; a decision based on our pilot work which showed that the overwhelming majority of family caregivers wanted to meet a health-care professional separately from their relative.²² Additionally, we have argued elsewhere that unless there is an increase in resources for palliative care providers, the focus of support should be the primary family caregiver in the first instance.³³ Nonetheless, consideration should be given to developing and evaluating approaches that involve the primary family caregiver and their relative/friend (for those who prefer this option), and perhaps other family members/friends (where suitable resources prevail). The Melbourne FSP was based in Australia and incorporated participants from metropolitan, regional and rural areas and a variety of cultural backgrounds. It is pleasing that some of this work has been tested in other countries³²; however, further exploration of its suitability in other countries/settings is warranted.

Future work should also focus on methods to help clinicians identify which specific interventions/strategies are most pertinent for family caregivers. Consideration should be given to systematic psychosocial screening and triaging of family caregivers⁴ allowing for a more targeted approach for interventions. The Melbourne FSP has focused primarily on psychoeducational initiatives. While we have justified this approach, these initiatives on their own will not provide the support that is required; some family caregivers will need comprehensive, focused interventions based on thorough assessment.

CONCLUSION

Although family caregivers are relied upon to provide much of the care to palliative care patients, they often

receive inadequate preparation, information and support; thus, empirically based strategies to rectify this are required. The interventions and resources arising from the Melbourne FSP provide several evidence-based approaches that attempt to lessen the psychosocial burden of the caregiving role. Although this programme arises from comprehensive pilot work, and a well-regarded conceptual framework and beneficial outcomes have been demonstrated, in several instances more rigorous methodological testing is advocated.

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