Towards better support for family carers: A richer understanding
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What is This?
Towards better support for family carers: A richer understanding

This special edition of Palliative Medicine aims to address the important topic of how best to support lay people (family, friends and significant others; hereafter called ‘family carers’) who provide care to patients during advanced illness and through the process of dying. It is widely recognised that these people have an essential role in providing physical care, emotional and social support; financial resources; advocacy and anticipatory care and in negotiating and coordinating care during the final phases of life.1,2 The presence of family carers who are able and willing to provide care is essential to facilitate important patient choices, such as place of care and place of death. It is a challenging and demanding role, which few people aspire to, but which many will have thrust upon them, in often difficult circumstances and following a ‘crisis’. Undertaking this role may have physical, psychological, social and financial consequences for carers, which outlast their period of care and may influence their bereavement. Yet remarkably until relatively recently, there has been little academic interest in how family carers adapt to and manage their role in caring for those who are facing death.

Family carers occupy an ambiguous position, being both providers and potentially recipients of care. Furthermore, the challenges they experience may stem from witnessing the last period of a patient’s life with the potential for vicarious distress and suffering, from the direct physical and emotional demands of being a carer or from their own emotional and social changes in bereavement. This creates a complex and ‘messy’ picture to capture in research. Rather than reflect on their own experience, carers may also often function as proxies when patients become too ill or distressed to participate in data collection. Palliative care research can be criticised for being overly reliant on carers’ rather than patients’ accounts. For example, in England, the National Health Service has adopted ‘VOICES’ – a retrospective questionnaire – which is given to bereaved family members following the death of the patient to monitor their experiences during the last phase of life and audit end-of-life care.3 This potentially provides important feedback to improve services and helps to acknowledge their central role in accompanying the dying patient.

There is a growing international interest in this field with two initiatives providing an impetus for development. The European Association for Palliative Care Family Carers Task Force published an overview of evidence about family carers and offered policy and practice recommendations.4,5 The International Family Carers in Palliative Care Research Collaborative has provided a focus for stimulating multidisciplinary research.6

We hope that this special edition will serve as a useful resource for everyone interested in improving support to family carers. It is written for researchers, clinicians, managers, educators and policymakers working in, or responsible for, palliative care and hospice services. It is focused on care provided by adults to adults who are in the palliative phase of their condition. It covers care provided in a range of settings, including the home, hospital, care home (nursing home) for older people, hospice and other settings. We were delighted with the global interest that our call for papers generated. It was a difficult task to select the 13 papers for inclusion. We made our selection based on a number of principles, in addition to the usual journal requirements for high-quality scientific rigour and clear presentation, including new methods of research, different levels of analysis from population to micro-systems and aspects of caring that are unrecognised or poorly understood.

We highlight some of the outstanding work that is published in this volume. It is important to be creative in using research data and methods of analysis that offer new insights into caring near the end of life. For example, Burns and her team7, in Australia, have used annual randomised population survey data with a sample of 23,706 people collected over 7 years, to identify what they describe as a network of informal care provision that is not captured in research data and methods of analysis that offer new insights into caring near the end of life. For example, Burns and her team7, in Australia, have used annual randomised population survey data with a sample of 23,706 people collected over 7 years, to identify what they describe as a network of informal care provision that is not captured in research data and methods of analysis that offer new insights into caring near the end of life. For example, Burns and her team7, in Australia, have used annual randomised population survey data with a sample of 23,706 people collected over 7 years, to identify what they describe as a network of informal care provision that is not captured in research data and methods of analysis that offer new insights into caring near the end of life. For example, Burns and her team7, in Australia, have used annual randomised population survey data with a sample of 23,706 people collected over 7 years, to identify what they describe as a network of informal care provision that is not captured in research data and methods of analysis that offer new insights into caring near the end of life. For example, Burns and her team7, in Australia, have used annual randomised population survey data with a sample of 23,706 people collected over 7 years, to identify what they describe as a network of informal care provision that is not captured in research data and methods of analysis that offer new insights into caring near the end of life.
caring or in bereavement likely to be available. At the other end of the sampling spectrum, Hennings and colleagues\(^8\), in the United Kingdom, have focused on a detailed narrative analysis of serial interviews conducted with 10 spouses who are caring for an older person with dementia near the end of life in a residential nursing care home. The detailed and nuanced analysis starts to reveal the ambiguity of their caring experiences, described by the authors as ‘living in two worlds’ – the nursing home where their spouse lives and in the wider society – where they are not widows but live alone, already functionally and socially bereaved. This article starts to illuminate the experience of a marginalised group of carers who are likely to become a more common group as global population ageing and dementia incidence increases.

Undertaking longitudinal research enables differences to be measured over time. For example, Guerriere and her colleagues\(^9\) in Canada measured the satisfaction of carers of patients with cancer of a multidisciplinary palliative care programme that offered physical symptom management and psychosocial support. These types of community-based provision are increasingly common in many countries, and it is important to base new service developments on rigorous evaluation that considers the impact of services on patients and their family carers.

It is important that we synthesise and build on existing evidence. Correspondingly, this edition also includes two reviews of the literature. Van Humbeeck et al.\(^10\) report a review of research into the experiences of older parents caring for an adult child with life-limiting illness, illuminating what is currently known for this relatively under-researched area. Whittingham et al.\(^11\) present a narrative review to identify dimensions that impact on caregiver burden and quality of life in family carers of patients with heart failure.

There are still important gaps in this edition. We had hoped for better international representation, including submissions from authors working in developing countries. Yet the only article involving data from outside Europe and English-speaking countries is a study by Yennurajalingam et al.\(^12\) that considers preferences for decisional control among Hispanics in the United States and Latin America. Articles reporting on trials of interventions and the health economics of caregiving are also missing, reflecting the relative lack of such studies in this field. Finally, while the edition contains several articles considering carers of patients with diagnoses other than cancer, research involving patients with cancer still dominates.

References

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