An international collaboration for family carer research

“Support for family carers is a core tenet of palliative care philosophy and practice. At the recent EAPC Research Congress in Venice, an open meeting was convened to discuss the inception of a research group to foster international collaboration related to projects associated with family carers.

International literature is replete with data acknowledging the psychological, physical, social and financial distress experienced by family carers.[1,2] Family carers report a variety of unmet needs, despite input from healthcare services.[3,4] Palliative care philosophy also encompasses support for family carers into the bereavement period. However, bereavement support has been the least well-developed aspect of specialist palliative care services.[5] Recent research shows that many family carers can identify positive aspects related to their family carer role,[6,7] which may help to prevent the family carer experience becoming pathologised. However, a suitable means to determine which carers are prone to psychosocial distress is yet to be developed. Although a conceptual framework for guiding family carer research has been described,[8] there has been a dearth of intervention studies,[9,10] hence it is not yet clear how best to meet carer needs. Also, given the seemingly limited pool of researchers focusing specifically on family carer research in palliative care and the limited research funding opportunities, a strategic and collaborative approach to family carer research seems wise.

The purpose of the meeting was to explore ways in which a more streamlined and strategic approach to family carer research might be achieved. Specific objectives were to: seek agreement to pursue the initiative; brainstorm what might be possible; and establish a core group of international researchers to take responsibility for managing the ongoing development of this initiative.

We were extremely pleased with the attendance: there were approximately 35 participants from countries including Ireland, Australia, England, Canada, Scotland, Norway, USA, Belgium and the Netherlands. Several research groups who were unable to attend expressed their desire to be involved in this initiative. Participants discussed advantages and disadvantages of the initiative; potential challenges; precedents or models in other areas of research; strategies for funding; family carer research priorities; governance issues and recommendations for developing the group in the short to medium term.

So, where to from here? The establishment of a steering committee will be an important step in developing the research collaboration. Clarification of the name for the group, terms of reference and specific objectives of the group are required. Email correspondence will be the major form of communication; the next face-to-face meeting will be at the EAPC Congress in Budapest (7–9 June 2007). At the very least, we anticipate that this will be an important vehicle for information exchange and, resources permitting, we hope that it can assist with the development of quality research studies that have international significance.

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We welcome questions or comments and we are keen to hear from other family carer researchers who wish to be involved. We would be pleased to receive recommendations from others who have experience with developing similar initiatives. We would like to thank the EAPC for providing the opportunity to convene the meeting, those who came to the meeting and those who support this initiative but were unable to attend. We look forward to developing this initiative in the hope that it will contribute to improved outcomes for family carers who support people with life-threatening illnesses.”

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References
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