

Commentary:

Palliative and end-of-life care

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Studying care for people who are dying is among the most challenging areas of healthcare research, as exemplified by the four papers presented in this issue of the Journal of Research in Nursing. There is a close link between the often missionary-like zeal of those working in palliative care who seek to enhance quality of care for the dying and those committed individuals who pursue research into the needs of people who are at the end of life. Again this is exemplified among these papers. The mission to extend and improve care is embedded in the studies described and championed by the researchers who have presented material relating to their work. It is this very activism that makes palliative care such an inspiring field in which to work, but also presents risks, since 'zeal' can create barriers to gathering evidence of the effects of a particular intervention in the round, or from standing back from situations in which one may be immersed.

It is little short of a scandal that, until recently, quality of care for people dying in nursing homes or from common conditions such as stroke have received such scant attention; until, that is, the contributors to the papers in this issue took it on themselves to pursue research into the care of such client groups following Field and Addington-Hall's (1999) call to arms by proposing that specialist palliative care should be extended to patients of all disease groups. Hockley et al. illustrate the scale of end-of-life care going on in nursing homes in stating that deaths in one year account for one-third of the residents of the 3,700 beds available across the Health Authority in which their study was undertaken. Rogers and Addington-Hall remind us that stroke accounts for 11% of all deaths, 20% of which occur within one month of the stroke occurring. These two care areas examined in three of the four papers represent a staggering volume of caring activity and about which little information is available. What is heartening is that the two empirically based papers — Hockley et al.'s

action research study to implement an integrated care pathway for the dying in eight nursing homes in Scotland, and Rogers and Addington-Hall's non-participant observation and interview study of the care of individuals dying following stroke in an Acute Stroke Unit — indicate a real commitment among health professional and non-health professional staff to providing high-quality end-of-life care, which, it would appear, is in many instances achievable. Also, the difficulties of providing such care can be addressed and in many cases overcome through supportive interventions such as facilitated collaborative learning groups and committed interprofessional teamwork. These studies, however, also point to the factors that may be holding back further improvements in the ability to provide care and indicate that these are important avenues for future research. The most important of these is highlighted by Rogers and Addington-Hall and lies in the difficulty of identifying that someone is dying. While the majority of the cases in their study died within five days of having their stroke, and in these instances care was relatively straightforward, there were others who lived longer than expected, or where professionals were uncertain as to whether their death was imminent or not. In these instances decisions about pursuing active treatment, providing intravenous fluids or nasogastric feeding became much more difficult and led to tensions between staff, and between staff and family members. Many of these difficulties could be overcome if we were better able to identify which patients were in the last week or so of life. This may require major research effort to uncover biological and possibly behavioural indicators of the dying process.

The challenges of undertaking research into issues relating to end-of-life care are illustrated by both the empirical papers, and both are brave and important. Rogers and Addington-Hall in particular had to face the difficult problem of deciding how to include observational data from patients who were not able to give consent to participation, and for some there were no next of kin that could be approached. Seymour et al. provide a useful overview of these challenges based on the experiences of the research team at the University of Sheffield. Assuring participation of even the most vulnerable, the difficult issues of gaining consent to participation among individuals whose physical and emotional state is inevitably changing and how to handle the highly sensitive material that studies of end-of-life care produce, present constant dilemmas. Froggatt usefully offers critical insights into the difficulties of realising government policy on issues such as patient choice about end of life, in care settings that lie outside of public provision, and among fragile and socially marginalised individuals. Again, these are important subjects for future research.

A few small worries

The work presented through these papers certainly demonstrates the value of qualitative research in tackling the difficult issues surrounding researching end-of-life care and in producing evidence for the value of care interventions. However, both studies presented could be criticised for not pursuing evidence to convince us about the broader dimensions of care, or of care outcomes, and returns me to my point about being convinced that evidence is incontrovertible in the face of 'zeal'. I am somewhat unconvinced by the very positive reporting of data from interviews of staff from the Scottish care homes study. Feeling more confident about care, and that care has gone well for care home residents that have died is important, but I also felt the need for other sources of evidence to back up 'insider accounts'. Likewise, Rogers and Addington-Hall present an optimistic picture of dying from stroke reporting 'few distressing symptoms', but I was left wondering how we are to know this since observational data taken only once a day may not be sufficient to make this claim. All four papers reflect an absence of the voice of the dying person — for important reasons; many are too ill, or are unable to participate directly. As a body of work, though, it leaves me wondering how we can go further in ensuring that the voices of dying people are not excluded. As I know the individuals who have contributed to these papers well, I know they are more than likely to have an answer to how and where end-of-life care research can and should go next and I wait with interest to see.

Reference

Field, D., Addington-Hall, J. (1999) Extending specialist palliative care to all. *Social Science and Medicine* 48:9, 1272–1280.