

School for Social Care Research

End of Life Care

Claire Goodman, Katherine Froggatt
and Elspeth Mathie

Improving the evidence base for
adult social care practice

Methods Review 12



The School for Social Care Research

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About the authors



Claire Goodman is Professor of Health Care Research at the Centre for Research in Primary and Community Care at the University of Hertfordshire. A district nurse by background, Claire is involved in a range of studies that focus on the needs of the oldest old living in community settings. This includes research on end of life care for older people with dementia living in residential care settings, on inter-professional working for older people with complex needs living at home, and on models of integrated care between primary health care services and (residential) care homes for older people.

Katherine Froggatt is a Senior Lecturer in the International Observatory on End of Life Care at Lancaster University. Her research interests concern the development of end of life care in care homes, palliative care for people with dementia, and public education on end of life issues with older people.

Elsbeth Mathie is a Research Fellow at the Centre for Research in Primary Care and Community Care at the University of Hertfordshire. Elspeth has experience of carrying out research in care homes with a particular focus on end of life. She has interviewed older people, including those living with dementia, about their future in the care home. She also has an interest in public involvement in research.

NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE
Email: sscr@lse.ac.uk
Tel: +44 (0)20 7955 6238
Website: www.sscr.nihr.ac.uk

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ABSTRACT

This review provides an overview of the range of research methods that have been commonly used in end of life care research and their relevance for social care. It provides a policy and service context for understanding end of life care research in social care and, using examples from relevant research, considers the advantages and disadvantages of different research methods and tools. The particular ethical challenges and practical issues that may arise are discussed along with some strategies and sources of support to address them.

RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

- Despite the many challenges of undertaking research in this area, people at the end of life often value the opportunity to participate in and find benefit from their involvement in research. Therefore, we would encourage more research in this area.
- More research is needed on the costs and resource use associated with end of life care in social care settings.
- There needs to be a robust evidence base to support the development of good social care practice in end of life care that complements palliative care research and develops resources that are specific to social care.
- There is a need to develop research approaches that can exploit narrative and online data sources about the experience of dying and access to support
- When researching health and social care and end of life, it is important to consider the complex interaction between different groups and health and social professionals and the wider context within which they operate.
- Research in end of life of care would benefit from more social care-appropriate theoretical frameworks.

KEYWORDS

end of life care research, palliative care, dying

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Beatrice Godwin, Centre for Death and Society, Department of Social and Policy Sciences, University of Bath

Sue Hall, Dunhill Senior Lecturer in Palliative Care, Department of Palliative Care, Policy and Rehabilitation, Cicely Saunders Institute, King's College London

Cheryl Holman, City University, St Bartholomew School of Nursing and Midwifery, London

Malcolm Johnson, Department of Social and Policy Sciences, University of Bath

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Jane Seymour, Sue Ryder Care Professor in Palliative and End of Life Studies, Sue Ryder Centre for Palliative and End of Life Studies, School of Nursing, Midwifery and Physiotherapy, University of Nottingham

Eleanor Wilson, Research Fellow/PhD student, Sue Ryder Centre for Palliative and End of Life Studies, School of Nursing, Midwifery and Physiotherapy, University of Nottingham

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END OF LIFE: GLOSSARY

ADLs	Activities of daily living
AQAAs	Annual Quality Assurance Assessment – documents completed annually by care homes providing information about residents and the care home workforce. All registered adult care service providers are now legally required to complete an AQAA
DNR	Do not resuscitate
DNACPR	Do not attempt cardiopulmonary resuscitation
EoLC	End of Life Care
GSF	The Gold Standard Framework is a palliative care tool designed to support the planning and delivery of care to people who are identified as approaching the end of life. This includes GP practices keeping a register of people likely to benefit from palliative care, training and facilitation in palliative care, having systems that support advance planning, communication with patients, families and practitioners, coordination of care and after death analysis. A GSF package of tools has been developed for care homes, however, unlike the NHS, care homes have to pay to participate and use the tools. www.goldstandardsframework.nhs.uk/
LCP	The Liverpool Care Pathway for the dying patient is an integrated care pathway that is used at the bedside to improve care of the dying in the last days or hours of life. The LCP has been implemented in hospitals, care homes, the individuals' own home/community, and hospices. www.mcpcil.org.uk/liverpool-care-pathway
MAR	Medication Administration Records. Sheets produced by the pharmacist listing medicines prescribed, used in long-term care settings for dispensing medication.
PPC	Preferred Priorities of Care (since January 2008, previously Preferred Place of Care). This document is designed to facilitate individual choice in relation to end of life issues. The PPC document aims to support discussion and record an individual's/carer's wishes. It can form the basis of care planning in multidisciplinary teams and other services, minimising inappropriate hospital admissions and interventions. www.endoflifecareforadults.nhs.uk/assets/downloads/ppc_1.pdf

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INTRODUCTION

Aim and scope of review

There is increasing interest in end of life care in social care settings and the contribution of social care practitioners and others, particularly those supporting very old people (Holloway 2009, National End of Life Care Programme 2010). However, the majority of end of life care research takes place in health care settings, such as hospitals, and/or is led by health professionals or health-based researchers looking at health-related issues. This review is informed by that work and by research undertaken from a social science perspective.

This review draws on the authors' experiences of researching sensitive subjects in social care environments, specifically care homes. It is a resource and reference point for researchers who are about to undertake social care research with adults who are living with life-limiting illnesses or are dying, and with carers, family members and practitioners that support them in a range of settings:

- Residential and long-term care settings (e.g. care homes);
- People's homes and community settings (e.g. day care);
- Any locations where social care practitioners, alongside health care, are involved in providing support to people who are living with life-limiting illnesses or dying (e.g. hospices and hospitals).

The aim of the review is to provide an overview of the range of research methods that have commonly been used in end of life care research and their relative advantages and disadvantages, and a discussion of the particular ethical challenges and practical issues that may arise when undertaking research in this area, along with some solutions to these challenges.

This review is informed by a scoping of journal and web published materials related to social care and health, using databases such as Pub Med, CINAHL, Social Care Online, SIGLE, Social Science Citation Index and Google Scholar. To manage the size and diversity of the literature we focused on seminal research papers and those that discussed methodological issues as part of their findings and reviews of evidence. Other examples are drawn from studies known to the authors, those identified by colleagues and responses to e-alerts sent out through the National Care Home Research and Development Forum and the British Society of Gerontology.

Review outline

We begin by defining end of life care and related terms and then provide a policy and service context for understanding end of life care research in social care. The state of palliative care research is summarised with reference to its relevance to social care. Common methodological approaches used in palliative care research are outlined, followed by a consideration of the data collection methods and tools available to social

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care researchers. The specific populations that are the focus of social care research are defined. Finally, the challenges of undertaking end of life care research are identified along with some strategies to address them. While literature from beyond the United Kingdom is presented, the policy context for the review is England.

Defining dying

There is little agreement among health and social care professionals and care home staff about when someone can be defined as dying. Some define it as the 12 months prior to death and others the last few days or 24 hours (Mathie *et al.* 2011, 2011; Godwin and Waters 2009; Shipman *et al.* 2008). Researchers that have studied the trajectories of people who are dying (Murray *et al.* 2005; Lunney *et al.* 2003) have suggested that there are three main recognisable patterns or pathways of dying:

- Steep decline in health and function just before death (often associated with people with advanced cancer);
- Gradual decline, interspersed with acute episodes of ill health, that then leave the individual with less functional ability than prior to the exacerbation (often associated with people who have a life limiting long-term or chronic condition, such as heart failure, chronic obstructive pulmonary disease, AIDS or renal disease);
- Steady progressive decline and protracted period of deterioration or 'dwindling' (often associated with people who are very old and frail or people with severe dementia).

Other studies and reviews have argued that there are variations within these trajectories and it may be impossible to predict with any precision who is near the end of life and who is not, particularly when an individual may have several health and social care needs (Mathie *et al.* 2011). In these situations (unlike in a hospice for example) a researcher cannot assume that the older person, family members, care home staff or health care professionals will recognise that someone is nearing the end of life.

Defining end of life care

For any researcher proposing to undertake a study on dying in social care settings it is important to recognise that there is not a shared language or understanding of what end of life care is across or within health and social care services (Shipman *et al.* 2008). A number of terms associated with caring for dying people are used: hospice care, terminal care, continuing care*, care of the dying, palliative care, supportive care and end of life

* Continuing care can be used in end of life care to refer to a situation where the remit is to provide care over an extended period of time, to a person aged 18 or over, to meet physical or mental health needs that have arisen as the result of disability, accident or illness. The term however is now more commonly used in health and social care to refer to a specific funding stream that supports a costed package of care from health and social care services to support (in the case of palliative care) someone who is dying.

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care (Payne *et al.* 2008). Drawing on a previous discussion about definitions in this area (Froggatt 2004), the commonest terms are defined here as being of relevance to people within social care settings and living with terminal, chronic, degenerative and life-limiting conditions.

Palliative care

Palliative care, as defined by the World Health Organisation (WHO 2002), concerns the active and holistic care of patients who live with an advanced, progressive illness. Importance is placed on the management of pain and other symptoms alongside the provision of psychological, social and spiritual support. Palliative care seeks to achieve the best quality of life for people living with these illnesses alongside their families.

Terminal care

Terminal care is usually associated with the last few days and hours of life, and based on the knowledge that the individual is dying.

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End of life care is a broader term that can encompass more than the terminal care phase. In the context of the care of older people (in Canada, as in some other countries, sometimes referred to as seniors) the term is defined as follows:

End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement (Ross *et al.* 2000, p.9).

This Canadian definition resonates with the English definition presented by the General Medical Council (GMC) that states that patients are 'approaching the end of life ... when they are likely to die within the next 12 months' (General Medical Council 2010, p.8). However, care needs to be taken with the use of the term 'end of life care', because it can be used just to refer to the last few days of life, or terminal care, as in Australia.

For the purposes of this review the broader definition of end of life care described above will be used. For social care research there is a need to understand the interfaces between social care and palliative care. It is important when preparing a study to be aware of the need to define what elements of end of life and/or palliative care the study might focus on and to recognise that narrower definitions of dying and end of life are often used.

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BACKGROUND AND CONTEXT OF END OF LIFE CARE

Policy on end of life care has, until relatively recently, focused on specialist palliative care for people dying with cancer (Department of Health 2000). As the population ages, more people live and die with long-term and life threatening conditions such as organ failure and dementia. Planning is required to meet this demand in health care and community settings (Gomes and Higginson 2008). Approaching the end of life, individuals (as well as those who are bereaved) can experience multiple and accumulating losses including function, abilities, roles and relationships (Knight and Emanuel 2007). There is an increasing recognition of the importance of research that addresses an individual's need for support from health and social care in a range of settings and for extended time periods.

The majority of dying still takes place within the home, but the majority of deaths take place in hospital (Exley and Allen 2007). There is an increased commitment to providing care in community settings and, specifically, policy support for people to die in their place of choice, which has widened the focus of policy on end of life care (National Institute for Clinical Excellence 2004; Department of Health 2006; National Audit Office 2008).

The *National End of Life Care Strategy* (Department of Health 2008a) provides a practical framework that health and social care services can use to build high quality services for people nearing the end of life. It covers twelve key areas of end of life care, including raising the profile of the importance of end of life care in commissioning, research, education and training, service planning and delivery, and support and involvement of carers.

The *National End of Life Care Programme* works with health and social care services across all sectors in England to improve end of life care for adults by implementing the DH's National End of Life Care Strategy, www.endoflifecareforadults.nhs.uk.

The Social Care Advisory Group for the Strategy has produced a framework for social care and support at the end of life, *Supporting People to Live and Die Well: A Framework for Social Care at the End of Life* (Department of Health 2010). This identifies ten key objectives for social care and complements work on the national standards and competences for end of life care. It maps out how social care commissioners and providers, together with those involved in training and education, can boost the role of social care in supporting people who are dying and their families. See www.endoflifecareforadults.nhs.uk.

A number of other relevant initiatives exist that relate to social care, including (also see the resources section towards the end of this document):

- End of life care in sheltered and extra care housing fact sheet: www.endoflifecareforadults.nhs.uk/assets/downloads/factsheet008.pdf
- Guidance on achieving quality end of life care in care homes. See www.endoflifecareforadults.nhs.uk/assets/downloads/RtS_Care_Homes___Final___20100804_1.pdf

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- Core National Occupational Standards (NOS) for the workforce providing end of life care – from health care professionals (doctors, nurses and allied health professionals), managers and social care workers such as care assistants and ancillary staff. Published by Skills for Health and Skills for Care this document estimates that up to 2.5 million health and social care staff workers are in contact with people nearing the end of their lives. www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.

The increasing policy emphasis on integration between health and social care, as exemplified by Health and Wellbeing Boards (Department of Health 2010), anticipates that local authorities will have a bigger role in helping to coordinate health and social care services. This could include providing end of life care. There is a need therefore for research in social care settings that can help provide a context-specific evidence base for education, training and services for end of life care.

THEORETICAL APPROACHES

Research in end of life care is undertaken by a broad range of disciplines, including biomedical and social sciences. How research questions are asked and understood is shaped by each discipline. Often research in end of life care has focused on the physical aspects of care, with increasing attention to psychological care, but much less attention to social or spiritual domains. Kellehear (2007a) observed that palliative care remains focused on a health services' agenda of research that continually promotes a concern with the body, its symptoms and management, and the problem of service design and delivery. Studies of those who provide care remain more common than studies of the recipients of care: dying and bereaved individuals. He identified a failure to acknowledge the plurality of diverse and shifting beliefs, definitions and experiences of death (Kellehear 2007a, 2007b). He further argued for a new 'public health of death' and dying that recognises that death and loss are increasingly social experiences for people that require active support and community development. It is a perspective that is arguably more closely aligned with the interests and preoccupations of social care.

There are examples of where theoretical approaches have been used to understand and interpret the particular experiences of people at the end of life and of their carers. For example, social justice theory has been thought about in the context of the experiences of women as caregivers in end of life care (Mackinnon 2009), dignity therapy has been used to frame interventions for older people at the end of life (Chochinov *et al.* 2008) and prospect theory has illuminated how individuals anticipate dying and decide to accept or reject life prolonging treatments (Winter and Parker 2007). There is also interest in organisational models of care that support integration and whole systems working (Bainbridge *et al.* 2009, 2010). Holloway (2009), in a discussion of dying in old age, suggested that research that understands the cumulative losses experienced in old age could inform how research questions are asked and interventions tested.

METHODOLOGICAL APPROACHES

In all research the appropriate method and design are dictated by the research question. However, as Moriarty (2011) has observed (in the review of qualitative methods in this series) the relationship between theory and method is complex. How dying is understood or who defines what a 'good death' involves, will reflect particular set of beliefs or world views that in turn influence how a question is framed and researched. For example, Randall and Downie (2006) argued strenuously that because quality of life is essentially qualitative and evaluative it cannot logically be rendered quantitative. They suggested that the moral and intellectual hazards of attempting to use scales to measure this at the end of life exceed any benefit to patients.

A fuller discussion of the usefulness and strengths and weaknesses of particular research methods in social care is provided by Moriarty (2011). This section of the current review provides some examples and discussion of research approaches, design and data collection methods that have been used in end of life care research and which are relevant to social care research.

Qualitative approaches to end of life care research

Qualitative research approaches in end of life care research in social care are valuable because they favour an interpreted understanding of the social world that is mediated by its participants. They can provide in-depth accounts of participants' experiences and the circumstances that create them.

Seminal research in the 1960s that was core to the development and refinement of grounded theory as a research approach was based in studies of dying, death and bereavement (Glaser and Strauss 1965, 1968; Sudnow 1967; Strauss and Glaser 1970). These studies informed the work of Lawton and Hockey on the body and sequestration of the dying and decision making about where and how people die (Lawton 2000; Hockey 1990, 1996).

Similarly, ethnography as a research approach has been used in palliative care and social care research to investigate in detail the complex lives of recipients and providers of care. It is an approach to research that relies on observation, and the use of research methods that enable the researcher to describe how those being studied understand their world. Ethnographic techniques can be identified in the observations of Cicely Saunders (for a collection of her writings see Saunders (2006)) and Elisabeth Kubler-Ross (Kubler Ross 1969), key figures in shaping the improvement of support for people who were dying and those who were bereaved. Subsequently, other ethnographies have been undertaken in long-term care settings (Gubrium 1975, 1993; Kayser-Jones 1981; Savishinsky 1991; Stafford 2003; Bern-Klug 2009). It can be a difficult process, shaped by personal skills, experiences and professional background, and often requires considerable time and researcher preparation. It nevertheless offers an approach that can help to explain why and how individuals work and react within organisations and, in particular, how

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conceptualisations of death and dying affect decision making and how good outcomes are defined.

Phenomenology describes the subjective reality of an event, as perceived by the participants in a study; it focuses on the study of a phenomenon and offers a description of everyday phenomena. It has relevance as a research approach that emphasises the individual's interpretation of the experience of approaching the end of life or caring for someone who is dying (Seymour and Clark 1998). It has been used, for example, to understand how practitioners 'are', and what they bring to the encounter, when supporting and communicating with those who are supporting recently bereaved people (Seno 2010). Unlike ethnography, the focus is on the individual account, often using unstructured interviews to understand the individual's experience and what that can reveal about receiving or providing end of life care.

Intervention-based research to test effectiveness in end of life care

Reviews of end of life care consistently identify the need for more evaluation and comparative studies so that the effectiveness of different interventions can be known (Lorenz *et al.* 2008). Conventional wisdom is that the randomised controlled trial (RCT) is the best method for the evaluation of effectiveness. Individuals are randomly allocated to receive either an experimental intervention or an alternative, such as standard treatment, a placebo, or remaining on a waiting list.

People who are dying are a group for whom there is often no second chance to improve care. This can raise ethical issues if it is perceived that the intervention represents better care. For a trial to be ethically justifiable there must be real uncertainty as to whether the new treatment is preferable to no treatment or existing treatments (Grande and Todd 2000). Practitioners and family members are often the gatekeepers through whom researchers obtain access to people nearing the end of life. They may find it hard to accept that someone is dying or they may consider participation in a research trial to be a low priority, particularly if there are specific procedures and data collection requirements associated with the trial. As Grande and Todd (2000) observed, because of the difficulties in identifying, recruiting and retaining participants, it is possible that randomised controlled trials (RCTs) in end of life care may, in effect, be evaluations of interventions on those who are best able to cope. It also means that trials often lack statistical power because of attrition and incomplete data. They recommend that research in end of life care that involves using a trial methodology should use a mixed method approach, including a blend of qualitative and quantitative methods, as well as measuring both the process and outcome of care and facilitating interpretation of quantitative findings.

Cluster randomised controlled trials

Randomisation by cluster may be more ethically acceptable as it is not the individual who is randomised to an intervention but the service, setting or, geographical areas they are linked with. Access to the trial is one step removed from the person who is dying as it has

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occurred before they were identified. For example, a Norwegian study defined Community health care districts as the clusters to be randomised to test an intervention (a multidisciplinary team that coordinated end of life care) that aimed to support people at home and die there, when compared with usual care (Jordhøy *et al.* 2000). However, one drawback is that cluster randomisation, requires higher numbers to yield the same statistical power as randomisation by individual.

Complex interventions

In social care research that focuses on end of life care most interventions are by definition complex, tailored to individual and family situations, provided to a vulnerable and frail population and delivered in contexts where the practitioners and settings may differ. An alternative to a strict RCT approach is the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Craig *et al.* 2008). This methodological framework aims to account for the difficulties of interpreting findings when there are multiple elements to an intervention, a range of possible outcomes and different ways that the intervention can be delivered. It assumes a staged approach that develops and refines the chosen intervention systematically *before* it is tested within a trial. This requires:

- Theory development and testing;
- Pilot studies that refine the intervention and identification of key outcome measures;
- Exploratory evaluations and feasibility testing of the intervention;
- Definitive evaluations.

An example of this methodological approach in end of life care research based in care homes is ongoing work by Hall *et al.* (2009a). They describe an intervention, such as dignity therapy, that aims to help both older people and their families to maintain a sense of dignity and reduce distress for residents reaching the end of life in care homes. Their protocol describes an exploratory study that will show if this intervention is likely to be effective, if it is acceptable to residents, their families and care home staff, and if it is feasible to offer it in this context.

A review of the impact of the Gold Standard Framework (a resource for care homes and NHS staff widely implemented in primary care and designed to support the management of end of life care) acknowledged the need for further research to test the impact of this intervention within a complex intervention evaluation framework (Shaw *et al.* 2010). It is a research approach that is, however, research and time intensive and may not be able to respond to rapid changes or innovations in service delivery.

Observational studies

For new initiatives that may be introduced at different times and in different locations observational studies may be more feasible and generalisable to everyday practice. The lack of randomisation and/or control of how an intervention is introduced can make such

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a study susceptible to bias. In end of life care research these significant limitations need to be weighed against the opportunities for learning and the extent to which the researcher can account for the possibility of bias in the analysis.

Multi-site evaluations

In end of life care, multi-site studies – for example, across several care homes or housing providers – tend to emphasise the impact of the intervention on the process and organisation of care, practitioner and user satisfaction, costs and perceived benefits (Easterbrook and Vallely 2008; Roe *et al.* 2008; Shaw *et al.* 2010). Summaries of research studies including end of life care in supported housing and extra care settings are available in the fact sheet *Extra Care Housing at the End of Life* (Croucher 2009).

Appreciative inquiry

Appreciative inquiry (Mohr 2001) uses participatory methods to improve practice working from a standpoint of identification of what works well and then building on this, rather than the identification of problems that then have to be solved. It is an approach that may be particularly useful when seeking to bring together the different ‘tribes’ of health and social care to develop and test interventions that can improve the delivery of end of life care. Findings from a study on supporting people with dementia living in care homes at the end of life suggest that the approach was able to address power imbalances between social care and NHS staff, affirm the complexity of their work and address priorities of mutual interest (Goodman *et al.* 2011; see also www.evidem.org.uk).

Research on end of life care consistently identifies relationships as crucial to good care. Appreciative inquiry is a research approach that aims to foster interventions that strengthen relationship-based approaches to working as an integral part of the research design.

All participatory approaches to research raise certain challenges. They tend to blur the boundary between practice and research. The researcher often has to act as the facilitator. This requires key skills to ensure that everyone understands the parameters of the study. Any research undertaken in this way will entail a negotiation of the inherent power structures in the organisation. It requires an awareness and attention to the culture and individuals’ location within the structures present (Hockley and Froggatt 2006). Attaining ethical approvals may require taking a two-stage ethical approval process, whereby the researcher has to seek a further stage of approval once the change has been identified by the participants. Informed consent may also need to be continually checked and reaffirmed. Thirdly, ensuring confidentiality within and outside of the research sites can be difficult.

Longitudinal research

Longitudinal research involves ‘repeated measures of the same respondents’ at several time intervals (Oppenheim 1992, p.33). Such research can last over decades, although this is so far very rare in social care. It is an important research design in order to understand

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patterns of ageing and dying (Huppert *et al.* 2000; Murray *et al.* 2010; Bytheway and Bornat 2010; Shirani and Weller 2010). It is particularly valuable in end of life care because it captures change in outlook and conditions, key events and exacerbations over time particularly for people with long term and debilitating conditions.

One longitudinal study carried out in New Zealand interviewed older people with heart failure every three months over a 12 month period (Waterworth and Jorgensen 2010) and another study in the United States used data from married couples participating in the Wisconsin Longitudinal Study in 2004 to examine spouses' effectiveness as end-of-life health care surrogates (Moorman and Carr 2008). A longitudinal evaluation of patients' perspectives on Parkinson's disease followed changes over three years (Schenkman *et al.* 2002). Longitudinal work can also identify when events and services do not happen. Clausen *et al.* (2005) used prospective data on the experiences of four people with lung cancer and advanced cardiac failure to show that social workers had not been involved in their support, even though the study revealed social care needs.

Cohort research

Cohort research is a form of longitudinal research that also follows a group of respondents over time. However, the group members are chosen as sharing the same, or similar, characteristics; for example, they were born in the same year, have the same diagnosis, or have undergone the same medical treatment. There are some well-known examples of cohort studies following children born in the same year (for example the Bristol study (O'Conner *et al.*, 2002)) and of older people in the community. The Cambridge City over-75s Cohort (CC75C) Study is a long-term follow-up study of a representative population-based sample of older people which started in 1985 from a survey of over 2,600 men and women aged 75 and above (Fleming 2007, 2010). It has been able to document where people die and their use of services and care settings in the year leading up to their death. Another study, which started in the late 1980s, is following over 18,000 individuals aged over 65 years to assess ageing and cognitive function over time (Brayne *et al.* 2006; see also www.cfas.ac.uk/). As these cohorts age there will be opportunities to understand how and where people die.

Mixed methods

Fleming *et al.* (2010) have argued that mixed-methods research, which combines qualitative research and RCTs, offers a potential solution to some of the problems that can arise in end of life care research. The rationale for combining quantitative and qualitative techniques is essentially pragmatic: the results from one method can inform or elaborate the results from another. Priority and sequence of employment of each method should be determined by the research question. For end of life care studies mixed-methods research offers the opportunity to understand the context in which interventions are effective, as well as the nature of their effectiveness.

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Case studies

Case study is a research strategy which focuses on a particular case (an individual, a group or an organisation) and may involve a range of methods to understand complex phenomena within the context of the case or cases. Walshe and colleagues (2004) suggest it is an approach particularly appropriate for understanding the complexity of provision between health and social services, voluntary and statutory agencies, especially when provision takes place within constantly shifting care environments that reflect local historical, political and organisational priorities.

Interviews and questionnaires

Face-to-face interviews have the highest response rate but are time intensive and rely on interviewers being willing and able to discuss sensitive topics. Gott *et al.* (2004) used semi-structured interviews (and focus groups) to discuss place of death at end of life with older people in the community. Kendall *et al.* (2007) similarly used a mixture of in-depth interviews and focus groups to explore the meaning of a 'good death' for people with cancer. Many studies have not asked directly about death; the questions have been framed in terms of asking about the future (Samsi and Manthorpe 2010).

In the EPOCH study Mathie *et al.* (2011) used the following interview prompts when talking to care home residents:

- Do you think into the future at all?
- What kind of things do you think about?
- Have you thought about dying at all?
- How would you like to be looked after when you are near the end of your life?

In another study by Godwin and Waters (2009) the participants (people with dementia) were asked; 'Have you thought about the end of your life?' This question was supplemented, if necessary, with: 'When the time comes when you are nearing the end of your life, have you thought about how you would like it to be?' Their carers (family carers and staff) were asked:

- When s/he lived at home, did s/he ever talk about what s/he would like to happen at the end of his/her life?
- Since s/he has been here, has s/he expressed any thoughts about dying?

The EPOCH study: Experiences of Older People in Care Homes

A study carried out in six care homes interviewed 63 residents three times over the period of a year.

The residents showed varying degrees of engagement when talking about their future; some lived in the past, the majority lived 'day to day' and a smaller minority could plan and talk openly about death and dying.

The residents did not appear to be offended by being asked about their futures and seemed to appreciate the opportunity to talk on a one-to-one basis about a whole range of issues (Mathie *et al.* 2011).

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- Have you discussed this with staff?
- Do you have any views about what you would like to happen at the end of his or her life?

It is worth remembering that end of life can hold different meanings for different people, so the term can refer to ‘the time when one is dying or one’s death’ or even ‘disposal’ (Froggatt and Payne 2006). So a qualifying question can be asked to make this clearer; for example, Godwin and Water (2009) introduced the question ‘If the doctor said that s/he only had a week to live, did s/he ever talk about how s/he would like that week to be?’

Table 1 summarises some of the advantages and disadvantages of interviews in research on end of life. One-to-one interviews over time can lead to relationships being formed which enable the participant and interviewer to get to know each other. In these situations thought needs to be given to how the relationship is ended – on both sides.

Telephone surveys also utilise skilled interviewers and allow a greater number of survey forms to be completed; but they are less discursive and may not be appropriate when talking about dying. Postal surveys can reach a larger number of people but are more often ignored. Surveys utilising the internet, using email or web-based methods, such as Survey Monkey, are increasingly popular, but it cannot be assumed that the target

Table 1. Some potential advantages and disadvantages of using interviews in research on end of life

Interviews in end of life research	
<i>Advantages</i>	<i>Disadvantages</i>
One to one (individuals offered opportunity to talk)	May cause unnecessary fatigue for the participant
Offers opportunities to be listened to and can have a therapeutic benefit (Allmark <i>et al.</i> 2009)	Impossible when an individual is ill, asleep, heavily sedated or comatose
Can explore subject in-depth on a personal basis	Difficult for individuals with speech difficulties or illnesses that affect speech
	Difficult for those with hearing loss
	How appropriate is it to ask palliative care patients questions when they are facing a particularly emotional time (imminent death)?

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population has access to computers and the internet within the workplace or home setting. Follow-up methods are usually built into the survey process with reminders being used to try to improve the response rate. These follow-up methods may repeat the method used earlier, for example a repeat postal questionnaire is sent, or follow up may occur via telephone, offering telephone completion as an alternative (Froggatt and Payne 2006). How data collection is undertaken reflects the wider issues of the population being sampled, the sample size required, the type and volume of data being sought, and the resources available to the study (Addington-Hall 2007).

Surveys of professionals, carers and family members are often used retrospectively in order to obtain information about care at the end of life (Lynn *et al.* 1997; Andershead 2006). A number of large retrospective surveys of family members have been undertaken seeking proxy accounts of the care provided to their relatives at the end of life (for example Klinkenberg *et al.* 2005). These have addressed dying from all causes and have also been targeted at understanding the experiences of particular groups, for example people dying following a stroke (Young *et al.* 2009).

High response rates for surveys about dying and end of life can be difficult to achieve in some social care contexts. Since the late 1990s care home survey response rates have been low ranging from 30 to 46% (Sidell *et al.* 1997; Froggatt and Payne 2006; Froggatt *et al.* 2009). The involvement of senior personnel in the care home organisation to endorse the survey may help improve response rates. Incentivisation or rewards are used in surveys to improve the response rate. Usually financial, these have been shown to improve participation in postal surveys beyond social care (Edwards *et al.* 2005); however, offering financial rewards has ethical implications and may cause selection bias. Other examples of incentives include offer of free training for staff on subjects of their choice (for example Hussein *et al.* 2010).

Nominal group techniques (NGT)

NGT is a method of structuring group discussion and working towards an evaluation or consensus on a given topic or issue. The ideal group size for NGT is between five and nine participants. It can be a useful technique to structure discussion and agree priorities. In end of life care research it can be difficult to discriminate between different priorities for end of life care. In one study NGT was used with a group of people with learning disabilities (Tuffrey-Wijne *et al.* 2007); participants were presented with a story and picture to which to respond. They were told:

This is Veronica. Veronica is very ill. She is not going to get better. The doctor knows that she is going to die. What do you think people should do to help Veronica?

The authors concluded that the approach helped to address a difficult and taboo subject and encouraged full participation with people with mild and moderate intellectual or learning disabilities.

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Nominal group techniques have four discrete stages (for more details see Carney *et al.* 1996):

1. Generating ideas, i.e. encouraging people to express their views;
2. Recording of ideas and discussion, i.e. display of what everyone has contributed;
3. Clarification of ideas (facilitated group discussion to make sure there is clarity and views have been accurately represented);
4. Ranking of ideas (voting by participants on what is most important).

Dyads and triads

Interviews are usually one-to-one but in some cases may be in twos or threes (dyads or triads), asking similar questions to a group of related or connected people in order to gain different viewpoints. For example, couples have been interviewed to provide their perspectives of negotiating uncertainty and meaning at end of life (Gardner 2008). Rich *et al.* (2010) conducted telephone interviews with family-staff pairs to identify differences in perspectives that may complicate the process of joint decision-making at the end of life.

In one study which interviewed people with advanced dementia about end of life, the interview triad consisted of the patient, one family carer and one practitioner (Godwin and Waters 2009). The study reported that people with advanced dementia were able to express views on end of life care. Kendall *et al.* (2009) listed the benefits of multi-perspective interviews as being: understanding relationships and dynamics between patients, families and carers; exploring similarities and differences in perceptions; understanding individual needs; and integrating suggestions for improving services from patients, carers and professionals.

Focus groups

Focus groups are group interviews aimed at enabling exploration of key issues or developing discussion on particular points (Goodman and Evans 2010). Groups usually consist of between six and twelve people who have something in common. They need a facilitator or moderator who has a list of prompts about subjects to ask the group to discuss. There is often a co-facilitator and a note-taker. Munn *et al.* (2008) carried out ten homogeneous focus groups drawn from a purposive sample of long-term care residents, family caregivers, care staff and professional staff in five nursing homes and eight residential homes care/assisted living communities. The focus groups discussed end of life experiences, and five themes emerged: components of a good death, normalcy of dying in long-term care, the role of relationships, hospice contributions to care, and stakeholder recommendations.

Focus groups were used by Seymour *et al.* (2002) to explore older people's attitudes to end of life care. The groups were shown a PowerPoint slide showing simple pictorial aide-

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memoires of the following topics: best place to be cared for, use of technology to prolong life, use of technology to give comfort, and who should decide? The groups then discussed the subjects; the power-point slides seemed to enable people to de-personalise the subjects and to talk freely about end of life issues. Seymour *et al.* (2004) have also used focus groups to discuss end of life matters, such as advanced care statements, with older people from six diverse community groups in Sheffield.

Biographical narrative

For people who are dying and their families, narrative methods of enquiry enable them to place their story and experiences in the context of their life and other experiences. It enables a process of sense-making. Biographical narrative is storytelling, relating key facts or events of a person's life. Biographical narrative approaches have been used to explore grief (Gilbert 2002). A biographical narrative and interpretative method by Wengraf and Chamberlayne (2007) was used to explore the living at home experience of frailty of people aged over 85, and the impact of changing circumstance on perceived physical, psychological and social worlds. Participants were encouraged to re-tell their life events, choosing their own significant events and history (Nicholson 2009).

Diaries and letters

The collection of diaries and letters is used less commonly than some other methods. One study used in-depth interviews and letters received from parents of 27 young adults in England, Scotland and Wales who died from cystic fibrosis between 1999 and 2002 aged 17–36 years (Lowton 2009). An ongoing study exploring the experiences of spouse carers of people with advanced dementia living in a care home is piloting the use of diaries as a means of data collection for this population (Hennings 2011).

Arts-based techniques

Methods that encourage personal expression (through art, poetry, online discussion and creative writing) have been rarely used (Froggett 2007). Harris *et al.* (2008) reviewed methods and approaches applied to end of life cancer research. They concluded that in addition to 'traditional approaches' such as interviews and focus groups, there was an increase in the use of mixed methods and use of arts-based methods that helped people to express visually feelings and experiences that were too difficult or sensitive to verbalise. Menezes (2010) has used artwork and photographs, drawing and other creative approaches with children with life-limiting illnesses, their siblings and other family members to explore their experiences of living with these conditions.

Case notes review

Case notes provide (some) data on the documented care received by individuals. However, the quality of the data available is only as good as the information recorded (Sampson *et al.* 2006). In social care research this may entail a case note review of more than one set of

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records held by different organisations, for example home care agencies, care homes, and primary care practitioners. These may be held at different sites in different formats. Gathering data from care homes poses a number of problems. Unlike in the US, there is no UK minimum data set (MDS) (Hawes *et al.* 1995), although there are international initiatives to develop assessment and care tools that can be used across long-term care settings that include categories for end of life/palliative care (see www.interrai.org). The EPOCH study found that across six care homes there were up to 11 different sources of information, kept in up to seven different locations, and the majority of these records had to be accessed via a member of staff (Mathie *et al.* 2011).

Enes *et al.* (2004) used a case note review to report on discharges across settings, from hospice to nursing home care (see also the section on care homes). Most studies have assumed that if consent is given to look at notes (medical or care notes) while a person is alive that this permission will continue after death. Researchers must make this intention clear in their ethics proposal. There can be logistical problems in accessing care, medical notes or GP records after a person has died because notes are often centrally stored, electronically copied or archived. The minimum period that GP-held patient notes are retained is ten years. In social care, the individual and the family, third sector providers and adult social services, can hold notes or case records. There is no central archiving process for all these notes and different organisations archive notes after a person's death for different time periods.

Other sources of data specific to end of life care

In addition to care notes, specific assessment and palliative care tools may be a source of data about care services for someone at the end of life. The Liverpool Care Pathway is an integrated care pathway designed to be used when it is believed that a person is in the last days and hours of life, regardless of setting. The pathway aims to guide members of a multidisciplinary team in considering current treatment options, discontinuation of treatment and comfort measures. It is organised into sections ensuring that evaluation and care are continuous and consistent and that both patient and carers understand that the structure and focus of care is on care and comfort during the end stages of life (Ellershaw 2007).

The Gold Standard Framework (GSF) (including the After Death Analysis and Preferred Priorities of Care tool) aims to develop a practice-based system to improve and optimise the organisation and quality of care for patients and their carers in the last year of life (see www.goldstandardsframework.nhs.uk). This includes the use of the 'surprise question' (for example 'would you be surprised if this person died within the next 12 months?'), to help identify people who might be approaching the end of life, the use of advanced care plans and preferred priorities for care, and after-death analysis to encourage reflection and review of care. It emphasises multidisciplinary working for people who are identified as being in the last year of life.

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Secondary and official data sources

Alongside care data available for secondary analysis, official sources of information for palliative care research exist. These include the national registries, for example the Office for National Statistics (ONS) in England which holds data relating to place and cause of death, and datasets collected for other purposes, for example regulatory and inspection data from the Care Quality Commission. ONS data from England are helpful in providing contextual data about place of death, but with respect to social care settings do not provide a fine level of detail.

Literary accounts

There is a large fictional and (auto)biographical literature on the experience of living with a life-limiting condition, facing death, being a carer and being bereaved. This is a largely unexplored source of data.

Issues to consider with place of death data

The ONS categories used for collating place of death data amalgamate social care residential settings under 'Other communal settings' incorporating residential care for all age groups. This potentially distorts data on place of death and the assumption that dying in residential care settings is not equivalent to dying at home as a preferred place of care. For example, while only 19% of people die in England in their own home, the figure rises to 35% if care homes are considered to be a person's normal home (www.endoflifecare-intelligence.org.uk).

When considering place of death records for older people, careful consideration should be given to the period leading up to death and the number of moves a person may experience in the last year of life.

Fleming *et al.* (2010) undertook a retrospective analysis of prospective data of 320 people over 85 years, to examine the place of residence or care less than a year before death. Findings showed that while only 7% changed their address in their last year of life, 52% died somewhere other than their usual address at the time of death. Two-thirds were living in the community less than 12 months before death, but less than one-third who had lived at home died there. Care homes were the usual address of most people dying there, but 15% of deaths in hospital were of people who came from care homes.

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, statutory adult services and the private and third sectors, to adults approaching the end of life. It has created a national repository of different data sources related to end of life care. This includes information on financial aspects of end of life care – costs and savings compared to alternative models of end of life care and hopes to generate ideas and solutions in relation to ongoing information requirements, e.g. the creation of an end of life care minimum data set. It also hopes to produce, promote and

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Table 2. Data sources relevant to end of life care

National Census
Office for National Statistics
Department of Work and Pensions
General Lifestyle Survey
Care Quality Commission Quality Performance Framework
Hospital Episode Statistics (HES)
National Centre for Health Outcomes Development (NCHOD)
Help the Hospices
Quality Outcomes Framework
Specialist Palliative Care Workforce Survey: the National Council for Palliative Care (NCPC)
Mental Health Observatory
The Information Centre for Health and Social Care
Projecting Older People Population Information System
Health Poverty Index
Audit Commission
Care Home UK database
Department of Communities and Local Government
Social Care Data: National Adult Social Care Intelligence Service (NASCIS)
Her Majesty's Coroners, Department for Constitutional Affairs

present expert analysis and robust methodologies for analysing data in end of life care and enable use of end of life care information to support audit and research programmes. The following sources of data and information are available through its website (www.endoflifecare-intelligence.org.uk) sets out its 'mission' as below:

End of life care profiles: These are a set of indicators to help identify and understand variations in end of life care across England. Indicators focus on place and cause of death, broken down by age and sex, by local authority area in England. To generate comparisons at a more local level, the local authority boundaries set before April 2009 (before some larger Unitary Authorities were created) have been used.

Data sources: This NEoLCN resource brings together information on all available data on end of life care from NHS, social care and other sources that have information relevant to end of life care. It is an invaluable resource that links relevant data sources to particular

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topic area. Currently, the topics covered with links to relevant datasets are Carers, Dementia, Demography, Emergency admissions, Hospice care, Hospital, Life expectancy, Mortality, Place of death, Primary care, Prisons, Residential and nursing homes, Social care and home help, Sudden death.

In England the inspection reports of regulated social care services produced for the Care Quality Commission are publicly available. They provide quantitative data on ratings according to specific standards and also qualitative text about the different services inspected. These data have been used to review the provision of palliative care in care homes from a regulatory perspective (Froggatt 2007).

Annual Quality Assurance Assessment (AQAA) reports

These are self-assessment reports submitted by care homes to the Care Quality Commission, comprising two parts:

- A self-assessment that asks the care home manager to state how well they think they are meeting the needs of the people who use their service;
- A data set that provides basic facts and figures about the service.

This is a useful resource for anyone undertaking research in a care home, as it includes information about numbers of residents, how many people died the preceding year, staffing levels and so on, and so can reduce the need to ask care home managers for information about the care home. It is not a public domain document and it is up to the care home whether it releases the AQAA report.

Access to death certificates: Care homes often do not have access to the death certificate of a resident, whether they have died in the care home or in hospital. Death certificates are issued to next of kin and do not routinely get passed to the place of death. As a result, the official cause of death may not be available for many care home residents.

Evaluating end of life care: tools and outcome measures

There is a shared rhetoric around what good (or effective) end of life care should be like and this informs how the process and outcomes of care are assessed in research. For social care, Clausen *et al.* (2005) have argued that there are particular areas of end of life care that are amenable to social care/work interventions:

- Loss and dependency;
- Family-centred issues;
- Carers' needs;
- Emotional and spiritual struggles;
- Support needs of staff.

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Lorenz *et al.* (2007), in their review of quality indicators for end of life care for vulnerable older people, identified 21 quality indicators that an expert panel judged as valid. These ranged from indicators that measured evidence of palliative care assessment, advance care planning and symptom management, to caregiver (carer) support. These indicators have the potential to inform research design and how evaluations of interventions are structured.

Intervention-based research that evaluates the effect of palliative care interventions may include validated outcome measures that can demonstrate amelioration and reduction in the severity of symptoms (often for people with cancer and in the end stage of life), such as pain intensity, nausea and vomiting, insomnia, mouth discomfort and difficulty breathing (Higginson *et al.* 2003). However, Corner (2008), in a discussion of palliative care and research studies that focus on symptom management alone, has asked if this fails to understand how symptoms are interpreted and assimilated into the experience of approaching the end of life. She argued that there is a need for research that helps practitioners to consider the distressing symptoms in terms of what is 'difficult' about them for the individual and their family carers. This is an approach that contextualises particular symptoms within the overall experience of dying.

How end of life care is evaluated is highly variable and encompasses (overlapping) measures that focus on satisfaction with care received, function, symptom management, wellbeing, psychological distress, carer strain, access to social support, dimensions of spiritual care, grief and bereavement. In one systematic review of end of life care and its outcomes, 135 patient-centred outcomes were assessed by 97 separate measures. Of these, 80 were used only once and only eight measures used in more than two studies (Mularski *et al.* 2007).

A comprehensive review of instruments to measure end of life care by Teno *et al.* (2001) (www.npcrc.org) recommended 35 measures (Toolkit of Instruments to Measure End of Life Care; see also the resources section for web link). Their recommendations were based on the following criteria:

- Measures were patient-focused, family centered;
- They were clinically meaningful, and manageable in their application;
- They were reliable, valid and responsive;
- They were user-friendly and relevant to quality evaluation and improvement;
- They incorporated both the patient and family perspectives;
- They examined both the process as well as the outcomes of care.

It may be that a structured tool is preferable for someone who is easily fatigued and where it is an ethical imperative not to burden the participant with in-depth and time-consuming interviews. A recent review of quality of life measures for use in palliative care

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identified a wide range of questionnaires with completion times ranging from 2-3 minutes to 2–3 hours (Albers *et al.* 2010).

It is important to distinguish between tools that are used for audit and clinical assessment and those that have been developed to assess research outcomes. Terwee *et al.* (2007) have developed quality criteria for content validity, internal consistency, criterion validity, construct validity, reproducibility, longitudinal validity, responsiveness, floor and ceiling effects and interpretability. They argue that there is a need for explicit quality criteria for measurement properties of health status questionnaires. The PRISMA collaboration funded by the European Commission builds on this approach and aims to provide evidence and guidance on best practice to ensure that research can measure and improve outcomes for patients and families (see <http://www.kcl.ac.uk/schools/medicine/research/cancer/palliative/arp/prisma/care/nh.html>).

OUTCOME MEASURES

The following are examples of measures that can be used in end of life care research. Some have been developed in health care and specialist palliative care settings where they are seen as a useful resource and may have transferability for social care based research and care settings. There is an increasing recognition of the need to standardise tools which cover the domains of quality of life, physical symptoms, emotional health, functional status, care giving and bereavement.

■ *Palliative Care Outcome Scale (POS)*: The POS has been piloted in hospice, home, hospital and other community settings (Bausewein *et al.* 2011). It is a questionnaire that covers physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs. The POS was originally used extensively in specialist and inpatient settings for research and audit purposes, a second version has been developed and it is hoped this will be particularly valuable for use with those people with end of life care needs who are diagnosed with a chronic or progressive disorder. Some POS questionnaires are designed to be used by staff involved in providing care, family carers and people who are dying. More information about and copies of the POS can be obtained at <http://pos-pal.org>.

■ *Schedule for the Evaluation of Individual Quality of Life (SEIQoL)*: This individual quality of life questionnaire has been developed specifically for a palliative care population (Kaasa and Loge 2003). It addresses three specific areas: identification of the areas of life important to an individual, how does the person assess how they are doing in each of these areas; and what is the relative importance of these areas. However, it is a relatively complex tool that is therefore of limited use for people with cognitive impairment, and the length of time it can take to complete may be impractical with people with advanced conditions.

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■ *Patient Dignity Inventory*: This tool developed by Chochinov *et al.* (2008) aims to measure sources of dignity-related distress among people nearing the end of life. It aims to cover physical, psychosocial, existential and spiritual facets of the individual's experience. The 25 questions draw on a dignity model for the terminally ill that includes illness related concerns and what the authors identify as a repertoire of attributes that help preserve an individual's personal and social dignity. Questions ask about a person's peace of mind, social support, dependency, existential distress (for example, feeling a burden to others, not feeling worthwhile, no longer having a purpose). The authors argue the tool takes little time or effort to complete, that it is applicable across a range of settings and that it enables people to disclose and discuss which specific issues are causing them distress.

■ *Family Perceptions of Care Scale (FPCS)*: The FPCS is a 25-item scale with each item having a seven point Likert scale specifically developed for use in residential care settings (Vohra *et al.* 2004). A recent review by Parker and Hodgkinson (2010) of scales suitable for use in residential aged care (care homes) identified this scale as simple to administer and score, with good content validity, covering all essential domains of palliative care.

■ *Quality of Dying in Long Term Care (QOD-LTC)*: The QOD-LTC by Munn *et al.* (2007) measure is designed to be completed by either a staff member or family member for people who have died in nursing homes, residential care or assisted living facilities. There are two versions, the first is the QOD-LTC that can be used for any (deceased) resident and the second, the QOD-LTC-C, is specifically designed for assessing care of residents who were considered cognitively intact in the month prior to death.

■ *Measures of spirituality*: Studies on dying and end of life care and bereavement consistently show that an individual's beliefs influence how they understand dying, express needs for meaning and purpose at the end of life and experience bereavement. This is not limited to people with formal religious or belief systems. Authors highlight how little research has engaged with people's spirituality, and the dominance of Christian participants in the studies reviewed and the need for a measure of spiritual wellbeing (Mularski *et al.* 2007; Vivat 2008). King and colleagues (2005) have developed a scale to assess strength of spiritual beliefs that can be used with people who do not have a formal religious belief and that draws on the narratives and responses of a range of people. Selman *et al.* (2011) completed a systematic review to identify and categorise measures of spirituality used in palliative care, advanced cancer, and/or HIV populations. They identified nine tools that used spiritual concepts relating to: beliefs, practices, and experiences; relationships; spiritual resources; outlook on life/self; outlook on death/dying; and indicators of spiritual wellbeing. They concluded that research addressing spirituality should provide a conceptual definition of spirituality, a rationale for instrument selection, and the ethnicity and/or first language of participants. They also suggest that researchers consider any possible bias arising from their own belief system.

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■ *Grief and bereavement measures*: A review by Mularski *et al.* (2007) identified eight measures. These included the Hogan Grief Reaction Checklist (HGRC) (Hogan *et al.* 2001), a 61-item measure across six constructs (despair, panic behaviour, blame and anger, disorganisation, detachment, and personal growth); the 17-item Core Bereavement Items (CBI) (Burnett *et al.* 1997); and the Grief Evaluation Measure (Jordan *et al.* 2005), which includes 58-item experiences and 33-item problems sections, was developed as a predictive measure for complicated grief – scores were correlated with related measures such as the Inventory of Traumatic Grief.

■ *Views Of Informal Carers Evaluation of Services (VOICES)*: The VOICES questionnaire was originally developed following a population-based interview survey of more than 3,000 bereaved relatives in the UK (Addington-Hall and McCarthy 1995) and has subsequently been re-developed as part of the PROMOTE study (Addington-Hall *et al.* 2004) to take account of changes in what matters to people at the end of life (Aspinal *et al.* 2006). The PROMOTE VOICES questionnaire includes questions on care in the last three months and days of life; symptom burden and treatment; and questions on support in bereavement. The questionnaire has been used successfully in general population surveys and service evaluations and has been used to assess care in the community, in hospital settings and hospices. It has not yet been developed for post bereavement studies relating to people living in other social care contexts, such as care homes or extra care housing.

Where it is more difficult to discuss and explore symptoms with an individual, because of limited capacity, assessments that have been developed for people with dementia to improve overall quality of care also have potential as outcome measures for intervention and education based research:

■ *End of Life in Dementia Scales (EOLD)*: These are a group of three scales that can be used individually or together (Kiely *et al.* 2006) and have been used in residential care settings for older people. The scales are: Satisfaction with Care at the End-of-Life (SWC-EOLD), Symptom Management at the End-of-Life (SM-EOLD) and Comfort Assessment in Dying (CAD-EOLD). The SWC-EOLD has ten items measured on a four-point Likert scale that cover decision making, communication with health care professionals, understanding the resident's condition and medical and nursing care needs. The SM-EOLD is a rating of nine signs and symptoms during the previous 90 days using a six-point Likert scale with higher scores indicating greater symptom control. Symptoms include pain, shortness of breath, depression, fear, anxiety, agitation, calm, skin breakdown and resistance to care. The CAD-EOLD asks carers to rate 14 symptoms (discomfort, pain, restlessness, shortness of breath, choking, gurgling, difficulty in swallowing, fear, anxiety, crying, moaning, serenity, peace and calm) during the last seven days of life on a three-point Likert scale from 1 to 3 (not at all, somewhat, and a lot) with higher scores indicating better symptom control.

■ *Assessment of pain for people dying with/from dementia*: Compared to those with other conditions people with dementia are more likely to experience a variety of symptoms including persistent pain, and are more likely to be untreated, in the last six

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months of life (McCarthy *et al.* 1997; Hirakawa *et al.* 2006). Research on the assessment of pain for people with end stage dementia is limited and has focused on the ability of carers to predict pain (Shega *et al.* 2004) and the validity and perceived usefulness of different pain assessment tools for end of life care (Abbey *et al.* 2004). Van Lersel *et al.* (2006) asked 185 care providers to compare two pain assessment tools (Abbey and PAINAD) with older people who could not verbally express their experience of pain. Approximately half of care providers evaluated both scales as being good measures of pain and easy to use, and identified three indicators as to the most valuable for measuring pain: facial expression, vocalisation and body language.

■ *Dementia and discomfort*: A series of studies developing and testing an assessment tool for discomfort in dementia (ADD) in people with late stage dementia, used analgesia and provision of non-pharmacological comfort intervention as outcome measures (Kovach *et al.* 1996; Kovach *et al.* 2001). Overall findings suggested that use of the tool could improve symptom recognition and administration of analgesia although its uptake and use by care staff were variable. Kovach *et al.* (2006a, 2006b) tested a five step clinical protocol to promote comfort and reduction of behavioural symptoms of psychological distress.

POPULATIONS, SAMPLING AND RECRUITMENT

In order to undertake forms of research where there is primary data collection, participants need to be identified and recruited. Issues that need to be addressed concern which perspective is being sought, how to identify and reach marginalised groups, how to sample within these populations and how to ensure informed consent processes ensure appropriate participation.

Population identified by life threatening and/or life limiting disease

Kendall *et al.* (2007) found that many people affected by cancer wanted the opportunity to participate in research and were motivated 'to give something back' and have the opportunity to influence future care and research. Common themes of altruism, hope, and self-benefit were given as motivations for participation in treatment trials by people with advanced cancer (Perkins *et al.* 2008; Todd *et al.* 2009). Similarly, people who share a particular life threatening illness or diagnosis can be identified as a population for investigation; for example, Parkinson's disease (Schenkman *et al.* 2002); AIDS (Krug *et al.* 2010; Young and Busgeeth 2010), heart failure (Hopp *et al.* 2010) or people with severe mental illness (Campbell and Kisely 2009). There are examples within these groups of where participation in research is seen as a positive and valued act.

Older people

More problematic is when the population might not consider themselves to be approaching the end of life, for example older people who are seen by others to be nearing the end of life due to their age or living arrangements. Older people living in a

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care home are not defined as 'end of life' but, given the median expectancy of an older person admitted to a care home is two to three years, and one to two years in a nursing home, many residents are approaching the end of life (Rahul *et al.* 1997). Seymour and colleagues (2006), in a collaborative venture between Help the Aged and the Universities of Sheffield and Nottingham, ran four 'listening events' where 74 older people living in their own homes expressed their views about end of life and demonstrated that older people can engage with end of life issues even if not immediately facing this situation (Clarke *et al.* 2006).

Carers or relatives of people who have died

Carers and relatives have been asked about their experience of bereavement or as a proxy when seeking to examine the views of the deceased (Higginson *et al.* 1994). Proxy methods rely on the accounts of others (family members, carers and health and social care professionals) about the experience of end of life and care. There are advantages and disadvantages of proxy information about end of life care (McPherson and Addington-Hall 2003; 2004). For example, there is a difference in the rating of symptoms and their severity between patients and their family members (Moorman and Carr 2008) and between staff and family members (Rich *et al.* 2010). Proxies may not have the knowledge required to answer questions retrospectively, which makes identification and recruitment of the most appropriate person to act in this role (perhaps the person who has been most closely involved in care) so important. Recall may be problematic if the time since the death is distant. Locating events around significant features in the year, for example Christmas, holidays and birthdays can help with this (Addington-Hall 2007). Relying in proxies can also mean that accounts focus only on the last days of a person's life.

Marginalised groups

Some people, because of their class, age, income, ethnic background, intellectual ability, gender or sexuality, may experience difficulty accessing mainstream services and having their needs and priorities understood. These groups are sometimes collectively referred to as the *disadvantaged dying*. For these populations it is important to explore and use research methods that ensure their perspectives are understood. Researchers need to try and reduce unequal power relationships between researcher and the researched and enable these people's voices and their everyday experiences and expectations around end of life care to be known.

Black and minority ethnic groups

Studies consistently demonstrate that there are differences in care giving and expectations about end of life care within and between cultures and ethnic groups (Koffman and Higginson 2003; Barnato *et al.* 2009; Bowling *et al.* 2010). However, it is reported to be particularly hard to recruit black and minority ethnic older people to studies discussing end of life (Seymour *et al.* 2002; 2007). It has been suggested that participants should be offered something in return for participation (information leaflets, information sessions,

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social event, art based activity) (Kendall *et al.* 2007) and it may be helpful to gain the approval of community leaders or key informants.

Surveys have been used to explore if there are racial and ethnic differences and preferences around end of life care (Barnato *et al.* 2009). Bowling *et al.* (2010), in their study of fear of dying, undertook secondary analysis of responses to the Ethnibus Surveys (www.ethnicfocus.com), a monthly nation-wide, rolling quota survey of the main ethnic minority communities living in the UK (Indian, Pakistani, Caribbean, Chinese people) to establish the views of community dwelling older people to standardised questions about preferences and fears associated with end of life.

People with learning disabilities

People with learning or intellectual disabilities who survive into adulthood are now more likely to die from prolonged life-limiting illnesses, similar to those seen in the general population. This includes deaths from respiratory and cardiovascular diseases and cancer. People with Down's syndrome have a high incidence of Alzheimer's disease. This population often has significant communication difficulties and this can be a significant obstacle for both undertaking research in and delivering end of life care. Research studies in which people with intellectual disabilities are participants, or even researchers themselves, are growing in number. In a review of research in this area, Tuffrey-Wijine and McEnhill (2008) noted that most studies were case reports and retrospective accounts. This research team has successfully used nominal group techniques (see data collection methods above) to encourage discussion about end of life among people with learning disabilities (Tuffrey-Wijine *et al.* 2007b).

Young adults with life threatening conditions

Children and young adults living with life-threatening and life-limiting illnesses are a marginalised group and often do not 'fit' existing services. One study, by Asprey and Nash (2005a, b, c), with children and young adults suffering from cystic fibrosis and neuromuscular disease, who were still in mainstream education, used the methods described below to encourage discussion and engagement. Some of these activities helped to prepare the younger people to think about their views before they participated in an interview. This non-confrontational approach could be used to talk about end of life and dying with a range of groups.

- *'About myself activity'*: designed to elicit the young person's perspective and set the tone for an interview. The young person was given a sheet of paper with a person (of the same gender) drawn in the middle and asked to draw circles around the edge to list any details about themselves.
- *Stickers*, showing red, amber and green and faces. Children and young adults were asked to use these to respond to lists of activities and circumstances on a chart. Red would indicate no involvement or lack of interest, green very involved, and so on, and

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the face stickers could be used to represent feelings.

- *Vignettes*: a series of written stories set out hypothetical problems that they might encounter. They were read out to them and they were asked if the story was familiar, then asked to describe their experience and how they felt about it.
- *Fantasy wishes*: the young person was asked to write down up to three things that would make them happier in an ideal world.
- *Secret box activity*, using a colourful sealed box with a slot. Participants were told that they may anonymously write down any problems or issues they have experienced but may not want to share openly and post it in the box. The researcher promised not to open the box until after the interviews are completed.

Lesbian, gay and transgender

The needs of lesbians and gay men at the end of their lives are not fundamentally different from any other dying individual's needs (Price 2011). There are, however, informal family dynamics, interactions with formal systems of care and social attitudes that can negatively affect the dying experiences of lesbians and gay men. Several authors have found that sexuality is often not addressed in end of life care (Hash and Netting 2006). Stein and Bonuch (2001), in a US study, found that gay men and lesbians have special interests in documenting their preferences regarding advance care planning and end of life care. As in social work practice, the researcher needs to consider if participation in research will raise issues of disclosure, privacy, and disenfranchised grief (Smolinski and Colón 2011).

Groups with complex needs or intermittent access to end of life care services

There are also groups for whom there may be difficulties of access because of the complexity of their situation and/or because they are difficult to identify and recruit in the health and social care system. This may be because they have multiple health and social needs, experience stigma (for example, people dying with AIDS (Young and Busgeeth 2010)), have particular difficulties in communication (for example, people with severe mental illness (Campbell and Kiseley 2009)), have difficult living conditions (for example, people who are homeless (Kushel and Miaskowski 2006)) or are prisoners (Bronstein and Wright 2006). For these groups opportunities to talk about care and treatment options and tailored care plans and discussions about end of life can be very important. A multi-pronged approach to recruitment of these groups is often required, either through service providers, who may have separate governance and ethical review procedures, advocacy groups and key workers and publicity in help centres, hostels and newsletters.

Processes of sampling

Within social care research the identification of informants may be a two stage process that first requires the sampling of services/organisations and then the identification of the

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relevant people within that service or community. Different sampling frames may be needed for each level of the sampling process.

Services/organisations

Different sampling frames need to be used to reach social care services based on the relative importance of different factors that relate to the focus of the survey. These include:

- Geographical by region, e.g. urban/suburban/rural, sociodemographic mix;
- Service type, e.g. size of service, ownership (private, public or not-for-profit);
- Population, e.g. demographic characteristics (old age, physical disabilities, learning disabilities, mental health), social and health care needs.

A *stratified* sampling frame may be utilised to ensure representation is achieved using relevant factors.

Sidell and Komaromy (2003) described a stratified sampling strategy for their national survey of 1000 English care home managers about the provision of palliative care. The levels for stratification were:

1. Regional – three regions of England that reflected different cultural needs and practices: North West, West Midlands, South East
2. Classification by size of care home – small (< 20 beds) and large (> 21 beds)
3. All types of homes were surveyed (at the time of this study) – residential (care) homes (Local authority, private and voluntary); Care homes with nursing (NHS, private and voluntary) and dual registered homes (private and voluntary)
4. Quota sample on basis of regional representation – South East (with greatest density of homes) was sent 42% questionnaires, 36% were sent to the North West, and 22% were sent to the West Midlands.

Other surveys of care homes have been undertaken that are regionally based and the total populations of care homes within that region may be used for the sample (see Froggatt and Payne 2006; Seymour *et al.* 2011), or provider based (Bowman *et al.* 2004), giving data on a national sample of care homes but within one provider organisation or company.

The data source to enable a sampling frame to be developed can be found in England in the public domain (via the Care Quality Commission (CQC) website or regional offices). However, these can quickly become out of date as services can close, change, become de-registered or be taken over.

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Environment, culture, context and models of care

In research on end of life care the physical environment of care is often overlooked, even though people, when asked, invariably state that they want to die at home. Organisations such as the King's Fund have evaluated projects that have worked to improve hospital and prison environments where people die (Arthur *et al.* 2010). Kayser-Jones *et al.* (2003), in an observation study of two US nursing homes and in subsequent work, discussed how physical layout and environment influence how end of life care is delivered, as did Rigby *et al.*'s (2010) review of the physical environment and end of life care for older people.

To understand the context of care it is therefore helpful to collect data that can provide information about the social care environment.

Working across social and health care organisations

The majority of care at end of life takes place within or involving the health care sector (such as hospitals and/or with the support of primary health care services). Any research therefore has to attend to the social care and health care organisational boundaries and the complexities of working and researching across them. A researcher's background may shape their ability to work across these different contexts. As Lawton (2000) identified in her study in a UK hospice, it was only after working as a volunteer in a day centre and thereby becoming known to hospice staff, that she was able to negotiate entry to the hospice. Knowing a setting because of experience can have advantages, in that professional language is understood and known. In end of life care research, time should be built in to a research project to help the researcher understand the physical environment and patterns of care and how these impact on the ability of researchers to undertake the research.

The culture and organisation of social care

Peace (2003), in a review of the development of residential and nursing home care in the UK, observed that while researchers have recognised the 'social death' of institutional care where residents have been seen as 'less than whole persons', they have not considered the experience of dying. In long-term care settings, such as care homes, the institutional philosophy and leadership of an organisation permeate all aspects of care. Some have argued that a person-centred philosophy that acknowledges the need to care for dying people, combined with some structured care planning, will achieve different resident outcomes to a care home that has a more task-oriented approach (Forbes-Thompson and Gessert 2005).

There is a range of frameworks and tools that can be used to inform a systematic assessment of the culture of a care home. There does not, however, appear to be a tool that is specific to the assessment of approaches to end of life care. The following are examples of different ways of assessing and categorising care that have been used in long-term settings:

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- Moos and Lemke (1992) developed the Sheltered Care Environment Scale;
- Davies (2001, 2003) classified care homes into three categories according to how they approached the delivery of care: controlled, cosmetic, and complete community;
- Short Observational work For Inspection (SOFI) is a tool that supports assessment of care approaches in dementia care (Brooker and Woolley 2007);
- Promoting Action on Research Implementation in Health Services (PARIHS) framework: This was developed to support practice development: through observations and field notes the framework can be used to assess a care home's environment and culture using an inventory form (informed by the PARIHS framework (Rycroft-Malone *et al.* 2002)). This includes an assessment of the physical environment, staff/resident relationship and resident wellbeing;
- Senses Framework: The Senses Framework is based on a model that advocates relationship-centred care: six dimensions are identified that, with supporting questions, help to structure a review of how care is organised and experienced by older people and of the staff who care for them. These dimensions are: a sense of security; a sense of continuity; a sense of belonging; a sense of purpose; a sense of fulfillment; and a sense of significance (Nolan *et al.* 2004, 2006; Faulkner *et al.* 2006).

Understanding the culture of dying in care homes is also important, as this will frame the research questions asked and how findings can be appropriately interpreted. Mathie *et al.* (2011) identified four beliefs/approaches to end of life care that seemed to affect how priorities for end of life influenced decision making around how care homes supported residents. This illustrates the importance of ensuring that studies explore participants' assumptions as part of the first phase of data collection in observational and intervention-based studies. Care home managers who worked in settings with no on-site nursing provision described their approach to supporting residents at the end of life as falling into four possible categories:

1. Care home for life: where the care home would always aim to keep the resident in the care home and support their end of life care wherever possible;
2. In and out of hospital: where clinical needs of the resident were separate and would be dealt with in secondary care settings (hospitals), although once stabilised the resident could return to the care home for end of life care;
3. Assessment and referral/transfer to specialist care: if a resident is assessed as dying they would be transferred to another care setting;
4. Care homes as end of life specialists: care home managers who would accept referrals from hospitals and hospices of people who had been assessed as dying.

Bern-Klug (2009), a social worker, through secondary analysis of ethnographic data developed a framework for categorising how members of staff in care homes interact

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with residents at the end of life. This echoes the work of Glaser and Strauss (1968). She identified five categories of social interactions related to dying and their related goals of care. These were:

1. Dying allowed
2. Dying contested
3. Mixed message dying
4. Not dying
5. Not enough information

She argued that a person's definition of a situation will define behaviour and that these categories reflect a combination of assumptions towards the dying status of a resident and what are seen as appropriate goals of care. These typologies offer an analytical framework for researchers to consider how end of life care is organised, documented and provided in care homes.

Researching end of life in care homes

Often research in care homes does not distinguish between care homes that offer personal care and support and those that offer nursing care. For research on end of life care this may be an issue because people in care homes with onsite nursing generally have a lower life expectancy and experience higher levels of dependency than people living and dying in (residential) care homes that offer personal care and support. The presence or absence of a clinician in the care home, for example, can affect the overall approach to end of life care. Dying is a difficult topic to research. Care home staff and organisations are aware that their residents will die in their care but prefer to emphasise quality of life, approaches that enhance health and, whenever possible, re-enablement and independence. Interviewing in care homes can also be difficult as doors often do not have locks, staff can walk in unannounced, or residents may be interviewed in dining rooms or a lounge where there is little privacy (Hall *et al.* 2009b; Luff *et al.* 2012).

Orientation to the care setting

Dewing (2009) identified a number of action points to help prepare researchers to undertake research in care homes. These have particular relevance for end of life care research in any setting and are summarised below:

- Develop an appreciation of the culture and context of the setting;
- Become familiar with the layout of the care home (setting) and how people use the space;
- Be open to when participants are ready and available and fit in with their preferences and daily patterns;
- Recognise participants may need more time than you initially plan;

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- Pace the access and consent gaining process;
- Use critical reflection skills to deal with dissonances observed;
- Engage with research supervision.

Kayser-Jones (2003) described how it was possible to feed back negative as well as positive findings on end of life care to care homes that participated in her research because she had recognised the importance of:

- Gaining access as 'laying the groundwork and creating and maintaining a climate of trust' (p.120);
- The importance of assuring the care homes' anonymity;
- Establishing relationships between care staff and researchers;
- Establishing reciprocity (between researcher and care staff). Kayser-Jones suggested offering training sessions for the care home staff, for example, speaking at monthly meetings.

Resource implications for organisational participation in research

Participation in research is time-consuming for care home staff and can deflect them from their work. Researchers should try to ensure that funding to reimburse care home time for research-related activities is built into any grant applications (Goodman *et al.* 2011). If no funding is available then it is important to consider how much staff time the study will require and whether other incentives can be offered such as staff training and evidence for education and training portfolios. The Enabling Research in Care Homes (ENRICH) initiative provides guidance on this and has suggested that care homes should be paid for supporting research activities.

CHALLENGES IN UNDERTAKING END OF LIFE CARE RESEARCH

A number of challenges exist when undertaking end of life or palliative care research that concern practical and ethical matters (Sigurdardottir *et al.* 2010a, 2010b; Scottish Partnership for Palliative Care 2011). These are interrelated in their shaping of the research process.

Ethical Issues

Several debates exist about the ethics of researching in end of life situations. Duke and Bennett (2010) identified vulnerability, consent, gate keeping, inclusion and research culture as key issues (see Table 3). They further observed that while there was recognition of the importance of dignity, rights and safety of research participants, less attention was given to the needs and rights of researchers and their responsibility in dissemination. There is much literature on the methodological problems associated with doing research on people who are dying and/or close to death (see Stewart *et al.* 1999; Waldron *et al.*

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1999; Sampson *et al.* 2005; Scottish Partnership for Palliative Care 2011). These include the ethics of involving people at what is described as such a 'difficult stage' of their life and dealing with highly sensitive material:

- Individuals may not be able to participate easily in research; for example due to reasons related to the illness they live with and the way it can fluctuate, or other conditions that affect communication (Seymour *et al.* 2005).
- Individuals may be in pain, discomfort, tired or confused. However, it is important that these individuals are given a 'voice' and the opportunity to participate (Clark 2003).
- Research in social care does not often involve a treatment and therefore may carry a reduced risk of harm to participants (Murphy and Dingwall 2007). However, when research takes place over a period of time, the participant's health may deteriorate, they may be in the last stages of dying and they may no longer be able to communicate. The person may have given their consent to have their medical or care home notes reviewed or to be observed, but it is questionable whether this consent remains valid as their condition changes (Lawson 2001). It is a debate which is shared by researchers working with people who have dementia (Dewing 2007).

There are potential conflicts of interest when practitioners are undertaking research with client groups and or other professionals (Seymour *et al.* 2005; Allmark *et al.* 2009). If poor practice is observed, Seymour *et al.* (2005) suggested that the interests and needs of the people involved need to be protected. However, how far the researcher gets involved in practice is often left up to the conscience of each individual (for example challenging practice when someone appears to be in pain or commenting on general care). Duke and Bennett (2010) also highlighted the ethical challenges of involving work colleagues and staff in supporting research, and suggest that there is a need to consider if practitioners that provide this kind of support may feel 'used'. They suggest that research training, joint decision making and joint review of the research conduct and process can foster ethical relationships and a positive research culture. Table 3 summarises the issues researchers should consider when undertaking research with participants who are approaching the end of life.

In settings such as care homes, there is a need to anticipate how researchers will work with care home staff and to have agreed protocols if problems arise (for example if bad practice is observed, or if staff or residents identify areas of concern). Kayser-Jones (2002) characterised this as establishing ground rules. It is helpful to agree these with the care home manager and to build in methods for care home staff to express their concern or feedback if residents are upset by the research.

Informed consent (see also section on capacity to consent): When undertaking research with people who are believed to be approaching the end of life it can be inappropriate for the researcher to raise the issue of dying if that has not been previously discussed, and there is a danger of revealing or emphasising their terminal status to a participant who

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Table 3. Areas to consider about ethical issues potentially arising from research on end of life care (adapted from Duke and Bennett 2010)

Question	Issues to consider	Strategy
Is the research morally appropriate?	Does it address an issue where there is disagreement about how care should be provided OR does it produce knowledge that could not be obtained another way? Are the risks outweighed by the benefits?	Ensure research does not expose to harm, discomfort or distress greater than participants would encounter in everyday life or when receiving treatment and care. Systematically consider the possible risks (where appropriate using a risk model). Ensure that protections are in place as part of the study design. Recognise the risk benefit balance may change over time and keep under review.
Are participants vulnerable?	Do they have capacity to consent? Is there any pressure to take part in the study? Will people be harmed/distressed through participating or might it affect their relationship with the researcher?	Assume they have capacity and where this is in doubt follow guidance for assessing capacity set out in Mental Capacity Act 2005 (see section on consent). Identify consultees where person does not have capacity. Ensure consent is ongoing and in the moment. Ensure there is a clear distinction between research and care received. Ensure people have time to consider possible participation and discuss with others. Ensure there is clarity about how to withdraw from study and more than one way of communicating a wish to withdraw. Consider how the researcher–participant relationship will be managed. Identify a third party that the participant can contact if they have concerns about the research. Consider how the researcher/participant relationship will be ended and if the loss of contact will cause distress.
Is the research as inclusive as possible?	Are there groups who are under-represented? Are there people who are less vocal and/or have fewer opportunities to participate in research?	Develop recruitment strategies and consent processes that are accessible to all groups. Develop links with user representative groups and charities to improve access to different groups.

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may be unaware of their condition (Seymour *et al.* 2005). Some ethics committees, care home staff and researchers are wary about including the words 'end of life' or 'palliative care' in information leaflets and paperwork (Kendall *et al.* 2007; Gardiner *et al.* 2010). In these situations it could be argued that standards of transparency are compromised and individuals are not fully informed because of the wish to do no harm (Seymour *et al.* 2005; Gardiner *et al.* 2010).

Distress: It is not unusual for participants to become upset during data collection. This is not necessarily a negative experience, but can be an opportunity to talk about someone they missed or felt sad about. If any resident or member of staff becomes upset or distressed during the research, the interviewee must be offered the opportunity to terminate the interview. It is important to ascertain if the interviewee would like someone (if possible) to sit with them or to have someone else informed (for example care staff, carer or relative) after the interview has taken place. The researcher should ensure that the person can talk further with an appropriate person/service if participation in the research raises issues they want to address or talk more about.

Intrusion: People participating in the study may feel that their right to self-determination is compromised, particularly if the study involves an intervention or is being undertaken in an institutional or closed setting, such as a care home. It is the responsibility of the research team to create opportunities for individuals to reflect on the study and withdraw from participation and/or highlight if participation in the research is disruptive and intrusive, perhaps because certain interventions are judged too intrusive on staff time and responsibilities and the everyday life of residents.

Confidentiality: All participants need to be reassured of complete confidentiality. The consent form and information leaflet which is provided at the start of the study should emphasise that all information given will be treated as completely confidential. The only exception to this is if information disclosed as part of the interview reveals that the individual or others are at risk of harm. All data collection tools (data extraction forms, interview sheets, questionnaires) should be anonymised. During data collection it will be necessary to keep a list of participants' names (and maybe addresses) so that the researchers can keep track of data collection and access case notes or approach individuals. Personal details need to be kept locked in a filing cabinet at the researchers' workplace. Names and addresses should not be kept on computers.

The consent process for social research is often derived from the clinical model of biomedical research (Wilson *et al.* 2010). Studies in social care settings may have more opportunities to continue conversations about participation and build in ongoing review of a person's willingness and capacity to continue to participate. There may be a need to 'reconfirm' consent as the study progresses, and consent should be 'ongoing' (Kendall *et al.*, 2007; Wilson *et al.* 2010), providing opportunities for people to withdraw. This may not however, always be possible in end of life research. Rees and Hardy (2003) have discussed a process of advanced consent in a medical setting for patients who could give their

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consent when they entered the hospital but might not be able to consent later at the time of randomisation for a trial for a particular drug.

Recruitment of people with diminished capacity and cognitive impairment

Older people with cognitive impairment and people with diminished capacity because of their illness and level of consciousness may not be able to consent to take part in research. These groups may have a third party (gatekeepers) through which contact is made, such as health professionals, carers, and other relatives, all of whom may want to protect access to the person. Health professionals can be 'overzealous gatekeepers' (Kendall *et al.* 2007) but so too may care workers (Seymour *et al.* 2002).

Hall *et al.* (2009b) also found that how care home staff introduced the researcher to the older person could confuse the resident as to who wanted to speak to them and why. If staff sometimes woke sleeping residents quickly, for example, this could lead to disorientation. These issues may be ameliorated by:

- Staged recruitment processes that allow sufficient time to establish relationships with health professionals, care workers and relatives, and to understand their priorities, concerns and goals of care, especially when discussing mortality and end of life care;
- Interviewing gatekeepers (such as carers) to understand the context of care and involve the carer/gatekeeper in the research study. McKeown *et al.* (2010a) describe the value of identifying 'gatekeepers' at the outset of a study and inviting them to collaborate in the development of the research protocol and to join a reference group;
- Ensuring that key professionals understand that the study has been through ethical review and that the researchers have the relevant experience and qualifications to undertake the research.

Assessment of capacity

The Mental Capacity Act 2005 (Department of Constitutional Affairs 2007) emphasises that a person should be considered to have the capacity to consent unless proved otherwise. A diagnosis of dementia, for example, does not mean that a person cannot give consent; capacity to consent is context specific and depends on the complexity of the decision (McKeown *et al.* 2010a). Often providing consent to participate in a study can be an ongoing process, repeated at each encounter, to ensure continued consent and maximise the opportunities for participation. In one study by Godwin and Waters (2009) the consent process was described as 'under constant review'. The researchers emphasised considering participants' demeanour and willingness to continue the dialogue, and verbal or nonverbal signs of an unwillingness to continue (for example, refusing eye-contact, remaining silent or walking away) as indicators that an interview should be immediately terminated. They sought verbal assent, as many of the participants in the study could no longer read or write. Oral consent should be witnessed and documented (see also the section below on dealing with distress and bereavement).

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Process consent

Dewing (2002) has widely researched and written about 'consent' when working with individuals with dementia. She writes

This method of process consent is meant for use with those persons who have extremely limited capacity for informed consent, who would generally be thought to be incapable of legally informed consent by others but on observation can communicate and express their wishes (Dewing 2007, p.22).

The principles are relevant for people at the end of life who, because of extreme fatigue, depression and fluctuating mood and experiences, will have varying capacity to participate in research. Dewing described a five stage process that relies on the researcher's ability to reflect critically on how participants are responding and the different ways that they may use to communicate interest or a desire to withdraw from the study:

1. *Background and preparation*: This includes developing relationships with relevant care providers, understanding something about the individual's biography that could help the researcher understand how the person communicates and what they may find upsetting (and how that would be expressed);
2. *Establishing a basis for capacity and other abilities*: This follows on from the background and preparation and ensures people are not coerced by others to participate and can feel that there is reciprocity in the researcher/researched relationships. This can be time-consuming and may involve a series of meetings;
3. *Initial consent*: This requires the researcher to ensure that the information about the study is provided in a way that is accessible to the person and sensitive to what is important to them;
4. *On-going consent monitoring*: This makes explicit the need to check continually that the person is willing to continue to participate, and acknowledges the importance of nonverbal communication and behaviours that may indicate a desire to withdraw;
5. *Feedback and support*: It is important to acknowledge the contribution and involvement of the individual and to mark when the research has ended and to ensure that disengagement does not cause distress or leave the individual with unanswered questions and issues.

Dealing with distress and bereavement

English society is not generally comfortable addressing dying, death and bereavement (Kendall *et al.* 2007; Sheldon and Sargeant 2007). Distress may be present in end of life research for both the participants and for researchers. For participants this issue is generally well addressed and considered as part of ethical review. Attention is paid to how people are recruited, for example when approaching bereaved relatives, either in

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person or by letter. Supports for participants are required to be in place, such as the availability of people to provide emotional support following research. This may be provided external to the project by nearby services (for example, a hospice or CRUSE), which therefore requires negotiation and possibly funding. Alternatively, support from within the project team may be identified and communicated to participants in the project information. While qualitative interviews may be cathartic for participants, if discussing end of life issues they have the potential to be distressing.

For researchers, too, encounters can be emotionally demanding (Nicholson 2009; Holman 2006). Researchers who are listening to stories of people's lives (and their sadness) can find these very challenging and emotionally draining. It can bring up unconscious anxiety in the researcher (Nicholson 2009) and researchers may deny participants a chance to express their sadness by 'filling in the silences' or attempting to 'cheer up' an individual. There may be a fear of upsetting participants and not knowing what to do if someone gets distressed. This may also reflect an identification between the research situation and the researcher's own experiences, past or current. Ideally, researchers should have regular supervision, facilitated by someone independent of the research team, which is built into the study.

It is important that all parties are offered the opportunity to have some form of support. In one survey staff members were provided with information on helplines and bereavement counselling (Partridge 2010). Emotionally difficult situations can arise and it is good practice within a research team to anticipate some of these situations and discuss how individuals can prepare themselves and access appropriate support.

Ethical review processes

All research which involves social care should gain approval by an appropriate body and be subject to independent ethical review. The Social Care Research Ethics Committee (<http://www.screc.org.uk/>) reviews adult social care research study proposals from researchers based in England. SCREC also reviews research where participants do not have the capacity to consent. It is part of the National Research Ethics Service (NRES), and its membership, expertise and procedures have been developed to reflect the social care context. Research should be carried out in accordance with the DH guidance Research Governance Framework for Health and Social Care (www.dh.gov.uk/research) and in accordance with guidance from the National Social Care Research Ethics Committee.

If research involves people recruited through the NHS who may lose or not have the capacity to consent then ethical review must be undertaken by designated committees with responsibility for research with people who may lack mental capacity. SCREC is one such committee.

A useful resource when carrying out research where participants may lose or not have the capacity to consent is produced by the British Psychological Society (Dobson 2008): www.bps.org.uk/publications/guidelines-for-practitioners/guidelines-for-practitioners.cfm.

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Ethics committees often have concerns about research on end of life and dying. Kendall *et al.* (2007) asked researchers what it was like to research end of life and found that 'many spoke of paternalism' of ethics committees. Ethics committees are likely to see the individual as vulnerable because they are dying, as opposed to seeing the person as someone who is living with a life threatening condition.

Governance

In addition to ethical review, studies in social care settings need to demonstrate that:

- The research will seek not to be disruptive to the organisation and the work of other practitioners;
- The researchers are qualified to undertake the research (including having Criminal Records Bureau (CRB) checks for contact with vulnerable people), have relevant experience for end of life care research, and have access to supervision;
- The researchers have the support and sponsorship of their organisation. Research in local authority social care settings needs to be agreed by the social care governance lead in the relevant local authority.

Each research study should consider having a protocol for establishing and dealing with bad practice. This should provide guidance on how to report matters of a serious nature: issues of abuse, unethical practice and serious misconduct.

Information and advice can be found on the following websites:

www.dh.gov.uk/en/Aboutus/Researchanddevelopment/AtoZ/Researchgovernance/index.htm

www.ethicsguidebook.ac.uk/Ethics-and-governance-314.

Role of the consultee

Where a person no longer has the capacity to give consent, a consultee has to be identified who, based on their knowledge of the person, could provide an opinion as to whether the person would have consented to participate if they had capacity. The Mental Capacity Act 2005 (Section 32) requires that a researcher must take reasonable steps to identify someone who is willing to be consulted about the participation in the approved project of the person who lacks capacity. Ideally, the consultee will be someone who knows the person who lacks capacity well but is not acting in a professional or paid capacity (a personal consultee). If this is not possible, the researcher must nominate a third party unconnected with the research who is willing to act as a nominated consultee (for example a GP or a social worker). A personal consultee could be:

- A family member, carer or friend;
- An attorney acting under a Lasting Power of Attorney (LPA), or;
- A court appointed deputy (Court of Protection), provided that they had a relationship

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with, or personal knowledge of, the person lacking capacity before their appointment as deputy.

The Department of Health (2008b) has produced a useful resource on nominating consultees.

Dobson (2008) has provided a practical guide for conducting research with people not having the capacity to consent to participation. This publication includes flow charts for the assessment of capacity and checklists, sample letters and pro forma for consulting with personal and nominated consultees.

USER INVOLVEMENT IN END OF LIFE CARE RESEARCH

Patient and public involvement (PPI) in health and social care research is government policy (Department of Health 2005) and, until recently, accepted as a 'good thing' with little critical evaluation (Beresford 2002). There is now acknowledgement that the evidence base underpinning PPI and user involvement needs strengthening (Boote *et al.* 2002b; Staniszewska *et al.* 2008; Staniszewska 2009). Staley (2009) has recently reviewed the impact of PPI on a number of research projects. Public involvement can take a number of forms and can have different terminology – public in research, peer researcher, co-researcher, peer educators – and sometimes there are different meanings for the same term.

Guidance about involving users and carers in research is available from INVOLVE (www.invo.org.uk).

At times, the 'public' has been involved in all levels of research projects: sitting on steering committees, designing research protocols or research tools, carrying out data collection and analysing data (Staley 2009). Research questions have been developed from the experience of individual patients and groups of patients; for example, people with spinal cord injuries (Abma 2005). However, there has been very little public involvement in end of life research.

Important work involving PPI in end of life research has been carried out by the Palliative and End of Life Care Research Group at the University of Sheffield and University of Nottingham. The work of Seymour *et al.* (2006, 2011a) and Clarke (2009) involved older people as peer educators 'sharing information with people of a similar age and background' which

Public involvement examples

Older volunteers helped to design and develop a booklet on end of life issues for Help the Aged (Sanders *et al.* 2006; Seymour *et al.* 2006).

The project went on to hold workshops where older volunteers ran discussion groups to hear the views about end of life among older people living in the community.

The volunteers were described as peer educators and carried out two 'listening events' (Clarke *et al.* 2006).

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was said to be a successful means of raising awareness about health issues among older people (Bernard and Ivers 1986) and a useful way for older people to discuss issues about planning ahead for end of life care (Sanders *et al.* 2006). The peer educators received training before and support throughout the project.

It is suggested that having 'peers' involved in research can be beneficial as the participants may:

- Relate to the volunteers because they are a similar age, perhaps in a similar situation;
- Use a language and vocabulary their peers recognise;
- Frame questions that reflect the priorities and interests of their peers and break down the unequal power relationship between researcher and participant.

CONCLUSION

Research methods in end of life care draw on a range of approaches and data collection options. This review has provided a broad overview of how these methods have been used, and their relative advantages and disadvantages when used with particular groups and in different settings. It needs to be reiterated that despite the many challenges of undertaking research in this area, people at the end of life often value the opportunity to participate in and find benefit from their involvement in research.

It is noticeable how little attention has been given to the experience of dying at home, inter-professional working between health and social care practitioners, and the impact of different kinds of social care and support. To date, research that exploits data in online accounts and blogs, the use of video diaries and creative, representational methods to enable self-expression is underdeveloped. There is also minimal discussion of research on the costs and resource use associated with end of life care in social care settings. Costs (both hospital and community) in the last year of life form a large proportion of lifetime health care expenditure (Scitovsky 1984; Zweifel *et al.* 1999; O'Neill *et al.* 2000; Polder *et al.* 2006). There are cost differences between approaches to end of life care that need further investigation in a range of settings, and through observing end of life care in an extended sample of people in the context of user and family preferences and experiences (Higginson *et al.* 2007).

The report of the Social Care Advisory Group of the National End of Life Care Programme *Supporting People to Live and Die Well: A Framework for Social Care at the End of Life* (Department of Health 2010) states that there needs to be a robust evidence base to support the development of good social care practice in end of life care. This review is a resource for that ambition.

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Resources

Department of Health in collaboration with the The Social Care Advisory Group:
Supporting people to live and die well: a framework for social care at the end of life
www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework

Department of Health (2008) *End of Life Strategy – End of Life Care Strategy – promoting high quality care for all adults at the end of life.*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277 (accessed 14 June 2010)

End of Life Care Programme (National Health Service)
www.endoflifecareforadults.nhs.uk/

NHS Evidence – supportive and palliative care
www.library.nhs.uk/palliative

End of Life Care in Sheltered and Extra Care Housing website:
www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing

GMC (2010) *Treatment And Care Towards The End Of Life: Good Practice In Decision-Making* (published May 2010 and came into force July 2010)
www.gmcuk.org/guidance/ethical_guidance (accessed 24 June 2010)

The Gold Standards Framework 'prognostic indicator'
www.goldstandardsframework.nhs.uk and www.gsfs.scot.nhs.uk (accessed 24 June 2010)

Marie Curie Cancer Care (2004) *Views about dying at home: survey of the UK general public*
www.mariecurie.org.uk (accessed 24 June 2010)

Reading List: 2009: End of Life Care
www.kingsfund.org.uk/document.rm?id=8351 (accessed 25 June 2010)

Websites of interest to end-of-life researchers and policy-makers
http://www2.warwick.ac.uk/fac/med/research/csri/ethnicityhealth/research/end_of_life/end_of_life_web.pdf (accessed 24 June 2010)

Ten questions to ask if you are scrutinising end of life care for adults. A guide designed to help Health Overview and Scrutiny Committees (OSCs) carry out their scrutiny work around various health, healthcare and social care topics
www.ncpc.org.uk/download/publications/EndOfLifeCare_TenQuestions.pdf

Teno, J. *Time: Toolkit of Instruments to Measure End-of-Life Care* Center for Gerontology and Health Care Research, Brown Medical School.
<http://www.chcr.brown.edu/pcoc/toolkit.htm> (accessed 6 August 2005).

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A selection of UK centres specialising in end of life research

International Observatory on End of Life Care, Division of Health Research, Lancaster University www.eolc-observatory.net

The Centre for Death and Society (CDAS), Bath University
<http://www.bath.ac.uk/cdas/index.html>

Department of Palliative Care, Policy & Rehabilitation, Cicely Saunders Institute, King's College London

Sue Ryder Centre for Palliative and End of Life Studies, School of Nursing, Midwifery and Physiotherapy, University of Nottingham Medical School, Nottingham.

Key terms

Used in health care settings associated with the processes of planning for future care (see also the legal framework enshrined in the Mental Capacity Act 2005 code of practice):

Advance care planning: 'The process of discussing the type of treatment and care that a person would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference, for example their preferred place of care and who they would want to be involved in making decisions on their behalf. It seeks to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs and involves and meets the needs of those close to the patient' (General Medical Council 2010).

Advance decision (England and Wales) or *advance directive* (Scotland): 'A statement of a person's wish to refuse a particular type of medical treatment or care if they become unable to make or communicate decisions for themselves. They are called advance decisions in England and Wales, and advance directives in Scotland. If an advance refusal is valid and applicable to the person's current circumstances, it must be respected. It will be legally binding on those providing care in England and Wales (provided that if it relates to life-prolonging treatment it satisfies the additional legal criteria), and it is likely to be legally binding in Scotland and Northern Ireland.' (General Medical Council 2010).

Advance statement: 'A statement of a person's views about how they would or would not wish to be treated if they become unable to make or communicate decisions for themselves. This can be a general statement about, for example, wishes regarding place of residence, religious and cultural beliefs, and other personal values and preferences, as well as about medical treatment and care' (General Medical Council 2010).