FORS GUIDES
to survey methods
and data management

Capturing the last phase of life in surveys

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Abstract:

The last phase of life – a crucial yet often underexplored stage – poses challenges for survey research. Common issues such as health shocks, cognitive decline, and mortality, lead to attrition and incomplete data. This FORS Guide highlights strategies from existing surveys to capture this sensitive period, offers recommendations to enhance data collection, and outlines key considerations for researchers analyzing such data.

Keywords: aging, end-of-life, death, mortality, data collection

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Statement on the use of artificial intelligence:

For this guide, the author used OpenAI’s ChatGPT to assist with the grammatical refinement of the paper. After using this tool, the author has carefully reviewed and edited the content as necessary and takes full responsibility for the final publication.

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1. INTRODUCTION

As populations age rapidly all over the world, the number of individuals experiencing prolonged periods of functional decline is increasing dramatically, creating new challenges for healthcare systems and societal networks (Cohen & Deliens, 2012). This end-of-life phase is also associated with substantial healthcare expenditures, with proximity to death driving a significant portion of costs. A large share of end-of-life care expenses occurs within the final months of life, particularly during the last month, due to intensive medical interventions, hospitalizations, and palliative care services (Luta et al., 2020). Examining the last phase of life thus offers valuable insights into improving care access and quality, addressing the challenges of aging populations and rising healthcare costs. It helps reduce disparities, optimize caregiving models, and develop compassionate, personalized care strategies that ensure dignity and support for patients and their families.

The last phase of life is a complex and diverse experience that most of the time encompasses a period of years or months leading up to death, which varies widely based on the underlying health conditions or a significant health event (Cohen-Mansfield et al., 2018). It also differs greatly among individuals, age groups, situations, contexts, and cultures. Although it is often linked to older adults, it can take place at any stage of life, from infancy to very old age. The last phase of life is characterized by distinct patterns of functional decline, such as sudden death with minimal prior deterioration, terminal illnesses, such as cancer, characterized by rapid decline in the last months, organ failure marked by fluctuations and acute episodes, and frailty involving prolonged disability, neurodegenerative disease, and dependence on care (Lunney et al., 2003). In addition to the varying health conditions, trajectories of decline, and the prevalence of comorbidities, this phase is marked by the complex care needs that often require one or more hospital admissions (Reich et al., 2013). The care provided during this phase often involves both formal caregivers, typically healthcare providers, and informal caregivers, such as family members or close friends (Tripodoro et al., 2024). Informal caregivers often bear significant emotional, physical, and financial burdens, balancing their caregiving role with other life responsibilities (Veloso & Tripodoro, 2016). The end-of-life period is also profoundly shaped by emotional and cultural sensitivities, as it is a time when individuals and their families confront existential questions and anticipate loss and grief (Cain et al., 2018). Preferences for care, including decisions around life-prolonging treatments or comfort-focused care, often differ across individuals and cultures, complicating care planning and delivery (Gysels et al., 2012). Furthermore, communication between healthcare providers, patients, and families becomes critical yet challenging, as it must address complex medical information, ethical considerations, and personal values and beliefs (Becker et al., 2020). Studying the last phase of life is thus essential for understanding the complexities of aging trajectories, healthcare delivery, and the support systems required by individuals and their families.

However, conducting research during the last phase of life presents significant challenges that can impact data quality and study outcomes. High attrition rates are common, primarily due to participants' deteriorating health, degenerative disease and mortality (Oriani et al., 2020). Such high attrition rates can lead to incomplete datasets, complicating analyses and potentially introducing bias. Cognitive decline among participants further complicates data collection, as it may impair their ability to provide informed consent and accurate information (Evans et al., 2020). Moreover, the sensitive nature of end-of-life experiences requires researchers to approach data collection with high ethical considerations (Kendall et al., 2007). Balancing methodological rigor with compassion is essential to minimize distress for participants and their families. Overprotective gatekeeping by ethics committees, clinical staff and families can further impede research efforts, underscoring the need for sensitive yet effective study designs. Finally, researchers must navigate their own emotional responses when engaging with terminally ill participants, as these can influence data collection and analysis (DeCamp et al., 2022). Therefore, research in end-of-life contexts demands careful consideration of participant vulnerability, ethical complexities, and methodological challenges. Addressing these issues is crucial for obtaining reliable data that can inform improvements in end-of-life care quality and practices.

To address these challenges, this FORS Guide offers practical insights and strategies drawn from existing surveys that have captured data on this sensitive phase. It provides recommendations for enhancing data collection processes, including techniques to mitigate attrition and improve inclusivity particularly in terms of reaching individuals with cognitive or physical impairments, limited digital access, social isolation, or from underrepresented socio-cultural backgrounds. Additionally, the guide discusses the implications of these strategies for researchers analyzing end-of-life data, offering tools to better understand this critical stage of life. By addressing these issues, this guide aims to support researchers and policymakers in designing and interpreting studies focused on the last phase of life. In doing so, it contributes to a more comprehensive understanding of the complexities of aging, caregiving, and end-of-life care, ultimately fostering evidence-based strategies to improve quality of life during this last stage of life. Finally, while this guide focuses specifically on the last phase of life, it is important to note that many of the challenges discussed such as cognitive decline, physical limitations, or emotional distress can emerge earlier in the aging process and affect broader segments of the older population.

2. KEY CONSIDERATIONS FOR SURVEYING THE LAST PHASE OF LIFE

2.1. THE COMPLEXITY AND DIVERSITY OF THE LAST PHASE OF LIFE

The last phase of life is a complex and diverse experience, varying significantly across individuals, age groups, circumstances, context, culture, and while it is most commonly associated with older adults, it can occur at any point in the life course, from infancy to advanced old age (Cohen-Mansfield et al., 2018). For infants and children, the main causes of death are often linked to congenital conditions, rare diseases, or perinatal complications; in younger and middle-aged adults, causes of death are more likely to include accidents, acute health shocks, or specific illnesses that follow shorter trajectories; in contrast, older adults, who represent the largest group experiencing end-of-life, often face chronic conditions, neurodegenerative diseases, and prolonged frailty (National Center for Injury Prevention and Control, CDC, 2021). These differences in age not only shape the experience of the last phase of life but also influence the types of care received, the possibility to plan for its own death, the decisions made by families and healthcare providers, and the emotional and societal impact of death (Chambaere et al., 2012). Understanding the diversity of the last phase of life is thus critical for designing surveys that can accurately capture the multifaceted nature of this phase. To better understand how to approach such surveys, the next part of the section will examine the theoretical trajectories of dying as proposed by Lunney et al. (2002), focusing on the four most common patterns of decline and their implications for end-of-life research and care.

The authors categorized individuals nearing the end of life into four trajectories based on patterns of functional decline. These trajectories reflect the typical progression of different illnesses and conditions (Lunney et al., 2002). The first category is sudden death and involves an abrupt end to life, often resulting from accidents or acute health events. There is little to no warning before these deaths, making them difficult to predict and prepare for. The second is terminal illness, commonly associated with cancers, this trajectory features a relatively stable period of health followed by a sharp decline in functioning as the illness progresses. The third one is organ failure, as seen in conditions like heart or lung disease. This trajectory is marked by a gradual decline punctuated with acute episodes of health deterioration, often requiring medical interventions, before an eventual death. And finally, the last category is prolonged frailty. Individuals in this category experience a slow and progressive decline over an extended period, often due to neurodegenerative diseases or age-related frailty. These four trajectories are useful for researchers and clinicians to understand the varied experiences of the dying process, highlighting the need for tailored approaches to end-of-life care (Cohen-Mansfield et al., 2018). Table 1 provides a summary of the diverse end-of-life trajectories, highlighting their main causes, prevalence, most probable age distributions, and typical durations leading to death.

Table 1. Diversity of end-of-life trajectories.

Type of death	Main causes of death	Prevalence in Switzerland	Most probable age range	Average time leading to death
Sudden death	External causes (accidents, suicides); sudden cardiac events, acute strokes.	~8%	Young adults (15–45), older adults (65+)	Minutes to hours
Terminal illness	Cancer (lung, colorectal, pancreatic cancers); progressive neurological diseases (e.g., ALS).	~25%	Middle-aged to older adults (45–80)	Weeks to months
Organ failure	Cardiovascular diseases (ischemic heart disease, hypertensive heart disease); respiratory diseases (COPD); COVID-19; chronic kidney or liver diseases.	~45%	Older adults (65+)	Months to years, with intermittent acute episodes
Prolonged frailty	Neurodegenerative disease; general age-related frailty.	~22%	Very old adults (80+)	Years (5+ on average)

Notes. Sources include: Alzheimer's Society, 2024; Chio et al., 2009; Gudmundsson et al., 2012; Hariharaputhiran et al., 2022; Kondziolka et al., 2014; Swiss Federal Statistical Office, 2024.

Table 1 underscores the complexity and variability of end-of-life experiences, providing valuable insights for understanding the different needs and challenges associated with each trajectory when collecting data. The various trajectories of end-of-life – whether sudden or prolonged, predictable or unpredictable – require tailored strategies to ensure accurate and ethical data collection. By accounting for this diversity, researchers can better address the challenges of end-of-life data collection and ultimately produce insights that are both comprehensive and meaningful.

2.2. CHALLENGES IN COLLECTING DATA ON THE LAST PHASE OF LIFE

Researching the last phase of life presents unique and significant challenges arising from the physical, cognitive, and emotional vulnerabilities of participants, as well as the ethical complexities of studying such a sensitive topic. These challenges have profound implications for data quality, study design, and the quality of life of participants. This section outlines the key difficulties encountered when collecting data during the last phase of life, including challenges in collecting cross-sectional data at a specific point in time (e.g., to evaluate health status, care needs, or decision-making preferences) and longitudinal data over time to assess the evolution of health trajectories, care pathways, and outcomes.

Attrition and incomplete data

Attrition is a significant challenge in end-of-life research, arising from various factors related to participants' health, social circumstances, and mortality. Understanding these diverse causes of attrition is essential for researchers to avoid incomplete datasets that could reduce statistical power and potentially introduce bias into study findings. One of the most prominent causes is the natural decline in participants' health, often due to chronic illnesses, acute health events, cognitive decline, or dementia. For example, participants with prolonged frailty or those with neurodegenerative conditions may experience declining cognitive or physical abilities over years, increasing their likelihood of withdrawal from studies (Hernandez et al., 2024; Jacobsen et al., 2021). In addition, some participants with physical disabilities, such as hearing or vision problems, as well as mobility issues, may find it difficult to attend study visits or complete assessments, ultimately leading to withdrawal (Strotmeyer et al., 2010). The same applies to mental health issues such as depression or dementia, causing participants to potentially quit the study (der Wiel et al., 2002). The emotional burden of participation, compounded by feelings of stress or overwhelm, may lead some to withdraw. Social and environmental factors are equally important. For instance, relocation, such as moving to a nursing home or a long-term care place, can disrupt participation, as it may lead to difficulties in maintaining communication with the research team (e.g. the facility may not allow such studies in their establishment), and/or the family may refuse to continue participation in the study (Lam et al., 2018). Other sources of social and environmental factors linked to attrition when studying the last phase of life could include participants struggling to balance increasing caregiving responsibilities, which may leave them with little time or energy for study commitments. Social isolation, often exacerbated by aging-related factors such as reduced mobility or shrinking social networks, can further hinder engagement. Cultural beliefs or stigma related to aging or death might discourage continued participation, while perceptions that the study lacks relevance to their personal circumstances can further reduce motivation to stay involved. Finally, in cases of death, the loss of participants creates gaps in data collection, potentially making it more difficult to reach the number of participants required to adequately answer the research question and introducing bias if the attrition is not evenly distributed across subgroups within the study population. However, the extent to which death impacts the representativeness of cohort studies depends on the broader context. Since death-related attrition influences both the study cohort and the broader population, changes in representativeness compared to national population data are potentially minor (Brilleman et al., 2010). This suggests that while death-related attrition poses challenges, it may not always significantly compromise a study's representativeness, as mortality is a natural part of aging and occurs universally across the population. By minimizing attrition, researchers can enhance the reliability and validity of their findings, ultimately contributing to a better understanding of the last phase of life and its complexities.

Cognitive decline and consent challenges

Cognitive decline is another major barrier to effective data collection in the last phase of life, particularly among individuals experiencing prolonged frailty. Conditions such as dementia and Alzheimer’s disease can impair participants’ ability to provide informed consent and accurate responses, posing a methodological dilemma (Weir et al., 2011). To address the challenges posed by cognitive decline in data collection, researchers can use specialized tools to assess decision-making capacity (Gilbert et al., 2017). These tools help evaluate participants' ability to understand, reason, and make informed choices, ensuring ethical and effective participation in research. While there is not one ideal tool, combining different assessments with increased awareness among researchers can mitigate the methodological and ethical challenges involved (Gilbert et al., 2017). Furthermore, when it is not possible to do the study with the targeted person, researchers may rely, if available, on proxy respondents, typically family members or caregivers, to provide information on behalf of participants who are unable to do so due to cognitive impairments. Proxies serve as substitutes by offering insights into the participant’s health, behaviors, and preferences (Weir et al., 2011). While this approach ensures data collection continuity, it comes with challenges. Proxy interviewing introduces biases as the proxies‘ perspectives might not fully align with the participant’s views or experiences (Neumann et al., 2000). They might also lack complete knowledge of certain aspects, particularly subjective feelings or nuanced preferences. Moreover, the quality and completeness of proxy data can vary depending on the proxy’s relationship to the participant, with close relatives, especially children, providing more reliable responses than non-relatives (Zaccaria et al., 2025). Additionally, emotional factors, such as stress or grief, can influence the proxy's responses. Ensuring clear communication and providing adequate guidance to proxies is essential to minimize these challenges and maintain the integrity and accuracy of the collected data.

Ethical and emotional sensitivities

Researching the last phase of life requires careful attention to ethical and emotional considerations. Participants and their families are often navigating profound emotional challenges and may have feelings of vulnerability and distress (Cain et al., 2018). Thus, researchers must approach their studies with compassion and care to ensure that participants feel respected, valued, and supported throughout the research process (Kendall et al., 2007).

In addition, the last phase of life raises significant ethical questions due to the vulnerability of the participants, the sensitive nature of the topic, and its emotional impact on individuals and their families (Henry & Scales, 2012; Seedsman, 2019). Researchers must balance the societal benefits of their work with the need to protect participants from harm. The first key concern is respecting participants' autonomy, which requires ensuring informed consent, even when cognitive decline or emotional distress may complicate comprehension. Autonomy also involves allowing participants to withdraw at any time without pressure.

Minimizing psychological distress is equally critical, as discussions about death or loss can evoke strong emotions. Researchers should use empathetic language, offer the option to skip sensitive questions, and avoid intrusive inquiries. Balancing research benefits with participant well-being is especially challenging in end-of-life studies. Vulnerable individuals may feel forced to participate due to trust in researchers, even if it causes discomfort. Protecting dignity and confidentiality is essential, requiring strict privacy measures and sensitive handling of data.

Another critical consideration when conducting research with vulnerable populations at the end of life is obtaining approval from an ethics committee or institutional review board. This step is fundamental, as such studies often involve sensitive personal data and participants residing in medical institutions (Casarett, 2005; Henry & Scales, 2012). It is important to highlight that ethical review is a decisive phase for ensuring the ethical integrity of a research project, protecting participants' rights, and maintaining public trust in scientific inquiry.

Inclusivity is also important to address disparities in end-of-life care, requiring cultural sensitivity to respect diverse values, beliefs, traditions, and practices, including those related to spirituality. This also involves identifying and addressing barriers to participation, such as language differences, mistrust of institutions, or logistical challenges, to ensure equitable representation.

Lastly, researchers must account for the impact on families and caregivers, ensuring their involvement does not add to their emotional or caregiving burdens. Ethical dilemmas may arise when the perspectives or decisions of family members conflict with the expressed wishes of participants. In such cases, it is crucial to navigate these situations carefully to respect and prioritize the participants' rights, autonomy, and preferences while maintaining open communication with their families. By addressing these ethical questions with care and sensitivity, researchers can ensure that studies on the last phase of life respect the dignity and well-being of participants while contributing to a deeper understanding of this critical stage of life.

Recruitment barriers and sample representation

Recruiting participants for research on the last phase of life presents numerous challenges that can affect both the process of recruitment and the representativeness of the sample. One significant barrier is the difficulty of accessing participants, as individuals in this stage of life are often in fragile physical and mental states (Walshe et al., 2024). Recruitment methods through in-person contact, mailed invitations, or public advertisements may be ineffective in this context because individuals in poor health may have greater difficulty responding and participating. Additionally, these methods may fail to reach individuals who are isolated, rely on caregivers, or reside in healthcare facilities, further complicating participant recruitment. Gatekeeping by healthcare providers, family members, or ethics committees can also restrict researchers' ability to directly approach potential participants, as these gatekeepers may prioritize protecting individuals over enabling their participation (DeCamp et al., 2022). This gatekeeping often comes from concerns about distress or doubts about participants' capacities, though research shows most patients and caregivers view end-of-life research positively, as it fosters empowerment and care improvements, with distress being manageable through flexible, inclusive approaches (Gysels, Evans, & Higginson, 2012).

Another potential obstacle lies in how participants or their families perceive the relevance of research during this critical stage. They may view research as intrusive or unnecessary, especially when their primary focus is on managing immediate health challenges or spending time with loved ones. In addition, cultural beliefs and stigma surrounding death and end-of-life discussions can discourage participation, particularly in populations where these topics could be considered taboo. Despite these challenges, many patients recognize research as an opportunity to make a meaningful contribution, whether by helping future patients or improving the quality of care (White & Hardy, 2010).

Sample representation is another critical issue. Marginalized groups, including minority populations, individuals with lower socio-economic status, or those living in remote areas, are often underrepresented due to systemic barriers, logistical challenges, or mistrust of research institutions. Furthermore, overprotective attitudes from caregivers, clinicians, or institutions can lead to the selective inclusion of participants perceived as "easier" to recruit, potentially resulting in a skewed sample. Cognitive or physical impairments in potential participants can also lead to exclusion, leaving gaps in data that fail to capture the full diversity of end-of-life experiences. Additionally, an overreliance on proxy respondents can shift the focus away from the participants' own perspectives, limiting the understanding of their subjective experiences and preferences. To address these challenges, researchers must build trust with healthcare providers, community leaders, and caregivers to facilitate recruitment. Culturally sensitive approaches are essential to overcoming stigma and ensuring diverse representation. Flexible recruitment methods, such as engaging participants through hospice care programs or conducting home-based visits, can help address logistical and emotional barriers. Similarly, adopting less intrusive data collection methods, such as brief surveys, CATI (Computer-Assisted Telephone Interviewing), or passive data collection (e.g., through medical records), can minimize the time and effort required from participants. By addressing these barriers and enhancing sample representation, researchers can improve the validity and inclusivity of studies on the last phase of life, ensuring that the insights gained reflect the full diversity of this population.

Emotional toll on researchers

Conducting research on the last phase of life not only presents challenges related to participants but also takes an emotional toll on researchers themselves (DeCamp et al., 2022). Engaging closely with terminally ill participants and their families requires navigating profoundly sensitive topics, such as death, grief, and loss, which can evoke feelings of anxiety, sadness, helplessness, or moral distress in researchers. This emotional labor can lead to burnout or compassion fatigue, especially when researchers feel personally invested in the well-being of participants. The intimate nature of end-of-life research often places researchers in close proximity to the suffering of others, demanding both professional detachment and deep empathy. Balancing these can be difficult, particularly when participants express fear, frustration, or existential concerns that resonate with researchers on a personal level. Reflecting on these deeply personal topics, such as the meaning of life or the inevitability of death, can prompt researchers to question their own beliefs and experiences, potentially generating feelings of anxiety or emotional discomfort. Furthermore, witnessing the decline or passing of participants over the course of a study can be emotionally draining and may create a sense of guilt or inadequacy if researchers feel unable to alleviate participants' suffering. To mitigate these challenges, research teams need to establish supportive environments. Debriefing sessions, peer support groups, and access to counseling services can help researchers process their emotions and maintain their mental well-being (Kavanaugh & Campbell, 2014). Building resilience through training on emotional coping strategies and establishing clear boundaries between professional and personal engagement is equally important. By addressing the emotional toll of this work, researchers can sustain their ability to conduct compassionate, ethical, and effective studies on the last phase of life.

2.3. TECHNIQUES FOR COLLECTING DATA ON THE LAST PHASE OF LIFE

Collecting data on the last phase of life requires a diverse set of methods tailored to the unique challenges posed by this sensitive stage. Researchers must balance methodological rigor with ethical and emotional considerations, utilizing both quantitative and qualitative approaches to capture the full complexity of experiences. Mixed-methods designs, which integrate numerical data with in-depth personal narratives, often provide the most comprehensive insights (Walshe, 2018). This section explores how different techniques can address the specific challenges associated with studying the last phase of life.

Adapting methods to different end-of-life trajectories

The diverse trajectories of the last phase of life require tailored approaches to data collection, as each trajectory presents unique challenges and methodological needs. Table 2 below provides a concise summary of these trajectories, highlighting the specific challenges they pose, the most relevant data collection methods, and examples of existing surveys that have successfully addressed these complexities.

Table 2. Adapting methods to the different end-of-life trajectories.

Type of death	Challenges in data collection	Most relevant methods	Examples of existing studies
Sudden Death	- Retrospective data only (no prior decline). - Emotional distress of proxies during interviews. - Recall bias or lack of information on the circumstances of death.	- Proxy interviews. - Administrative data (death certificates, hospital records).	Oregon Sudden Unexpected Death Study: community-based study using medical records, and autopsy data to study sudden cardiac death.
Terminal illness	- High attrition as decline accelerates. - Limited capacity of respondents due to physical and emotional burden. - Ethical sensitivities when discussing end-of-life decisions.	- Longitudinal surveys capturing decline. - Proxy interviews for continuity. - Healthcare records.	Irish Longitudinal Study on Ageing (TILDA): gathers longitudinal data on aging. Irish National End-of-Life Survey: Collects retrospective data from bereaved families.
Organ failure	- Intermittent and unpredictable decline leads to missed acute episodes. - Difficulty in capturing transitions between recovery and deterioration. - Low survey participation during acute phases.	- Longitudinal monitoring with flexible intervals. - Mixed-methods approaches (self-reports + proxies or caregivers' reports).	The iLIVE project: collects data at two time points from patients, healthcare providers, and bereaved families on end-of-life care experiences across countries.

Prolonged frailty	- Increased risk of attrition - Cognitive impairments reduce reliability of self-reports. - Proxy responses may lack details on subjective experiences.	- Simplified longitudinal surveys. - Proxy interviews. - Healthcare records.	SHARE[1], HRS[2], and ELSA[3]: allow proxy assistance during surveys and include exit interviews with proxies for deceased participants.
[1] SHARE: Survey of Health, Ageing, and Retirement in Europe; [2] HRS: Health and Retirement Study; [3] ELSA: English Longitudinal Study of Ageing.			

Notes. Sources include: Börsch-Supan et al., 2013; Chugh et al., 2008; Kearney et al., 2011; National Care Experience Programme, 2024; Sonnega et al., 2014; Steptoe et al., 2013; Yildiz et al., 2022.

Building on the insights from Table 2, which highlights tailored approaches for different end-of-life trajectories, researchers must employ diverse, flexible, and compassionate strategies to address the complexities of collecting data on the last phase of life.

Quantitative approaches

Quantitative methods, such as questionnaires with standardized longitudinal or cross-sectional questions, proxy interviews, and the linkage of administrative data and routinely collected records (e.g., health records or social security data), are essential for capturing changes over time, maintaining continuity when participants face cognitive or physical limitations, and reducing participant burden by integrating health records and death registries.

Longitudinal surveys and proxy interviews

Longitudinal surveys allow researchers to track changes in health, functional status, care preferences, and individuals' adaptation competencies over time. Studies like HRS and TILDA rely on face-to-face and CATI interviews with participants and, when necessary, mortality follow-up with proxies after a participant's death (Kearney et al., 2011; Sonnega et al., 2014). Proxy interviews help maintain data continuity but may introduce recall bias, particularly when discussing sensitive topics such as death and end-of-life. Moreover, it is important to be aware that proxies are not always available and that the proxy's relationship with the person at the end of life (spouse, children, friend, new companion, legal representative, etc.) can also generate biases.

Administrative and routine data

Administrative and routine data such as healthcare records, death registries, and hospital data provide large-scale insights with minimal participant burden and can offer population-level insights into palliative and end-of-life care, improve resource efficiency, and help evaluate interventions (Davies et al., 2016). Studies such as the National Care Experience Programme use these sources to analyze trends in palliative care utilization and quality (National Care Experience Programme, 2024). However, administrative data often lack detailed personal experiences, necessitating their integration with qualitative social science data such as panel data. In addition to administrative and clinical data, the integration of biomarkers, including genetic, inflammatory, hormonal, and physiological markers, is becoming increasingly common in panel surveys. These data enhance the understanding of aging processes, frailty, and mortality risk.

An increasingly valuable approach in end-of-life research is data linkage, which connects multiple administrative and routinely collected data sources, such as health insurance claims, hospital discharge records, or electronic health records, to reconstruct patients' healthcare trajectories. By integrating hospital records, palliative care databases, prescription histories, death certificates, etc., researchers can gain a more comprehensive understanding of end-of-life care pathways, treatment intensity, and disparities in service access. This method reduces recall bias and allows for objective, large-scale analyses while minimizing respondent burden.

However, data linkage in research in general, and health research in particular, presents significant challenges in terms of data protection and privacy, especially in Switzerland, where strict legal and institutional frameworks can make such linkage particularly complex. The use of sensitive personal information requires strict ethical and legal safeguards, including anonymization techniques, secure data storage, and compliance with regulations. Access to linked data often involves lengthy approval processes, limiting the feasibility of real-time analysis. Additionally, discrepancies in coding standards between datasets can affect data quality and comparability, necessitating careful validation procedures (Gysels et al., 2008).

Qualitative approaches

Qualitative approaches, including in-depth interviews, ethnographic observations, and narrative storytelling, provide nuanced insights into personal experiences, care preferences, and the emotional dimensions of this stage.

In-depth interviews and ethnographic methods

Qualitative approaches provide rich, context-specific insights into end-of-life experiences. Gysels et al. (2008) highlight that interviews with terminally ill patients and their families, while emotionally challenging, reveal valuable perspectives on decision-making and care quality. Ethnographic research, such as Lawton (2002) on palliative care, captures lived experiences in greater depth than structured surveys.

Narrative storytelling

Encouraging participants to share their stories fosters engagement and allows for a nuanced understanding of emotional and social dimensions. Studies using life story approaches have demonstrated their effectiveness in capturing the complexity of end-of-life care choices (Duke & Bennett, 2010).

Mixed-methods and technological innovations

Integrating quantitative and qualitative data

Mixed-methods designs, combining quantitative data with qualitative data, offer a holistic view and a more comprehensive understanding of end-of-life experiences and care. The iLIVE project exemplifies this approach by integrating patient-reported outcomes with caregiver interviews and health records (Yildiz et al., 2022). Mixed-mode approaches such as combining self-administered paper questionnaires, online surveys, and face-to-face interviews, along with diverse follow-up methods can improve participation rates (Legleye et al., 2016; Strotmeyer et al., 2010).

Digital and remote data collection

Digital tools and technology are invaluable for overcoming logistical barriers by enabling remote interviewing and monitoring of health deterioration without active participation, improving data accuracy (Sleeman et al., 2019). Remote data collection through Computer-Assisted Video Interviewing (CAVI) or CATI facilitates the inclusion of participants with mobility or health constraints, while passive monitoring devices gather continuous data without active participation.

However, the use of digital tools in end-of-life research is not without challenges. Older adults, particularly those in advanced age or with cognitive impairments, may struggle with digital literacy, limiting their ability to engage with online surveys or mobile applications. Additionally, patients experiencing severe illness, fatigue, or sensory impairments (e.g., vision or hearing loss) may find it difficult to use technology-based tools, reducing participation rates and data completeness.

To address these challenges, researchers may need to provide alternative modes of data collection, such as telephone interviews, assistance from caregivers or face-to-face interviews. For instance, SHARE conducts face-to-face interviews with trained interviewers to ensure data quality and accommodate the needs of older participants. Simplifying interfaces, offering personalized support, and ensuring accessibility features (e.g., large fonts, voice-assisted technology) can also improve usability and inclusivity for diverse end-of-life populations.

Ethical considerations and inclusive practices

Consent and participant well-being

Research with terminally ill participants requires ethical sensitivity and adaptability to ensure their comfort, dignity, and autonomy (Kavanaugh & Campbell, 2014). A dynamic consent model is essential, as it allows individuals to give, modify, or withdraw their consent at any time (Bruns & Winkler, 2024). This approach respects participants' autonomy by giving them the option to withdraw or modify their level of involvement as needed.

To prioritize participant well-being, data collection methods should be tailored to minimize the burden. Surveys should be kept concise, with the length and complexity of questions adjusted according to the population being studied. Older or cognitively impaired participants may require simpler wording and shorter response formats to avoid fatigue or confusion. In face-to-face interviews, researchers must be attuned to the health conditions of participants, ready to pause or terminate the interview if the individual becomes too fatigued, distressed, or unwilling to continue. Sensitivity to nonverbal cues is crucial in assessing when to stop or adjust the approach.

Additionally, when necessary, researchers should involve caregivers, healthcare professionals, or proxy respondents to facilitate participation. This may include seeking input from medical staff to determine appropriate interview timing, engaging proxies for participants who are unable to communicate their experiences directly, or allowing a trusted caregiver to be present for support. However, the use of proxies should be carefully managed to avoid overshadowing the participant’s own perspective.

Finally, ensuring post-participation support, such as offering grief counseling or emotional resources, acknowledges the emotional weight of end-of-life research and demonstrates respect for participants and their families. By integrating these considerations, researchers can uphold ethical standards while fostering a compassionate and inclusive approach to studying the last phase of life

Cultural sensitivity and inclusivity

To ensure inclusivity and cultural sensitivity, researchers must adapt their methods to reflect diverse beliefs and practices. Tailored instruments, multilingual surveys, and partnerships with community leaders help build trust and encourage participation, particularly in underrepresented populations. Collaborating with hospice organizations and engaging community stakeholders ensures that the study design aligns with participants' cultural expectations and fosters a sense of respect and inclusion (Gysels et al., 2008). Furthermore, it is essential to acknowledge and respect participants' and their families' values concerning death and end-of-life care from both cultural and religious perspectives. Beliefs surrounding dying, palliative care, and post-mortem practices vary widely across cultures and can influence individuals’ willingness to engage in research. Researchers should be mindful of these differences, ensuring that discussions about end-of-life experiences are conducted with sensitivity and in alignment with participants' worldviews. This may involve adjusting interview techniques, modifying question phrasing, or seeking guidance from cultural mediators or religious leaders to facilitate a respectful and meaningful dialogue.

To conclude, research on the last phase of life necessitates diverse, adaptable, and ethically sound data collection strategies. By integrating longitudinal surveys, qualitative interviews, administrative data, and technological innovations, researchers can develop a comprehensive and nuanced understanding of end-of-life experiences.

Combining diverse data sources enhances the reliability and depth of findings. Frequent, short data collection intervals and exit interviews with proxies or caregivers capture both real-time changes and retrospective insights. Cross-validation between surveys, proxies, and health records ensures accuracy and comprehensiveness. By employing these techniques, researchers can address the challenges of studying the last phase of life while producing meaningful, inclusive, and ethically sound findings.

3. IMPLICATIONS FOR DATA ANALYSIS IN THE LAST PHASE OF LIFE

This section explores the implications for data analysis of the last phase of life, focusing on managing missing data, integrating diverse data sources, handling longitudinal complexities, and balancing ethical considerations with methodological rigor.

3.1. HANDLING ITEM NON-RESPONSE AND MISSING DATA

The sensitivity of topics related to end-of-life preferences, illness and death may result in item non-response, where respondents skip or decline to answer certain questions. In addition, attrition is a common issue in studies on the last phase of life, driven by participants' health decline, withdrawal due to emotional or logistical challenges, and mortality (Oriani et al., 2020). These issues can cause significant missing data, particularly among individuals experiencing the most severe health declines, which can introduce bias into analyses if not addressed appropriately. For example, the "healthy survivor effect" can occur when healthier individuals are more likely to remain in studies over time, which can potentially skew the results (Murphy et al., 2011). Addressing these gaps requires tailored strategies, including multiple imputation, weighting methods, sensitivity analyses, and the use of auxiliary data sources such as healthcare records or proxy reports.

Multiple imputation is a statistical method that addresses missing data by estimating absent values based on patterns in the existing data (Wijesuriya et al., 2024). It creates multiple versions of the dataset, each with slightly different estimates to reflect uncertainty. Researchers then analyze these datasets together, combining the results to produce more reliable findings. This approach is particularly useful in longitudinal studies, where missing data are common due to attrition (Malter & Börsch-Supan, 2015). However, in aging and end-of-life research, missing data often reflect meaningful changes such as functional or cognitive decline. Imputing these values may mask important transitions or introduce bias. Researchers should carefully assess the nature of missingness and report imputation decisions transparently (Okpara et al., 2022).

Weighting methods allow researchers to adjust survey weights to account for non-response, giving greater weight to participants who remain in the study but are similar to those who dropped out (Biemer & Christ, 2008). By doing so, this approach helps correct for biases and ensures that individuals who are underrepresented, such as those with the most severe health conditions, are adequately reflected in the analysis. In longitudinal surveys, for example, weights are typically provided by the researchers or by the entity that collects and prepares the data to correct the sample for issues like attrition and non-response over time (Börsch-Supan et al., 2013; Sonnega et al., 2014; Steptoe et al., 2013). Weighting can improve representativeness in aging studies by correcting for non-response, but it may also overrepresent individuals in small or selective samples, such as those near the end of life. Researchers should apply weights cautiously, test robustness through sensitivity analyses, and clearly report limitations (Okpara et al., 2022).

Sensitivity analysis is also a method that researchers can use to test how different assumptions about missing data affect their results (Carreras et al., 2021; Preston et al., 2013). For example, they might compare results from a complete-case analysis (using only data from participants with no missing values) to results from datasets where missing values have been imputed. This comparison helps assess whether the findings remain consistent and reliable, ensuring the results are not overly influenced by how missing data was handled.

When **proxy respondents** are used in a study to provide information on behalf of participants who are unable to respond due to cognitive, physical impairments or due to mortality, their input helps maintain data continuity and capture valuable insights. For instance, in longitudinal studies, it is typically indicated when a proxy is involved in assisting the respondent, ensuring transparency and accuracy in documenting data collection methods. However, proxy data has limitations, particularly the risk of bias if the proxies' perspectives differ from the participants' actual experiences (McPherson & Addington-Hall, 2003). For instance, in longitudinal demographic and health surveys, the findings highlighted that proxies tend to over-report disabilities affecting communication or requiring assistance (e.g., hearing or dressing) and under-reported less visible disabilities (e.g., remembering or concentrating) (Elkasabi, 2021). To address this, researchers can implement several strategies: they can compare self-reported data with proxy responses when available to identify and quantify discrepancies; adjust analyses to account for systematic differences between proxies and participants; and, where possible, validate proxy-reported data with objective measures such as medical records.

Integrating diverse data sources in end-of-life research enriches the findings but also presents challenges. Combining surveys, healthcare records, administrative data, and interviews offers a comprehensive view but requires harmonizing formats and addressing biases (Harron, 2022). Strategies like linking datasets, cross-validating for accuracy, and using methods to account for group differences ensure data reliability and representativeness. Ethical and legal considerations, such as confidentiality and consent, are critical, and qualitative insights add depth, enhancing the understanding of care experiences. As highlighted in the FORS Guide on Data Linkage, combining data from multiple sources enhances dataset richness and improves data quality. However, it also presents challenges, including issues related to data access, legal compliance, privacy protection, and the technical complexities of ensuring accurate and secure data integration (Vaccaro & Swerts, 2022).

Finally, when analyzing **longitudinal data** on the last phase of life, researchers must account for the nuances of participants' life events (Hardy et al., 2009). Missing data often reflect meaningful aspects of end-of-life trajectories, such as health deterioration or transitions to care, rather than simple survey failures. Understanding the timing of missing data, such as gaps coinciding with a participant's death, is critical. Censoring techniques can help address this by incorporating partial trajectories, data collected up to the point of dropout or death, into the analysis (Turkson et al., 2021). These methods ensure that valuable information is not lost and that the findings remain accurate and reflective of the participants' experiences. Moreover, advanced statistical models are essential for handling these complexities. Survival analysis, such as Cox proportional hazards models, is useful for time-to-event data like time-to-death, accommodating incomplete data due to attrition (Sedgwick, 2013). For instance, in end-of-life research, a Cox model can examine how factors like age, socio-economic status, or medical interventions impact survival time, providing insights into relative risks while accounting for censored data. Mixed-effects models analyze repeated measures over time, addressing within-individual variations and irregular follow-ups (Wu, 2009). Joint models combine longitudinal health data with time-to-event outcomes, offering a comprehensive view of interrelated patterns (Ibrahim et al., 2010). Inverse probability weighting corrects for biases caused by selective dropout, particularly in vulnerable populations (Mansournia & Altman, 2016). By combining contextual understanding with advanced modeling approaches, researchers can better capture the progression of end-of-life experiences and produce robust, reliable insights.

3.2. THE SWISS CONTEXT: INSIGHTS FROM SHARE

In Switzerland, one of the most prominent and valuable sources of data for understanding the last phase of life is the Survey of Health, Ageing and Retirement in Europe (SHARE) (Börsch-Supan et al., 2013; SHARE-ERIC, 2024). SHARE is a longitudinal survey that collects data on individuals aged 50 and older across Europe, including Switzerland. With its extensive information on health, care needs, socio-economic status, and social networks, SHARE provides a unique opportunity to study end-of-life trajectories and experiences in a standardized and comparable way. SHARE approaches the challenge of capturing data on the last phase of life through its longitudinal design and specific tools such as end-of-life interviews. By following participants over multiple survey waves, researchers can observe changes in their health, care needs, and socio-economic circumstances as they move closer to the end of life. When participants die, a so-called end-of-life interview is conducted with family members or close contacts to gather retrospective information on the deceased’s final year. These interviews provide a detailed account of the participant’s health status, including any significant changes or terminal conditions leading up to their death. They also capture information on the type, frequency, and intensity of care received, whether provided by professional healthcare services, family members, or informal caregivers. Additionally, the interviews document the location of death, such as at home, in a hospital, or a care facility, offering insights into the circumstances surrounding the end of life. This comprehensive data helps to contextualize the participant’s final phase of life and assess the support and resources available during this critical period. These end-of-life interviews are critical for filling gaps caused by attrition due to mortality, providing valuable insights into the circumstances surrounding end-of-life experiences. However, while SHARE includes valuable end-of-life interviews, its two-year interval and focus on general aging means that it captures the broader trajectory towards death rather than the immediate terminal phase.

Since the launch of SHARE in 2004 (Wave 1) through to 2022 (Wave 9), a total of 468 end-of-life interviews have been collected in Switzerland. Overall, end-of-life interviews were successfully conducted for approximately 75% of deceased panel participants (Bergmann et al., 2019). Although the sample size is relatively small for detailed analysis, these interviews provide valuable insights into end-of-life trajectories and care for adults aged 50 and older in Switzerland. The sample encompasses a broad spectrum of death types, ranging from sudden death, e.g., accidents or stroke, to terminal illnesses such as cancer, organ failure including cardiovascular diseases, and prolonged frailty characterized by severe functional decline. However, the representativeness of these interviews needs consideration. According to the last SHARE release 9.0.0, end-of-life interviews were predominantly completed for older adults with close social networks, as 49% were conducted by their spouse or partner, who was in many cases also participating in the SHARE study. Additionally, 57% of the interviews were conducted for deceased men, suggesting a potential gender imbalance in the data. To address these limitations and enhance the robustness of the findings, researchers can build on SHARE’s insights by integrating complementary data sources and employing advanced analytical methods. This approach can provide a more comprehensive understanding of end-of-life experiences and inform policies and practices aimed at improving the quality of life for individuals and families navigating this critical phase of life.

In addition to SHARE, other Swiss studies have contributed to improving data collection at the end of life. For example, SWISS100, the first nationwide, population-based study on centenarians in Switzerland combines interviews with centenarians and their representatives across all language regions, using an interdisciplinary approach to assess psychological resilience, vulnerability, and living conditions through both self-reports and proxy respondents (Jopp, 2024).

4. IMPLICATIONS FOR SURVEY PRACTITIONERS

Recommendation 1 – Anticipate challenges in longitudinal research and plan accordingly

Understanding the last phase of life often requires following participants over several survey waves. Be aware that the time required to collect and analyze usable data may be longer than initially anticipated due to the complexity of capturing transitions over time, high attrition rates, and mortality.

Recommendation 2 – Address attrition proactively to ensure data quality

Implement strategies to minimize attrition, such as offering flexible participation options, maintaining regular contact with participants or their proxies, and simplifying survey processes.

Recommendation 3 – Design sensitive and inclusive recruitment strategies

Develop culturally sensitive approaches to recruitment and build trust with communities, caregivers, and healthcare institutions. Ensure that recruitment methods are inclusive, reaching diverse populations and those with limited mobility, cognitive impairments, or caregiving responsibilities.

Recommendation 4 – Adapt data collection methods to end-of-life trajectories

Tailor data collection methods to the unique characteristics of end-of-life trajectories, whether they involve sudden death, terminal illness, organ failure, or prolonged frailty. Mixed-methods approaches, combining quantitative surveys with qualitative methods such as semi-structured interviews and narrative storytelling can provide a more comprehensive understanding of diverse experiences. Use proxy interviews or linked data sources such as administrative data (e.g., insurance claims, hospital discharge records) or clinical health records (e.g., electronic patient files) to fill gaps left by participants who are unable to respond.

Recommendation 5 – Mitigate ethical and emotional challenges in end-of-life research

Ensure that all aspects of the research respect participants' dignity, autonomy, and well-being. Use dynamic consent models to allow participants to modify their involvement over time. Train researchers to navigate sensitive topics with compassion and professionalism. Provide emotional support for both participants and research staff, acknowledging the emotional toll of end-of-life studies.

Recommendation 6 – Maximize the utility of existing data sources

Where possible, leverage data from existing longitudinal surveys, such as SHARE, to complement new data collection efforts. Integrate diverse data sources, such as health records and administrative data, to enhance the robustness of findings. Ensure that data linkage complies with data protection regulations and ethical guidelines.

5. FURTHER READINGS

A good starting point for understanding the complexities of end-of-life care is Cohen and Deliens' (2012) comprehensive volume "*A Public Health Perspective on End of Life Care*" . This work offers a foundational overview of the societal, ethical, and healthcare challenges involved in end-of-life contexts. For methodological insights, Lunney et al. (2003) provide a widely-cited framework categorizing the trajectories of functional decline during the last phase of life, essential for tailoring survey designs. Oriani et al. (2020) discuss strategies to manage attrition and improve data quality in palliative care studies, while ethical challenges, including obtaining consent from cognitively impaired participants, are addressed by Evans et al. (2020) and Gilbert et al. (2017). Researchers interested in proxy interviews as a method to supplement or replace direct responses should consult McPherson and Addington-Hall (2003) and Neumann et al. (2000), who critically examine the potential for bias and strategies to mitigate it. For mixed-methods research, Walshe (2018) offers practical guidance on integrating quantitative and qualitative approaches in palliative care.

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