INPLASY

Communication about death and dying between parents and adult children: a Mixed Methods Systematic Review

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ADMINISTRATIVE INFORMATION

Review Stage at time of this submission - Formal screening of search results.

Conflicts of interest - None declared.

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Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 3 October 2024 and was last updated on 3 October 2024.

INTRODUCTION

*R*eview question / Objective Question: How do parents and adult children communicate about death and dying and what are the impacts of different communication behaviors?
Objectives:
- To describe communication about death and dying from the perspective of parents and adult children
- To identify barriers and facilitators in communication about death and dying between parents and adult children
- To identify strategies for enhancing communication about death and dying between parents and adult children
- To explore the consequences of different communication patterns regarding death and dying between parents and adult children.

Rationale 1. Expected Demographic Changes and Caregiving Dynamics

Due to declining birth rates and increasing life expectancy, the global population is ageing rapidly, which is the most important social, demographic, and medical problem worldwide(Rudnicka et al., 2020). By 2050, the global population aged 65 and over is expected to increase to 1.6 billion (World Social Report 2023: Leaving No One Behind in an Ageing World, n.d.). On one hand, adult children are becoming one of the primary sources of care for their aging parents (Scheinfeld & Lake, 2021; Seltzer & Bianchi, 2013). On the other hand, the possibility of parents facing the death of their adult children is also rising. During the end-of-life period, most people may be unable to make medical decisions independently (Silveira et al., 2010). Thus, both adult children and parents are potential caregivers and decision agents for each other, highlighting the importance of communication about death and end-of-life issues between parents and adult children.
2. Importance of Communication in End-of-Life Care

Given the current inadequacies in the quality of end-of-life care, communication about death and dying is one of the areas in healthcare most in need of improvement (Byock, 2012; Connors, 1995). Evidence suggests that family conversations about difficult health decisions are crucial (Keating et al., 2013; Scott & Quick, 2012). Some studies indicate that openly discussing death may lead to greater consistency with end-of-life care preferences (Gardner & Kramer, 2010), reduced stress (Keeley, 2017), improved relational well-being (Li & Loke, 2014), and better family adjustment after the loss of a loved one (Gardner & Kramer, 2010).

3. Intergenerational Education and Influence

It is noteworthy that such communication can also serve as intergenerational education and influence. Scholars in communication, social work, psychology, and health education have extensively explored the impact of parental influence on children's behavior. Specifically, researchers have examined the role of parental communication and behavior in various risky health behaviors, such as alcohol consumption (Miller-Day & Kam, 2010), drug use (Kelly et al., 2002), and sexual behavior (Fisher, 1988; Newcomer & Udry, 1985). Each study consistently demonstrates the ongoing role of parents in shaping their children's health behaviors. However, research on how communication between parents and adult children affects the latter, particularly regarding death and end-of-life issues, remains limited. While we understand the profound impact of parents on children's social, cognitive, and emotional development (Gittleman et al., 1998), the influence of parent-adult child communication about death and dying is relatively unexplored. These communication experiences may continue to have lasting effects, influencing adult children's future health communication behaviors and attitudes toward death.

Condition being studied The widespread anxiety about death arises from the conflict between the desire to survive and the inevitable understanding of death. According to the approach-avoidance model, individuals may have different cognitive and emotional responses (approach or avoidance) when facing a stressor like death (Roth & Cohen, 1986). On one hand, people seem to want to express their feelings during painful experiences to release stress and promote self-understanding (Stiles et al., 1992). Overall, the willingness and desire to openly discuss death appear to be increasing, possibly because the internet provides a platform for discussing these sensitive topics (Taubert et al., 2014). In a Canadian population survey, over 70% of people planned to discuss end-of-life issues with others (Polchenko, 2013). Another survey indicated that most people over the age of 55 wanted death and dying to be more openly discussed (Catt et al., 2005), and the desire to communicate often triggers communication (McCroskey, 1977).

On the other hand, some studies report that people avoid discussing topics related to death or end-of-life with family members (Abba et al., 2019; Scheinfeld & Lake, 2021) or caregivers (von Blanckenburg et al., 2022). Some researchers suggest that death anxiety or concern about death can trigger avoidance behaviors (Benites et al., 2022) and initially become an obstacle to communicating about death-related topics (Brown et al., 2014; Soleimani et al., 2017; von Blanckenburg et al., 2022). This may be because avoidance is a common response to fear (Brown et al., 2014). Additionally, families often adopt mutual protection strategies or avoid discussing fears and worries to protect each other (Bachner et al., 2009, 2011; Nagelschmidt et al., 2021).

Effective communication seems to be a key factor in coping with death (Carmel et al., 2020). Caughlin and Scott indicate that the quality of family communication about end-of-life issues is more important than the quantity (Scott & Caughlin, 2012, 2014). However, there is limited evidence on what makes end-of-life communication within families more effective or ineffective (Scott & Caughlin, 2015).

The relationship between open communication and well-being in previous studies remains controversial. Some research suggests that openly discussing death may be associated with greater consistency with end-of-life care preferences (Gardner & Kramer, 2010), stress relief (Keeley, 2017), better relational well-being (Li & Loke, 2014), and better family adjustment after the loss of a loved one (Gardner & Kramer, 2010). However, other studies indicate that open communication about conflictual topics may not be beneficial (Langer et al., 2009; Manne et al., 2010; Robbins et al., 2014), and may even be harmful (Ramos et al., 2020).

Furthermore, current research has less focus on intergenerational communication specifically between parents and adult children, with most studies concentrating on communication between patients or elderly individuals and their families. Given the current state of research, understanding the communication experiences between parents and adult children regarding death and end-of-life issues, as well as the facilitating and hindering factors, will help to comprehend the mechanisms and impacts behind their willingness and behaviors to communicate about this sensitive topic. Ultimately, this will provide tailored strategies and

recommendations for parents and adult children who face uncertainty and hesitation in discussing death and end-of-life issues.

METHODS

Search strategy 1. Databases or sources:
- Bibliographic databases: MEDLINE (PubMed), Embase (ELSEVIER), CENTRAL, CINAHL (EBSCO), PsycINFO (EBSCO), Web of Science, Scopus (ELSEVIER)
- Additional Searching: Google Scholar
- Trial registries: ClinicalTrial.gov
- Dissertations and theses: ProQuest
- Reference and Citation Searching (all identified reviews and included studies): Web of Science and/or Google Scholar and/or citationchaser(web tool)

2. Terms

The research topic comprises four main components: communication, death and dying, adult children, and parents. For each component, both controlled vocabulary (eg. MeSH terms, Emtree, etc.) and free-text terms are used. For example, in PubMed:

- Communication："Communication"[MeSH Terms] OR "Disclosure"[MeSH Terms] OR "Self Disclosure"[MeSH Terms] OR "communicat*"[Title/Abstract] OR "discuss*"[Title/Abstract] OR "talk*"[Title/Abstract] OR "express*"[Title/Abstract] OR "conversation*"[Title/Abstract] OR "disclos*"[Title/Abstract] OR "speak*"[Title/Abstract] OR "voice*"[Title/Abstract] OR "conceal*"[Title/Abstract] OR "holding back"[Title/Abstract] OR "silen*"[Title/Abstract] OR "avoid*"[Title/Abstract] OR "interact*"[Title/Abstract] OR "cope"[Title/Abstract] OR "coping"[Title/Abstract]

- Death & Dying："Death"[MeSH Terms] OR "Palliative Care"[MeSH Terms] OR "Terminal Care"[MeSH Terms] OR "Advance Care Planning"[MeSH Terms] OR "Decision Making"[MeSH Terms] OR "death*"[Title/Abstract] OR "die"[Title/Abstract] OR "dying"[Title/Abstract] OR "mortality"[Title/Abstract] OR "bereave*"[Title/Abstract] OR "loss"[Title/Abstract] OR "end of life"[Title/Abstract] OR "eol"[Title/Abstract] OR "palliative"[Title/Abstract] OR "hospice"[Title/Abstract] OR "advance care"[Title/Abstract] OR "advanced"[Title/Abstract] OR "terminal*"[Title/Abstract] OR "end stage"[Title/Abstract]

- Adult Children："Adult Children"[MeSH Terms] OR "adult child*"[Title/Abstract] OR "grown up child*"[Title/Abstract] OR "grown child*"[Title/Abstract] OR "mature child*"[Title/Abstract] OR "married child*"[Title/Abstract] OR "adult daughter*"[Title/Abstract] OR "grown up daughter*"[Title/Abstract] OR "grown daughter*"[Title/Abstract] OR "mature daughter*"[Title/Abstract] OR "married daughter*"[Title/Abstract] OR "adult son*"[Title/Abstract] OR "grown up son*"[Title/Abstract] OR "grown son*"[Title/Abstract] OR "mature son*"[Title/Abstract] OR "married son*"[Title/Abstract] OR "adult offspring"[Title/Abstract] OR "grown up offspring"[Title/Abstract] OR "grown offspring"[Title/Abstract] OR "mature offspring"[Title/Abstract] OR "married offspring"[Title/Abstract] OR "young adult*"[Title/Abstract] OR "middle aged adult*"[Title/Abstract]

- Parents："Parents"[MeSH Terms] OR "Parent-Child Relations"[MeSH Terms] OR "Aged"[MeSH Terms] OR "parent*"[Title/Abstract] OR "father*"[Title/Abstract] OR "dad"[Title/Abstract] OR "daddy"[Title/Abstract] OR "mother*"[Title/Abstract] OR "mom"[Title/Abstract] OR "mommy"[Title/Abstract]

This research does not confine the exploration to a specific timeframe, covering data from the inception of the databases up to the retrieval date. Considering the contextual nuances prevalent in discussions about death and dying, authors may opt for publication in their native language, hence, there are no language restrictions. Searches will be updated before submitting the article.

The search strategy was initially developed for the Medline (Pubmed) database and subsequently adapted for the other databases. The search strategies were developed in collaboration with a medical librarian with systematic review experience and an information specialist has been invited an information specialist to conduct a peer review assessment of the search strategies employed across all sources, under the PRESS guidelines.

Participant or population Inclusion criteria
1*. Parents who have/had at least one adult child.
2*. Adult children (The average age of the research population of adult children is 18 years or older.)
3. No criteria on language, sex and ethnicity
4. In case, studies are identified in which our population of interest is a subpopulation of the entire study population, studies will be considered eligible when 1) data can be subtracted for the population of interest, or 2) population of interest comprises ≥80% of the study population.
*The population studied included individuals meeting either Criterion 1 or Criterion 2, or the study population studied included two groups of individuals each meeting one of the two criteria. Specifically, the study population comprised either parents or adult children, or both.

Exclusion criteria

1. With cognitive impairment, depression or mental illness sufficient to interfere with daily communication and interaction.

Intervention Given that this review also focuses on exploring barriers, facilitators, and strategies for communication about death and dying between parents and their adult children, it is pertinent to incorporate intervention studies. Such studies typically involve communication intervention programs designed to evaluate the influence of these interventions on the quality of communication and their effects on both parents and adult children. They also examine the barriers and facilitators impacting this communication. The research will include any studies that involve interventions or strategies influencing communication behaviors between adult children and their parents.

Comparator In the inclusion of intervention studies, all comparators conducted among parents and adult children are deemed eligible. These comparisons may include but are not limited to, waitlist controls, non-exposed controls, or any other interventions aimed at enhancing the quality of communication on death and dying topics between parents and adult children, along with their outcomes.

Study designs to be included Inclusion criteria: 1. Qualitative studies; 2. Quantitative studies (such as cross-sectional, longitudinal, interventional studies, etc.); 3. Mixed-method studies. Exclusion criteria: 1. Case-series, case reports; 2. Non-empirical studies.

Eligibility criteria Inclusion criteria:
1. Phenomenon of Interest: The exploration of communication about death and dying encompasses a wide range of discussions, including direct conversations and reflections on death and dying in everyday contexts. It also involves communication triggered by aging, illness, or other conditions that lead to coping with death and dying scenarios.
2. Publication Type: Journal article, dissertation/thesis, clinical trial registers.

Information sources Extensive systematic searches will be conducted across the following sources:
1. Electronic databases;
2. Trials registers (in addition to reviewing trial registry information, project leaders will be contacted to obtain any missing project data);
3. Grey literature: dissertations/theses;

4. Additional searching: Google Scholar, reference and citation searching.

Main outcome(s) Current Status and Influencing Factors of Communication About Death and Dying Between Parents and Adult Children
1. Occurrence of Communication: Including the contexts in which parents and adult children engage in death-related communication, whether they have had such communication experiences, or the frequency of these discussions.
2. Willingness and Preferences for Communication: Preferences of parents and adult children regarding when and how they are willing to engage in death-related communication, including specific timing preferences (e.g., whether they prefer to communicate during deteriorating health conditions).
3. Depth and Content of Communication: Whether discussions related to death and dying involve specific end-of-life decisions, personal wishes, or advance care planning (ACP), or if they remain superficial.
4. Facilitators and Barriers: Analyzing the factors that facilitate or hinder communication between parents and adult children, such as cultural factors, family relationships, personal beliefs, etc.

Additional outcome(s) Consequences of Different Communication Patterns regarding death and dying Between Parents and Adult Children
1. Psychological and Emotional Wellbeing: Analyzing the psychological and emotional impact of different communication patterns on parents and adult children, such as feelings of relief, anxiety, depression, or stress resulting from communication.
2. Physical Wellbeing: Examining whether there is evidence that communication or avoidance of communication has direct or indirect effects on physical health, including long-term health outcomes.
3. Relationship Wellbeing: Assessing the impact of communication behaviors on the relationship between parents and children, whether communication improves or exacerbates conflicts within the family.
4. Adaptive responses: Investigating the impact of communication behaviors on bereavement adaptation, future death-related decisions or care planning.

Data management Records obtained from various sources will be imported into Endnote for deduplication and management.
The deduplicated records and full texts of studies included for full-text screening will be imported into Rayyan (a web-based tool) to assist the

research team in screening and evaluating relevant records.

Quality assessment / Risk of bias analysis The risk of bias will be assessed by two independent researchers. Potential disagreements will be resolved by a discussion between the two researchers. As different study designs may be included in this review, the risk of bias will be assessed using the assessment tool for mixed-method systematic review.

Strategy of data synthesis The strategy of data synthesis depends on the results of literature retrieval, including the types and quantity of literature. Generally, synthesis can be conducted through the following methods: Narrative summary, Qualitative Data Synthesis (QDS), Meta-analysis, or Mixed methods synthesis.

Subgroup analysis At this stage, it is unclear whether sufficient data will be available to conduct subgroup analyses. Should relevant data become available, subgroup analysis will be considered.

Sensitivity analysis Depends on the types of studies included and the heterogeneity of the data, which will inform the synthesis approach.At this stage, it is unclear whether sufficient data will be available to conduct sensitivity analyses.

Language restriction No language restrictions.

Country(ies) involved Netherlands.

Keywords Death and dying, Communication, Parent-Adult Child.

Dissemination plans 1. The results of this systematic review will be presented and discussed at relevant conferences.
2. The systematic review will be part of the first author's doctoral thesis.
3. After completing of the review, we plan to submit a manuscript to an appropriate international journal for publication.

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