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Information and death: towards a conceptual framework for studying information as it relates to dying, death, mourning and digital afterlife

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Abstract

Introduction. This paper presents a work in progress to develop a conceptual framework for studying information as it relates to the phenomenon of death, including dying, mourning, legacy, and digital afterlife.

Method and Analysis. A framework is derived using the results of a previously published systematic review of literature at the intersection of death and information management (Dinneen et al., 2024). Specifically, we conceptualised the factors identified in the review into the *information and death framework*.

Results. We present and discuss the first component of the framework: six key perspectives that represent different vantage points from which to view the problem, each with their own focus and concerns.

Conclusion. Though still in development, the framework looks promising for supporting empirical and theoretical research on pressing and global information-related issues surrounding the experience of loss, death, dying and digital afterlife.

Introduction and background

This paper presents a work in progress on a conceptual framework of Information and Death that can support empirical and theoretical research on information-related issues surrounding the experience of loss, death, dying and digital afterlife. While much scholarship in information behavior focuses on information as it relates to life and the information needs of the living (for an overview of key research directions, see Given et al., 2023; Huvila & Gorichanaz, 2024), far fewer center on the needs of the dying and dead (Dinneen et al., 2024; Doyle & Brubaker, 2023; Fourie 2024). However, in an ageing information society and the increasing complexity of our digital world, death as an information phenomenon is becoming a growing area of research (Basset, 2022; Holt et al., 2024) and needs urgent attention.

People's information collections and digital footprints are constantly growing, often beyond their control, but not many people explicitly plan for what happens with/to their information at the end of life. Information collections are often excluded from legacy and wills, but nevertheless, information outlives its owner, creating a number of practical, ethical, and legal challenges. These challenges and possible ways to address them have significant implications for the living, the bereaved, the dying and the dead (Massimi et al., 2011), affecting the dignity of the dead and the well-being of the living (Bollmer, 2013; Harbinja, 2017; Zaleppa & Dudley, 2020).

Intersections of death and information have a broader societal impact and are of interest to information industries (Öhman & Floridi, 2017). Personal information of the deceased – photographs, diaries, emails, social media posts and various memorabilia – are valuable resources used by the digital funeral and digital afterlife industries (Morse, 2023; Nansen et al., 2023). The promise of digital immortality and the resurrection of lost loved ones are powerful motivators to engage with these industries and the increasingly AI-generated surrogates they offer to recreate. However, researchers urge the industry to apply generative AI in their services responsibly (Hollanek & Nowaczyk-Basińska, 2024; Öhman & Floridi, 2018; Savin-Baden, 2021) as our knowledge about the impact of AI-mediated grief on mental and physical health is still evolving and legal responses to the fast-changing technological landscape are slow (Edwards and Harbinja, 2020; Lindemann, 2022; Sofka et al., 2012).

There is no simple solution to the management of information after death, ethically, legally, culturally, or technically, and any progress towards improved policy, best practices, information services, and technology, whether from research or otherwise, must reckon with the breadth and unique considerations of the problem space.

Following up on a recent literature review where we summarised relevant findings and identified numerous gaps around information and death (Dinneen et al., 2024), here we begin to develop a conceptual framework to inform and guide information science research that could address those gaps. In particular, to create a starting point for a broad and multifaceted research programme, our construction of the conceptual framework is guided by the following questions:

- What key perspectives – groups of concepts, factors, issues, and questions from information science and other fields – are pertinent to understanding information as it intersects with death?
- How might technical solutions, information services and policy, and future research benefit from the conceptual framework?

A goal of the conceptual framework is to guide research and information policy and services, for example, by reducing the risk of fragmentation and oversight of interconnected elements in this highly intertwined, multidisciplinary topic. In the following sections, we describe the first step in the development of the framework and its possible use.

Methodology

Our understanding of what a conceptual framework is and how to develop it follows Ravitch & Riggan's (2017:10) definition, which focuses on key factors or constructs to be studied and the presumed relationships among them. While there is no single definition and way to develop conceptual frameworks (Van der Waldt, 2020:3), the process of identifying and justifying relationships and factors that will form a conceptual framework can be informed by previous research and existing theories in multiple ways (Ravitch & Riggan, 2017). Conceptual frameworks can have multiple and overlapping purposes, such as to organise and map ideas, to clarify a problem space, to focus research, to aid interpretation, to identify relevant theory, or to argue for the importance of the problem (Van der Waldt, 2020).

Van der Waldt (2020:5) prescribes steps that need to precede the generation of the conceptual framework, and they include isolating the key concepts and/or constructs of the chosen topic and then conducting a literature review to identify related concepts and variables. We completed those steps in a comprehensive literature review (Dinneen et al., 2024) with the purpose to '*summarize the landscape of death-related information research, outline remaining challenges for individuals, families, institutions, and society, and identify promising directions for future information science research*'. Here we present work in progress on the next step Van der Waldt suggests (2020:6): generating the conceptual framework. Instead of offering a finalised framework and full visual representation, we focus on describing the framework's purpose and initial perspectives that form its building blocks.

The information and death framework: perspectives

Below we describe six key perspectives – different vantage points from which to view the problem, each with their own focus and concerns – and list factors and aspects (which, at this point, are indicative rather than exhaustive) that should be taken into account when exploring death-related issues from a particular perspective. It is worth noting that ethical aspects are not separated as a perspective but taken into account within each perspective.

PERSON/USER-CENTRIC PERSPECTIVE

The focus is on the actors: The Living, The Bereaved, The Dead, The Interested (society, industry), The Agents/Mediators (AI-generated surrogates, deadbots), and The Accidental (those who encounter information about the dead without choice).

- **Information behaviour:** How applicable is what we know about cognitive and affective aspects of information behavior, information experience and personal information management in death-related contexts and with respect to different actors?
- **Culture and community:** How does belonging to a culture or a community influence death information practices and attitudes towards issues such as data ownership and privacy?
- **Reminiscence:** How to use insights from the psychology of reminiscence and legacy to support the information needs and practices of different actors?
- **Self-representation:** What differences exist between a self-directed form of self-representation and a portrayal through accidentally amassed information collections? How do those differences affect the experience of authenticity for different actors?
- **Autonomy:** How does information support or hinder the autonomy and choice of different actors whether to create/ interact with digital surrogates of the dead?

- **Well-being:** What elements of digital surrogates have a positive or negative impact on well-being during mourning? What protective mechanisms should be put in place for minors interacting with deadbots?
- **Dignity:** How can information protect or jeopardise the dignity of the dead?

INFORMATION/OBJECT-CENTRIC PERSPECTIVE

The focus is on the characteristics of digital possessions and their management, during life and post-mortem, including after inheritance.

- **Legacy creation:** What does the process of creating and managing legacy collections entail?
- **Digital remains:** What elements of information collections persist online as digital remains and digital footprint? Which information actions enable it the most, and which disrupt it?
- **Sensemaking:** What contextual information needs to be recorded to allow making sense of the content and minimising misinterpretation?
- **Deletion:** How does the action of deleting relate to the notion of forgetting and a second loss?
- **Repurposing:** What type of information enables the training of AI for digital resurrection purposes?
- **Ownership:** What information phenomena occur when collections change owners and continue to grow?
- **Inheritance:** How are digital information assets characterised in digital property law?

EVENT-CENTRIC PERSPECTIVE

The focus is on events that trigger a change in information management perceptions, attitudes, or practices.

- **Anticipation:** How death as a sudden experience as opposed to life attitude (in preparation for death...) changes information attitudes and practices?
- **Context of death:** What is the relation between the nature of death experience (tragic vs 'normal') and information?
- **Life transitions:** Which life transitions prompt the preparation of legacy collection?
- **Ageing and illness:** What is the impact of aging and illness on information practices?
- **Mourning:** Which grief and mourning practices use the personal information of the deceased, and in what ways (e.g., online memorials)?
- **Legal triggers:** How do legally bounding practices (such as making a will or inheritance decisions) affect further information practices of different actors?

TECHNOLOGY/PRODUCT/SERVICE-CENTRIC PERSPECTIVE

The focus is on services and products that use personal information to support or promote digital afterlife, digital immortality, and resurrection, including training AI.

- **Augmentation through technology:** What are the information-related features of thanatosensitive technologies and technology-augmented funeral and mourning practices?

<ul style="list-style-type: none"> • Design: What are current and ongoing challenges in designing and training of deadbots and thanabots? • Features and functions: What features and functions of general information tools (not specifically thanato-technologies) can prompt changes in information practices and death thinking? Should this be a must-have or optional feature? • Sustainability: How to assess the continuity and reliability of data afterlife services? • Ethical consent: How do recreation services ensure informed consent and ethical use of personal data?
<p>POLICY PERSPECTIVE</p> <p><i>The focus is on information policies and other related policies that affect postmortem data use and management.</i></p> <ul style="list-style-type: none"> • Privacy: Which death-related aspects appear in policies regulating privacy issues? What other aspects of information policies affect death matters? • Sovereignty: How is death approached in data ownership and sovereignty policies? • Rights: How does the ‘right to be forgotten’ policy affect death-related information practices? • Global perspectives: What conflicts or compatibilities exist in addressing information aspects of death matters in policies at organisational, national, and global levels?
<p>LIBRARY AND INFORMATION SCIENCE (LIS) PROFESSIONAL PERSPECTIVE</p> <p><i>The focus is on the impact and values the LIS profession brings to studying information matters in society.</i></p> <ul style="list-style-type: none"> • Values: Which LIS ethical values, codices, and manifestos appear relevant for death-related information practices and policies and what makes them relevant? • Inclusion: How can LIS's understanding of diversity and inclusion guide the development of death-related services and technologies? • Advocacy: How is the LIS profession raising awareness, advocating, and educating about death matters? • Collaboration: What collaborations on death-relevant issues exist between LIS and other professions, and which are missing? How do LIS professional values correlate to ethics and values of other professions relevant to death? • Proactive promotion: How do information institutions promote death information literacy in their services, resources, and spaces?

Table 1. Perspectives in information and death framework.

By selecting and outlining six distinct perspectives, this framework offers a multi-layered, focused approach to addressing a complex topic. The framework considers the actors involved (person/user), the digital assets themselves (information/object), the moments that cause change (event), the tools used (technology), the rules that govern them (policy), and the professional values and principles (LIS). It acknowledges that managing digital legacy is not a static process but rather highlights specific triggering events such as a death, a service update, or a personal decision that prompt changes in perception, attitude, or practice. The inclusion of the LIS-professional perspective brings central LIS values such as access, preservation, ethical use, and societal impact, to the forefront.

Conclusion

This paper presented the initial directions in the development of the conceptual framework of Information and Death, particularly six key perspectives useful for such a framework. We conclude by reflecting on its potential purposes:

1. To identify topics and concepts relevant to studying death and information and connections between them.

As such, the framework helps delineate what is ‘*within topic*’ and is especially useful considering the multi-disciplinary research approaches. It can guide future research, and researchers can use it for overview and inspiration (e.g., to decide which topic to focus on in their research and how their chosen topic connects to other topics and aspects). Future work could collaborate with experts from different areas to see what perspectives might be missing or seen in a different light.

2. To argue for the development/prioritisation of particular concepts

The framework highlights areas and their intersections which can be used in future work to identify and/or prioritise particular concepts and topics (for example, multi-generational information, changing values and ethics over time, cultural differences, sustainability, etc.). Future work could explore the concepts in depth and as they manifest in users’ / institutions’ death-related challenges.

3. To motivate/guide LIS researchers and distinguish the LIS approach from other fields

For example, to clarify LIS values in this problem space and how they can be applied (e.g., code of ethics of LIS, CS, HCI and other professional bodies and death-industry approaches). The perspectives identified in the framework can inform policy creation and help unify language among researchers. Future work could analyse existing studies of death to see if and how they had embodied the identified values.

While these purposes prioritise research, they can equally guide death services and policies.

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