How social media data are used to research experiences of mourning: A scoping review

A thesis submitted by

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Thesis Abstract

Introduction: Increasingly, people are using social media (SM) to express grief, and researchers are using these data to investigate the phenomenon of mourning. As this research progresses, it is important to understand how studies are being conducted and how authors are approaching ethical challenges related to SM data. The aim of this scoping review was to explore the concept of using data from social media in research about experiences of mourning.

Methods: Due to the broad nature of the review topic and the novel use of SM data, a scoping review methodology was considered appropriate. The JBI Scoping Review methodology guided this review. Eligibility criteria were determined using the PCC framework, and relevant key words and phrases derived from these criteria were used to search eight databases in September 2021 (CINAHL, Embase, LILACS, OpenGrey, ProQuest, PsycINFO, PubMed and Scopus). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines were used to report results.

Results: Database searches resulted in 3418 records, of which, 89 met eligibility criteria. Four categories of grief and mourning were identified. Most records were qualitative in nature and used natural data. Only 20% of records reported ethics approval by an Institutional Review Board, with several including measures to protect participants, for example, using pseudonyms.

Conclusion: The unique review included in this thesis mapped the diverse range of mourning-related topics that have been investigated using SM data and highlighted the variability in approaches to data analysis. Ethical concerns relating to SM data collection are identified and discussed. This is an emerging and rapidly changing field of research that offers new opportunities and challenges for exploring the phenomenon of mourning.

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

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<div align="right">Julia Muller Spiti</div>

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For my supervisors Janet, Ellie and Paul, I have so much gratitude. Their patience and care toward me made all the difference. They have all brought a lot to this project. Their insight and experience were much appreciated, and I could not have finished it if not for them.

Chapter 1: Introduction

Background

Social media (SM) platforms are used worldwide by people from many different walks of life and interests, and for many different purposes (Kemp 2022). On these platforms, SM users can connect and share experiences using various forms of expression, including written text, videos and images (Andalibi 2017; Silvén Hagström 2017). The ease of access and culture of disinhibition associated with SM platforms contribute to the production of large volumes of raw material that can be used as data for research (Hollenbaugh & Everett 2013; Lapidot-Lefler & Barak 2015; Suler 2004).

It is no surprise that data from SM have been used in research over the last 20 years (Roberts & Vidal 2000; Stone & Pennebaker 2002). A variety of social phenomena have been investigated using data from SM, by many different disciplines, such as: living with an eating disorder (Pater et al. 2016), the shift from mental health discourse to suicidal ideation (De Choudhury et al. 2016), experiencing a miscarriage (Cesare et al. 2020), and mourning (Babis 2020).

The expression of peoples' grief, including posts, pictures, videos, 'likes' and emojis, have been collected and analysed by researchers using a plethora of approaches to data analysis (Sloan & Quan-Haase 2017). Of interest to this project is the way in which SM data have been used to investigate mourning. Mourning is the visible manifestation of the emotion of grief (Lofland 1985; Walter 2015a), and with so many people resorting to SM platforms to express their grief and connect with other people that are mourning, researchers have been able to capture their expressions and interactions as natural data (Carroll & Landry 2010; Scourfield et al. 2019).

One significant criticism of research conducted with SM data is that it has been conducted without informed consent or even the knowledge of users (Ayers et al. 2018; Hunter et al. 2018; Stommel & Rijk 2021; Taylor & Pagliari 2018b; Woodfield 2017). Questions that arise include: 'Who owns data from SM – do they belong in the private or public domain?' and 'Are SM users aware their posts may

be used in research, and would they consent if they were?'. These pertinent questions have been raised by the research community (Moreno et al. 2013; Myles, Cherba & Millerand 2019; Townsend & Wallace 2016), as well as by SM users (Ayers et al. 2018). Questions such as these are of particular relevance when data are used to investigate vulnerable populations, such as the bereaved, or are related to practices that have been culturally considered intimate, such as mourning a loss (Walter et al. 2011).

While SM research about the experience of mourning has aided in understanding the expression of grief in this post-modern era, particularly in generations Y and Z, who comprise 70% of SM users (Kemp 2022), no study has been conducted to provide a comprehensive overview of the topics, study designs, type of data and ethical considerations involved in SM research about mourning. Given the emerging nature and broadness of this area of research, a scoping review methodology was deemed suitable. As such, the overarching aim of this scoping review was to explore how SM data are being used to research the experience of mourning.

Research Context

The internet has opened new avenues for populations to mourn, with an increasing number of people not only turning to SM to express their grief, but also potentially disclosing more information than they would in face-to-face interactions. Researchers have identified the opportunity to capture and understand the experience of mourning in a different way by using SM data. However, as the research output about mourning online increases, it is necessary to understand how these studies are being conducted for two main reasons: to inform future research, particularly in vulnerable populations, and to report and discuss the ethical challenges inherent to the use of natural data from SM platforms.

Statement of the Problem

As this is an emerging field of research, with studies being undertaken across diverse disciplines, using a variety of research methodologies and approaches for data analysis, the primary question for this review was 'How are social media data being used to research the experience of mourning?'. This

question was intentionally broad, to capture the extent and breadth of literature relating to the central topic.

Four specific sub questions were also considered and include the following:

a) 'Which topics related to mourning are being studied using SM data?'

b) 'What study designs have been employed in the analysis of SM data about the experience of mourning?'

c) 'What type of data (natural or generated) have been predominantly used in SM research about the experience of mourning?', and

d) 'How are ethical aspects considered in the published research?'

These were constructed to provide focus for the exploration of the included studies and to provide guidance for data extraction and analysis.

Thesis by Publication

This thesis contains a manuscript, as required by the University of Adelaide. The scoping review report is included in the thesis as Chapter 4 and has been peer-reviewed and published by the journal PLOS ONE.

The thesis is structured with the following sections: introduction, literature review, methodology, published report, and discussion. Each section is included as a chapter, and are briefly described below.

Chapter 1: Introduction

Chapter 1 introduces the subject matter and the structure of a thesis by publication for a Master of Clinical Science at the University of Adelaide.

Chapter 2: Literature Review

Chapter 2 outlines a review of academic literature related to the use of social media data for research, specifically in research about mourning. It highlights the variability of approaches for data analysis, topics investigated, and ethical conduct in this unique area of research.

Chapter 3: Methodology

Chapter 3 provides a justification for the selection of a scoping review methodology to underpin this research, and describes all steps of the review, from search strategy to results and discussion.

Chapter 4: Published report

The article: 'How social media data are being used to research the experience of mourning: a scoping review', is included in Chapter 4. This article contains an Abstract, Introduction, Methodology and Methods, Results, Discussion and References.

Chapter 5: Discussion

Chapter 5 answers the four sub-questions and discusses the findings from the review in the broader context of current academic literature. It draws from the results section of the review and provides a critical synthesis of how social media data are being used to research the experience of mourning.

Chapter 2: Literature Review

Social Media and Research

Social media (SM) are "web based services that allow individuals, communities, and organizations to collaborate, connect, interact, and build community by enabling them to create, co-create, modify, share, and engage with user-generated content that is easily accessible" (McCay-Peet & Quan-Haase 2017, p.17). In 1997 the first social network site was launched; SixDegrees.com allowed users to create profiles and connect with other users (Boyd & Ellison 2007). At that point in time, online social networking, under the bigger umbrella of SM, was a novelty available to those who had access to the internet. The number of people with access to the internet grew quickly, from a global total of 44 million in 1995, to a total of 412 million in the year 2000 (OurWorldInData). As of January 2022, 4.95 billion of the 7.91 billion people in the world had internet access, and 4.62 billion were active SM users – with 45% of them aged between 10 and 27 years (Kemp 2022). The acceptance and reliance on SM platforms for sharing data has grown significantly since the late 1990s, and has led to the establishment of hundreds of different SM platforms catering to different demographics, interests, and forms of expression (Kemp 2022).

Unsurprisingly, the dynamic nature of large volumes of user-generated content (UGC), and high level of self-disclosure available on SM platforms has drawn the attention of researchers. In 2004, Donath and Boyd pioneered SM research, discussing public displays of connection and how the online environment is used as a space for self-representation. Clarke and Van Amerom (2008) were among the first authors to utilize data from SM to gain an understanding of social phenomena. Subsequently, several disciplines have used data from SM to gain insight into human behaviour and understand social trends, including marketing (McCarthy et al. 2014), journalism (Lewis & Molyneux 2018) and health sciences (Greaves et al. 2014). The access that researchers have to large amounts of data, paired with the level of disclosure that is demonstrated on SM platforms, offers the opportunity to investigate

social phenomena in a way that has not previously been possible with traditional methods of research (Lafferty & Manca 2015).

Researching grief and mourning with social media data

Online mourning is a growing area of research where data from SM is used to gain further understanding of the human experience of grief (Akhther & Tetteh 2021; Brubaker & Hayes 2011; Carroll & Landry 2010; Cassilo & Sanderson 2019; DeGroot, 2012, 2014; Frizzo et al. 2017; Klastrup 2015; Patton et al. 2018; Varga & Paulus 2014). The terms 'grief' and 'mourning' are frequently used interchangeably in society and in research literature (Giaxoglou 2014; Lofland 1985). Throughout this project grief is considered the intense emotion that follows a loss (Lofland 1985; Walter 2015b, 2015c). Mourning, on the other hand, is the visible behavior enacted by the griever – what is done in response to what is felt. Mourning demands an action from the griever (Lofland 1985; Walter 2015c). In the case of social media, what is seen through posts, comments, images, and videos is grief being expressed: mourning. Therefore, in this project, all forms of expressions of grief online will be considered mourning.

The common occurrence of loss and death means that grief is an emotion frequently experienced in life. Grief can be felt after any loss, either physical (e.g. death) or psychological (e.g. expectations, plans, perception of self) (DeGroot & Vik 2017). For example, an unexpected diagnosis (Chan et al. 2013; Gill & Lowes 2014), or a divorce (Lin & Brown 2020) can cause deep grief that is not necessarily associated with death.

There is significant heterogeneity in research approaches used to explore mourning in SM. For example, Carmack and Degroot (2013) employed an instrumental case study approach with data from a blog to describe parental grief; Brubaker et al. (2012) used automated coding when examining bereaved individuals' distressed messages on SM; Moore et al. (2019) employed grounded theory to explore how people grieve on SM.

There are also differences in the type of data collected. Two types of data are available in SM: natural data and generated data (Moreno et al. 2013; Potter 2002; Zhou 2021). The main difference between these two forms of data is whether the researcher participated in the generation of the data. In natural data, the researcher has no influence in the generation of data (Golato 2017; Kiyimba, Lester & O'Reilly 2019). The researcher can watch interactions but is not involved in, and cannot change, the interactions themselves. Whereas in generated data, the researcher has, in some manner, participated in the generation of the data. This could be represented by the researcher posing an anonymous question in a SM platform, participating in a discussion thread, or asking participants to create content (Moreno et al. 2013; Zhou 2021).

Both types of data present advantages and risks. In natural data the participant cannot predict or anticipate the expectation of the researcher (Golato 2017). By excluding the influence of the researcher, the use of natural data can offer an *emic* perspective, which is person-centred and context rich (Golato 2017). This can enable the researcher to see a situation from the users' perspective. An example of this is the exploration of a mother's grief via the analysis of publicly available blog posts published by DeGroot and Carmack (2013).

Generated data allows for encouraged interaction between individuals who share a common experience through the involvement of the researcher (Moreno et al. 2013). These data were used by Wittenberg-Lyles et al. (2015), who created a SM group and invited people that had a loved one being cared for in a hospice facility to connect. Later, they analysed the posts and published their findings.

Whilst there are benefits to the use of SM for exploring social phenomena, the possibility of harm to participants needs to be considered when using both types of data. With generated data, harm could result from the involvement of the researcher and the prompting of questions that cause participants distress. The use of both generated data and natural data presents the possibility of participants being reidentified via their posts, especially when written text is published *verbatim* (Franzke et al. 2020).

Ethical considerations in social media research

The ethical conduct of SM research has been increasingly considered by researchers (Carmack & Degroot 2013; Franzke et al. 2020; Gerrard 2020). During the preliminary scoping of literature to inform this project, it was identified that several researchers did not consider the possibility of harm to participants when using their data in published research. For example, when researching online memorials, De Vries and Rutherford (2004) published direct quotes from people posting on SM to illustrate their themes. While this is common practice in qualitative research, in traditional research only the researcher has access to the raw data, and even when selected quotes are published *verbatim* the participant cannot be identified from the data. In SM research, raw data are publicly available, and therefore there is the danger that users' may be re-identified from their posts, and any other additional identifying information available on SM platforms (Ohm 2009). This is a complex issue in SM research because SM users, mostly unaware that their data have been used in research, can become the targets of attention (beyond what is expected from posting on SM) because of what they posted. Of course, this is an inherent risk of any form of expression on a public platform, however, there is a potential for compounded risk to SM users if their raw data are published in research, and a duty of care to be considered by researchers (Stommel & Rijk 2021).

As this area of research has evolved, so too have researchers' awareness of the ethical issues related to the use of data from SM. Some published studies in the area of online mourning justified the use of SM data by saying that as the data are publicly available, the users cannot have any expectation of privacy, and the use of said data in research is therefore acceptable (Croson & Keim-Malpass 2016; DeGroot & Carmack 2013; Döveling 2015; Irwin 2015). On the other hand, some authors argue that even though the data are available on public platforms, the SM users did not intend for the data to be used in research, which makes said data private (Eriksson Krutrök 2021; Kasket 2012; Vitak, Shilton & Ashktorab 2016; Vitak et al. 2017).

In response to the growing body of research using data from the internet (secondary data), as well as concerns from the research community regarding ethical conduct in this novel area of research, the

Association of Internet Researchers (AoIR) was created, and published, in 2002, the first set of recommendations for ethical decision making in internet research (Ess 2002). In 2012, an updated version of the guidelines was published and it was recommended that researchers consider the risk of harm to participants when conducting research using online data (Markham & Buchanan 2012).

The focus on the ethical use of secondary data in research was also reflected in the Australian National statement on ethical conduct in human research, published in 2018, where it is stated that consent and respect for privacy should be considered in research using secondary data, specifying that even though consent may be impracticable in this context, the risk associated with the use and publication of secondary data must be considered by researchers (NHMRC 2018).

These complex aspects of ethical conduct in research have been addressed by researchers in many ways (Townsend & Wallace 2016). Given the diversity encountered in research about the experience of mourning using data from SM, not only in approaches to ethical conduct, but also to data analysis, it is important to map how research is being conducted in this area. This will inform future research and provide clarity to the research community. Because this is a new area of research and there is great variability in conduct of research, a scoping review methodology has been adopted to guide this review.

Chapter 3: Methodology

Scoping reviews are an increasingly popular approach to reviewing the literature to comprehensively summarise and synthesise knowledge (Arksey & O'Malley 2005; Peters et al. 2020; Tricco et al. 2016). Scoping reviews address broad research questions, are exploratory and descriptive in nature (Peters et al. 2020) and are usually conducted to explore the breadth and depth of the literature on a particular topic, to 'map and summarise the evidence, and inform future research' (Aromataris & Munn 2020, p.409).

Scoping reviews are indicated for a variety of reasons, for example, as a precursor to a systematic review; to identify the types of available evidence on how research is conducted in a given field; to identify and analyse knowledge gaps; or to clarify key concepts in the literature (Munn et al. 2018). Whilst scoping reviews are successfully used to explore established fields of research, this type of review is particularly useful in emerging areas of research where there is variability in methodologies and approaches to data collection and analysis, poor indexing in databases, and a distribution of research across academic disciplines (Colquhoun et al. 2014; Taylor & Pagliari 2018a).

As with any emerging methodology, there have been challenges related to variability in terminology, definition, methodological conduct, and reporting of scoping reviews over the last 15 years. Arksey and O'Malley (2005) proposed a seminal methodological framework for what they called "scoping studies" and described five stages to conducting a rigorous review. These stages include: 1) identifying the research questions; 2) identifying relevant studies; 3) study selection; 4) charting the data, and 5) collating, summarising, and reporting the results.

The initial framework published by Arksey and O'Malley was further elaborated and advanced by several authors (Colquhoun et al. 2014; Daudt, van Mossel & Scott 2013; Levac, Colquhoun & O'Brien 2010; Lockwood, dos Santos & Pap 2019; Peters et al. 2015; Pham et al. 2014; Pollock et al. 2021). In 2014 the Scoping Review Methodology Group was created by the JBI and Joanna Briggs Collaboration (JBC), and following extensive revision of the literature, discussions, workshops, and consultation with

methodology experts, this group published detailed guidance for authors of scoping reviews to address the 'need for scoping reviews to be rigorously conducted, transparent and trustworthy' (Peters et al. 2015, p.2120). The updated JBI manual provides detailed guidance on the systematic conduct of scoping reviews (Aromataris & Munn 2020).

In 2016, Tricco et al. conducted a scoping review on the conduct of scoping reviews and found that several terms were being used to describe scoping reviews, such as scoping studies, systematic scoping reviews and scoping exercises (Tricco et al. 2016). They also found significant variability in methodological steps and the absence of a reporting guideline, highlighting the need for a standardised approach to reporting scoping reviews. In 2018, the same group of researchers published the PRISMA extension for scoping reviews (PRISMA-ScR) checklist (Tricco et al. 2018). These reporting guidelines have been used and rigorously followed in this review; the completed checklist is available in Appendix A. The methods used in this review are detailed below.

Methods

Following the methodological recommendations from JBI and the PRISMA-ScR guidelines for reporting, an *a priori* review protocol was developed and outlined eligibility criteria, search strategy, study selection and data extraction for this review. Conventionally, review protocols are registered with PROSPERO, however, scoping reviews are not eligible for registration on this platform, and the alternative was to register the final version of the protocol with Open Science Framework (https://osf.io/a2udy/). The protocol is available in Appendix B.

Eligibility criteria

Eligibility criteria for this review are described using the Participants, Concept and Context (PCC) framework (Aromataris & Munn 2020). These were guided by the preliminary scoping of literature conducted to inform this review, where an array of different SM platforms, study designs, and forms of expression of grief online were identified. The intention of this PCC framework was to capture the diversity represented in this area of research.

Participants

Participants included people that had expressed grief on SM. There were no restrictions based on age or other demographic aspects. Even though several authors of included records have reported demographic information (Blando, Graves-Ferrick & Goecke 2004; Liu et al. 2019; Nager & de Vries 2004; Peruzzo et al. 2007; Schotanus-Dijkstra et al. 2014), given the nature of SM, and the barriers to confirm such information, these details were not considered in the review.

Concept

This review considered records that report primary research projects that analysed SM data to explore the experience of mourning. Records that report the use of SM to recruit participants but did not collect data from SM were not eligible for inclusion. In the preliminary scoping of literature an array of different forms of expression of grief were identified, therefore all forms of online mourning were considered, including written, audio-visual, and photographic expression.

Context

In the preliminary scoping of literature, it was identified that research using data from SM to explore the experience of mourning was not limited to a specific discipline but was distributed across many disciplines. As a result, this review considered records from any academic discipline where data were collected from SM regardless of geographical location or type of SM platform.

Types of sources

Records of published and unpublished primary research studies, in either English or Portuguese, were eligible for inclusion in this review. There were no limitations relating to study design or approach to data analysis. There were no limitations on year of publication as the analysis of data from SM for research purposes is a relatively recent phenomenon and is therefore chronologically self-limited.

Search strategy and information sources

An initial limited search of MEDLINE and CINAHL was undertaken to identify records on the topic. The text words contained in the titles and abstracts of relevant records, and the index terms used to

describe the records, were used to develop a full search strategy for CINAHL (see Appendix C). The search strategy, including all identified keywords and index terms, was adapted for each included information source. This process was guided by the assistance of an academic librarian. The reference lists of all records retrieved for full text review were screened for additional papers. The search was concluded in September 2021. The databases that were searched included CINAHL (EBSCO), Embase (Elsevier), LILACS (BIREME), OpenGrey (INIST-CNRS), ProQuest Dissertations and Theses Global (ProQuest), PsycINFO (APA), PubMed (NCBI), and Scopus (Elsevier).

Selection of sources of evidence

All identified citations were collated and uploaded into the reference management system EndNote (Clarivate Analytics, PA, USA - Version X9) and duplicates were removed. In preparation for title and abstract screening the reviewers met several times to discuss nuanced elements of the inclusion criteria, considering this is an emerging area of research, and to pilot the screening. This was an iterative process that provided clarity for the three reviewers (JMS, JK, PM) prior to the lead reviewer (JMS) proceeding with the title and abstract screening. The main reviewer screened titles and abstracts. When the main reviewer was unsure of including or excluding records based of title and abstract, another reviewer (JK or PM) would be involved, and a consensus reached.

The full text versions of selected records were screened independently by two reviewers (JMS and JK or PM). Reasons for exclusion of full text records were recorded and are presented in the PRISMA flow chart (Figure 1).

The decision to include records in Portuguese was made to gain a potentially different perspective into the topic from another cultural point of view. This was possible because the main reviewer is a fluent Portuguese speaker. During the planning stages of the projects the authors decided to include records in different languages and if necessary, seek the assistance of a translator, if there were significant numbers of records in a particular language. During the title and abstract screening, the main reviewer considered all languages if there was an abstract available in English. The only language

that had a significant number of records was Portuguese, and most records in Portuguese originated from the same group of researchers from Sao Paulo, Brazil.

To review titles and abstracts of the records in Portuguese, the main reviewer contacted JBI Brazil – which is based at the same University where most records in Portuguese originated from – and JBI Portugal. JBI Portugal responded very promptly and offered assistance. The main reviewer contacted Dr Vitor Parola from the University of Coimbra, who is a specialist in Palliative Care and very experienced in Scoping Reviews. Together with the main reviewer, Dr Parola conducted the full text screening and assisted in the extraction of information from the included studies in Portuguese. No disagreements arose between reviewers at any stage of the study selection process.

Fig 1: PRISMA Flowchart
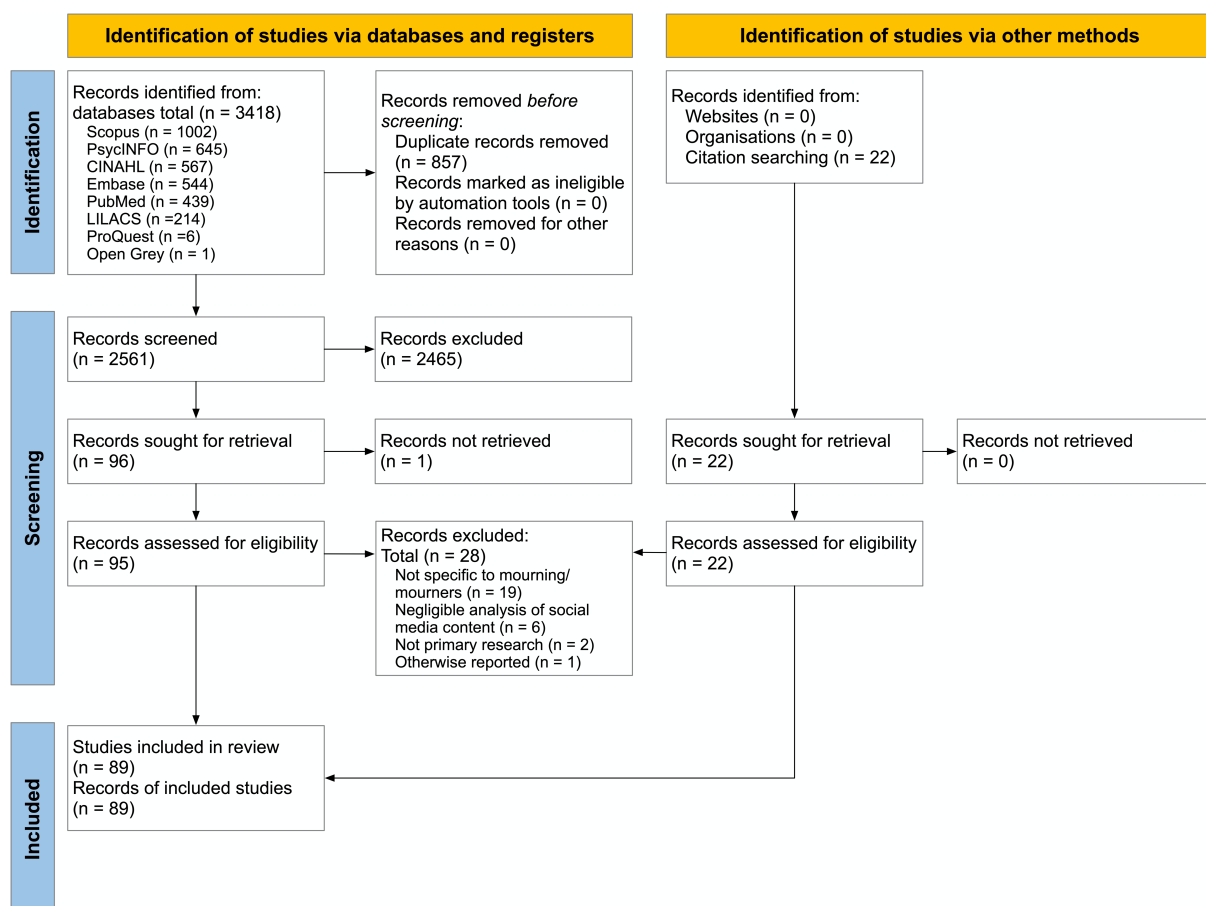
Data charting process

Three reviewers (JMS, JK and PM) piloted the extraction tool (Appendix D) and discussed what aspects of the records would address the research questions and add depth to the discussion. Following the piloting of the tool, the reviewers proceeded to the piloting of the extraction itself. Three reviewers (JMS, JK and PM) piloted the extraction of five randomly selected records in English. The reviewers met in person to discuss similarities and differences from the individual extraction, prior to extracting data from another five randomly selected records in English. In the second meeting, the reviewers found that the understanding of each aspect of the tool and the extracted data were consistent and aligned. The main reviewer then proceeded with the extraction of the remaining records. During this process, the reviewers met on several occasions for quality control and to discuss the data that was being extracted. These data included specific details about the topic investigated, approach to data analysis, type of data, and ethical considerations.

The main reviewer created a spreadsheet on Excel (Microsoft – version 16.55) and included the extracted data from each study. Following the population of this spreadsheet, a pivot table within Excel was produced to allow for the comparison of specific aspects in multiple records. This facilitated the organisation and visualisation of data prior to analysis.

Analysis and writing of results

The writing of results was guided by the research question and sub questions. All reviewers met prior and several times during this process to discuss the data and ensure the analysis addressed all sub questions. The high degree of variability in approaches to data analysis, as well as topics investigated, posed a challenge in the presentation of results in a meaningful way. The first step taken was to divide the approaches to data analysis, and topics investigated into categories. Approaches to data analysis were divided into qualitative, quantitative, and mixed methods.

The categorisation of the topics investigated was not straightforward and required robust discussion and consideration. Categories and the allocation of topics were determined by how the authors from

included records described the expressions of grief and the reviewers' perception of the data. The final four categories for topics investigated were: death of a loved one, grief, unspecified death, and mediatised death. A table for each category was developed to map the study designs used for data analysis, the year of publication, the country of the first author, the type of data used, the type of SM platform where data were collected, as well as ethics approval by an Institutional Review Board or equivalent. The creation of these tables allowed for a deep understanding of the data, and subsequent analysis.

Prior and throughout the analysis of data and writing of discussion the research question and sub questions were considered to ensure the focus of the review was maintained and that a map of how SM data are being used to research the experience of mourning was provided to the research community. A comprehensive analysis of each aspect was conducted and each of the four sub questions were addressed in the discussion section of the review. The final report was submitted as a manuscript to PLOS ONE and is presented in Chapter 4.
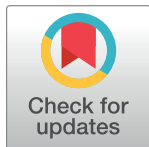
Chapter 4: Published Scoping Review

RESEARCH ARTICLE

How social media data are being used to research the experience of mourning: A scoping review

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Abstract

Background

Increasingly, people are using social media (SM) to express grief, and researchers are using this data to investigate the phenomenon of mourning. As this research progresses, it is important to understand how studies are being conducted and how authors are approaching ethical challenges related to SM data.

Objective

The aim of this review was to explore how SM data are being used to research experiences of mourning through the following questions: a) 'Which topics related to mourning are being studied?'; b) 'What study designs have been used to analyse SM data'; c) 'What type of data (natural or generated) have been used?'; and d) 'How are ethical decisions being considered?'.

Methods

The JBI Scoping Review methodology guided this review. Eligibility criteria were determined using the PCC framework, and relevant key words and phrases derived from these criteria were used to search eight databases in September 2021 (CINAHL, Embase, LILACS, OpenGrey, ProQuest, PsycINFO, PubMed and Scopus). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines were used to report the results of this review.

Results

Database searches resulted in 3418 records, of which, 89 met eligibility criteria. Four categories of grief and mourning were identified. Most records were qualitative in nature and used natural data. Only 20% of records reported ethics approval by an Institutional Review Board, with several including measures to protect participants, for example, using pseudonyms.

Conclusions

This unique review mapped the diverse range of mourning-related topics that have been investigated using SM data and highlighted the variability in approaches to data analysis. Ethical concerns relating to SM data collection are identified and discussed. This is an emerging and rapidly changing field of research that offers new opportunities and challenges for exploring the phenomenon of mourning.

Introduction

Social Media (SM) platforms have altered, arguably forever, the way humans communicate and express themselves. As of January 2021, 4.6 billion of the 7.8 billion people in the world had access to the internet, and 4.2 billion were active SM users [1]. Unsurprisingly, the dynamic nature of large volumes of user-generated content (UGC), and high level of self-disclosure that is available on SM platforms has drawn the attention of researchers. In 2004, Donath and Boyd [2] pioneered SM research, discussing public displays of connection and how the online environment is used as a space for self-representation. Clarke and Van Amerom [3] were among the first authors to utilize data from SM to gain an understanding of social phenomena. Subsequently, several disciplines have used data from SM to inform decisions and understand social trends, including marketing [4], journalism [5] and health sciences [6]. The access that researchers have to large amounts of data, paired with the level of disclosure that is demonstrated on SM platforms, offers the opportunity to investigate social phenomena in a way that has not previously been possible with traditional methods of research [7].

The definition of SM has evolved over the last 10 years as society has adopted new versions of technology [8]. McCay-Peet and Quan-Haase [9] have proposed that "social media are web-based services that allow individuals, communities, and organizations to collaborate, connect, interact, and build community by enabling them to create, co-create, modify, share, and engage with user-generated content that is easily accessible" [9 p.17]. While SM platforms may differ in purpose, they are essentially all internet-based forms for communicating UGC [9].

Two perceived benefits of SM are the invisibility and anonymity it offers to users. The largely text-driven environments can eliminate concerns about physical appearance, tone of voice and body language when sharing messages, and delays or eliminates experiencing any reaction or feedback from recipients [10]. If users want to take a step beyond being physically invisible, there are options to remain anonymous when posting. Anonymity online is the act of hiding one's true self from others, and is known to provide users with a sense that their actions on SM platforms will have no impact on their 'real' (offline) lives [10].

Invisibility and anonymity are not the only benefits recognized by people who share personal information or opinions online. Researchers have found that disclosing stressful or sensitive information on SM has benefited individuals, by allowing them to connect with people with whom they identify [11, 12]. When analyzing posts and pictures linked to the hashtag "Depression" on Instagram, Andalibi [13] found clear evidence of social support and a sense of community. This was confirmed by Zhang [14] when investigating the influence of SM on university students' mental health. Zhang found that self-disclosure on SM was higher during stressful life events and was positively associated with life satisfaction and reduced incidence of depression. People are more likely to disclose thoughts and emotions on SM because of

anonymity and invisibility, but they also use SM for self-disclosure because it has the potential to improve their well-being through social connection [15].

Data from SM can come in different forms such as text, images, or videos. Different SM platforms allow for different forms of expression and target specific demographics. For example, YouTube is a video sharing platform [16] and most users are males aged 18 to 34 [17]. Whereas Snapchat, a messaging and photo sharing platform, has mostly female users aged from 13 to 24 [18]. Social media are unique in the sense that large amounts of data are available from people from varied walks of life and demographics [1]. The access to data from diverse demographics allows researchers to explore specific topics and gain greater (or at least different) understanding of peoples' experiences [19–21].

There are two main types of data used in SM research: natural, and generated data. Observational SM research relies on natural data, which refers to data collected without the awareness of participants [22]. An example of this type of data collection was published by Hilton [23], who analyzed posts from Twitter to investigate self-harm, but had no influence over the generation of data. The use of natural data has been effective in deepening researchers' understanding of sensitive topics, such as miscarriage [21], eating disorders [24], and even to identify shifts from mental health discourse to suicidal ideation [25].

Interactive SM research uses data generated through the active involvement of the researcher on SM platforms [26]. This may be initiated by the researcher extending a 'friendship request' to a prospective participant or through following someone on Twitter to gain access to posts. The researcher may also contact potential participants with requests to create content, or may already be active on the platform from which data will be extracted [7]. This approach has been successfully employed by Caplan [27], who analyzed personal accounts of poverty posted on Reddit in response to an anonymous question from the researcher.

While research using SM data can be valuable in the quest to understand social phenomena, it raises significant questions regarding privacy and ethical conduct in research. These ethical considerations have been explored and expanded upon by several authors. Elgesem [28], in 2002, published a seminal discussion paper exploring questions about consent and the private vs public nature of the data. Also in 2002, the first set of recommendations for ethical conduct in internet research were published by the Association of Internet researchers [29], and were further updated in 2012 [30] and 2020 [31]. De Montjoye et al. [32, 33] highlighted the challenges that modern information technologies bring to individuals' privacy. The issues discussed in these documents are as relevant today–if not more–as they were 20 years ago. Questions that arise include: who 'owns' data from SM–do they fall into the private or public domain? Are SM users aware their posts may be used in research, and would they consent if they were? Should the original intent of the poster be respected? These are pertinent questions that have been raised by the research community [26, 34, 35], as well as by SM users [36] and are of particular importance when data are used to investigate vulnerable populations, such as the bereaved, or are related to practices that have been culturally considered intimate, such as mourning a loss.

The use of SM data to explore grief and mourning is the focus of this review. Grief, in the context of this review, is defined as the intense emotion, sorrow or regret keenly felt following a loss, whereas mourning refers to the practices performed by people in response to their grief [37–39]. Bearing witness to death is a natural part of the life experience, but for many, this experience is radically different to bygone eras because of SM. Peoples' experiences of death now invade our daily lives via televisions, radios, portable devices, and mobile phones [40]. It is almost impossible to be ignorant of a celebrity's death, or the occurrence of a natural disaster on the other side of the world [41].

In pre-modern societies, death resulted in a *bereaved community* [41]. Families lived together or in geographical proximity–neighbors knew and depended on each other for survival. When someone in a community died, all members of that community experienced loss, and would mourn together through rituals designed to memorialize the deceased. Modern societies, on the other hand, are said to have produced *bereaved individuals* [41]. Urban developments accompanied by geographical mobility have resulted in a reduced sense of community, leading to increasingly private and isolated experiences of grief [42].

Walter et al. [41] suggest that in the post-modern society, with the advent of the internet, we are offered the opportunity to grieve as a community once again, resulting in *communities of the bereaved*. This is possible because the internet can connect those who have suffered similar loss. Online communities provide a space for connection and public expression of grief and as such, represent a profound change in how people mourn when compared to the pre-internet era [41].

Expressing grief online has become so commonplace that a new term has been coined to represent this behavior: 'Mourning 2.0'. This term alludes to Web 2.0 –the web of interaction and sharing of information, as opposed to Web 1.0 where information was available without interaction. It encapsulates how mourning has expanded from the private sphere to the public arena [43]. There are numerous support groups available for grievers on SM. The social support offered to individuals on SM contributes to the recognition of their grief, through the acknowledgement of their loss and validation of their feelings [41].

While SM research about the experience of mourning has aided in understanding the postmodern expression of grief, particularly in generations Y and Z (70% of SM users [1]), no study has been conducted to provide a comprehensive overview of the topics, study designs, type of data and ethical considerations involved in SM research about mourning. As such, the overarching aim of this review is to explore how SM data are being used to research the experience of mourning.

There is value in mapping how SM data are being used in research because the internet has changed the way we mourn, with an increasing number of people not only turning to SM to express their grief, but also potentially disclosing more information than they would in face-to-face interactions. Researchers have identified the opportunity to capture and understand the experience of mourning in a different way by using SM data [44–46]. However, as the research output about mourning online increases, it is necessary to understand how these studies are being conducted for two main reasons: to inform future research, particularly in vulnerable populations, and to report and discuss the ethical challenges inherent to the use of natural data from SM platforms.

Methodology

Scoping reviews are an increasingly popular approach to reviewing the literature to comprehensively summarize and synthesize knowledge [47–49]. Scoping reviews address broad research questions, are exploratory and descriptive in nature [49], and are usually conducted to explore the breadth and depth of the literature on a particular topic, to map and summarise evidence, and inform the direction of future research [50].

Scoping reviews are indicated for a variety of reasons, for example as a precursor to a systematic review; to identify the types of available evidence or how research is conducted in a given field; to identify and analyze knowledge gaps; or to clarify key concepts in the literature [51]. Whilst scoping reviews are successfully used to explore established fields of research, this type of review is particularly useful in emerging areas of research where there is variability in methodologies and approaches to data collection and analysis, as well as poor indexing, and a

distribution of research across different academic disciplines [52–55]. The decision flowchart available in Pollock et al. [56] was used to guide this decision to adopt a scoping review approach to this review and the selection of the JBI methodology for scoping reviews, as it is currently the most detailed and rigorous approach available [50].

Review questions

As this is an emerging field of research, with studies being undertaken in diverse disciplines and with a variety of research methodologies and approaches to data analysis, the primary question for this review was 'How are social media data being used to research the experience of mourning?'. This question was intentionally broad, to capture the extent and breadth of literature relating to the central topic.

Four specific sub questions were also considered and include the following: a) 'Which topics related to mourning are being studied using SM data?'; b) 'What study designs have been employed in the analysis of SM data about the experience of mourning?'; c) 'What type of data (natural or generated) have been predominantly used in SM research about the experience of mourning?'; and d) 'How are ethical aspects considered in the published research?'. These were constructed to provide focus for the exploration of the included studies and to provide guidance for data extraction and analysis.

Protocol and registration

A protocol was developed in accordance with the Scoping Review methodology proposed by Arksey and O'Malley [48] and JBI [50], and outlined eligibility criteria, search strategy, study selection and data extraction for this review. The final version of the protocol was registered prospectively with Open Science Framework (https://osf.io/a2udy/). The reporting of this review is guided by the PRISMA Extension for Scoping Reviews reporting guidelines [57] (S1 Appendix).

Eligibility criteria

Eligibility criteria for this review are described using the Participants, Concept and Context (PCC) framework [50]. Participants included people that had expressed grief on SM—such as posting messages to the deceased on SM or creating online memorials to celebrate the deceased's life. There were no restrictions based on age or other demographic aspects. The concept explored in this review included records that report primary research projects that analyzed SM data to explore the experience of mourning. Records that report the use of SM to recruit participants but did not collect data from SM were not eligible for inclusion. All forms of online mourning were considered, including written, audio-visual, and photographic expression. The context included records from any academic discipline where data was collected from SM regardless of geographical location or type of SM platform.

Records of published and unpublished primary research studies, published in either English or Portuguese, were eligible for inclusion in this review. There were no limitations relating to study design or approach to data analysis. There were no limitations on year of publication as the analysis of data from SM for research purposes is a relatively recent phenomenon and is therefore chronologically self-limited.

Search strategy and information sources

On the advice of the academic librarian, an initial limited search of MEDLINE and CINAHL was undertaken to identify eligible records. The text words contained in the titles and abstracts

of relevant records, and the index terms used to describe the records were used to develop a full search strategy for CINAHL (see S2 Appendix). The search strategy, including all identified keywords and index terms, was adapted for each included information source. This process was guided by the assistance of an academic librarian. The reference lists of all records retrieved for full text review were screened for additional papers. The search was completed in September 2021. The databases that were searched included CINAHL (EBSCO), Embase (Elsevier), LILACS (BIREME), OpenGrey (INIST-CNRS), ProQuest Dissertations and Theses Global (ProQuest), PsycINFO (APA), PubMed (NCBI), and Scopus (Elsevier).

Selection of sources of evidence

All identified citations were collated and uploaded into the reference management system EndNote (Clarivate Analytics, PA, USA—Version X9) and duplicates were removed. In preparation for title and abstract screening the reviewers met several times to discuss nuanced elements of the inclusion criteria, in this emerging area of research, and to pilot the screening. This was an iterative process that provided clarity for the three reviewers prior to the lead reviewer (JMS) proceeding with the title and abstract screening.

The full text versions of selected records were screened independently by two reviewers (JMS, JK and PM). Reasons for exclusion of full text records were recorded and are presented in the PRISMA flow chart (Fig 1). JBI Portugal and Brazil were contacted for assistance with screening records published in Portuguese. A reviewer from JBI Portugal assisted with screening full text records published in Portuguese, which resulted in the inclusion of 5 records. No disagreements arose between reviewers at any stage of the study selection process. The results of the search are presented in the PRISMA flow diagram as per the PRISMA 2020 guidelines [58].
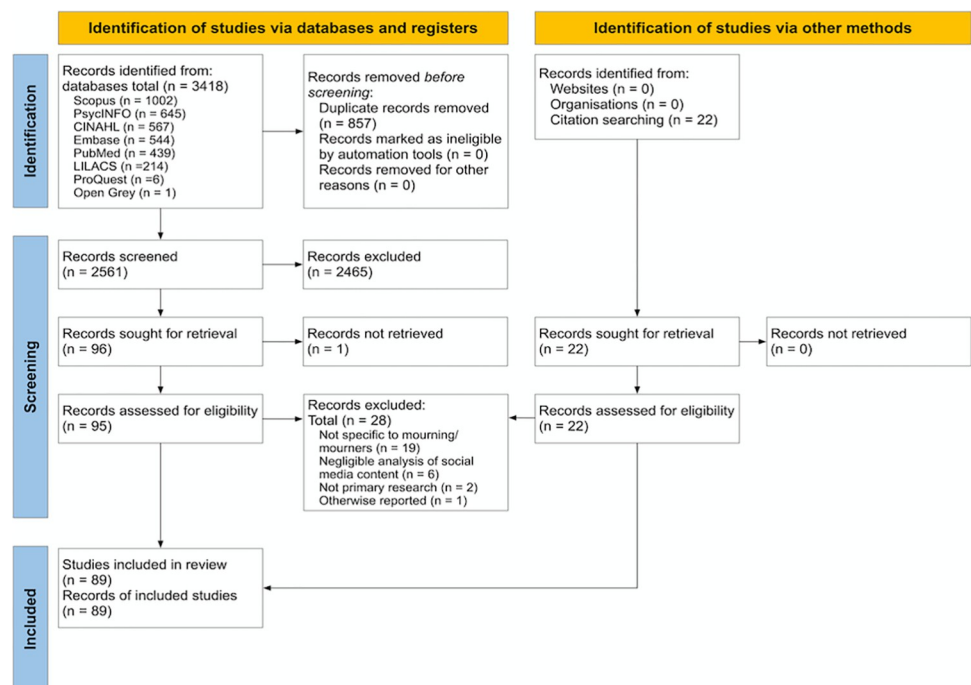
Fig 1. PRISMA flowchart.

Data charting process

Data were extracted from included records by the lead reviewer (JMS) after pilot-testing of the data extraction tool by three reviewers (JMS, JK & PM). The extraction was piloted on two occasions using randomly selected samples of five documents. Extractions were compared and found to be congruent. The lead reviewer proceeded with the extraction of the remaining records. As per JBI guidance for conducting SC Re the reviewers met on several occasions to discuss the data that was being extracted to ensure the data being extracted were sufficient to address the review questions. These data included specific details about the topic investigated, study design, type of data, and ethical considerations.

Results

The database search resulted in 3418 records (see PRISMA diagram, Fig 1). After duplicate removal and title and abstract screening, 95 full text records were assessed for eligibility. Of these, sixteen were excluded as they did not focus on mourning; six were excluded as the analysis of SM content was negligible and two were excluded as they did not report primary research projects. An additional 22 records that met the eligibility criteria were identified through pearling the included records. Of these,

three were excluded as they did not focus on mourning. One record was a journal article that presented the methodology and results from a PhD thesis: therefore, the article was excluded, and the thesis remained, as it described each aspect of the study more comprehensively. In total, 89 records met the eligibility criteria (full citations listed and complete data from the included records are available in S3 Appendix). The search was completed in September 2021.

Most records included in this review were conducted by researchers based in North America (n = 51; 57%), Europe (n = 22; 25%) [20, 46, 59–77], and Oceania (n = 8; 9%) [78–84] (Table 1). All included records were published between 2000 and 2021, and each record reported on a distinct study. Journal articles represented most of the sample (n = 76; 85%), followed by theses (n = 9; 10%) [68, 69, 85–91], and conference proceedings (n = 4; 5%) [92–95]. The most prevalent academic disciplines of first authors included Communication (n = 27; 30%) [45, 46, 59, 61, 62, 87, 88, 91, 95–113]. Psychology (n = 14; 16%) [20, 67, 74, 75, 79–81, 89, 114–119], Nursing (n = 7; 8%) [120–125], Sociology (n = 7; 8%) [43, 44, 66, 77, 78, 126, 127], and others (n = 34; 38%). The most widely used type of SM was social networking sites (n = 35; 39%), with Facebook the main platform used (n = 29; 32%) (Fig 2).

Data were collected in written form, as well as images and audio-visual content. Forty-eight records (54%) did not report how content was collected, whereas manual collection was reported in 33 (37%) records [19, 44, 46, 60, 61, 69, 73, 79, 86, 89–91, 98, 103, 104, 107, 108, 111, 112, 115, 120, 125, 126, 128–132], and automated data collection was used in 6 (7%) records [65, 95, 116, 133]. Two records [68, 70] reported using both strategies to collect data. Most records used written units for analysis (n = 71; 87%). In these records, there was a large variation in sample size (range = 8–291443 units). Two records used images [127] or audio-visual posts [78], one record analyzed emojis from posts [84], and 9 records analyzed multiple data types [20, 46, 63, 68, 83, 85, 88, 109, 126].

Study designs and topics that were explored

While most records did not specify the overarching methodology underpinning their research (n = 67; 75%), of the records that did mention a methodology, two main methodologies were used by researchers to explore mourning on SM: ethnography (n = 13; 15%) [61, 72, 73, 83, 88, 90, 109, 111, 126], including digital ethnography–also referred to as netnography, or virtual, or

Table 1. Summary of 89 included records.

Records characteristics	Included records, n (%)	Records characteristics	Included records, n (%)
Region of first author		**Method for data collection**	
North America	51 (57)	Unclear	48 (54)
Europe	22 (25)	Manual	33 (37)
Oceania	8 (9)	Automated	6 (7)
South America	4 (5)	Combination of manual and automated	2 (2)
Asia	3 (3)	**Type of data**	
Middle East	1 (1)	Natural data	83 (94)
Publication Type		Generated data	4 (4)
Journal Article	76 (85)	Other	2 (2)
Conference proceedings	4 (5)	**Approach to data analysis**	
Dissertation/thesis	9 (10)	Qualitative	70 (79)
Discipline of first author		*Content Analysis*	*21 (24)*
Communication	27 (30)	*Coding*	*12 (14)*
Psychology	14 (16)	*Thematic Analysis*	*11 (12)*
Nursing	7 (8)	*Textual Analysis*	*6 (7)*
Sociology	7 (8)	*Other*	*20 (22)*
Social Work	6 (7)	Mixed Methods	10 (11)
Education	4 (5)	Quantitative	9 (10)
Other	24 (26)	*Sentiment Analysis*	*8 (9)*
Sample type		*Content Analysis*	*1 (1)*
Written text only	76 (86)	**Ethics approval**	
Video only	2 (2)	No	71 (80)
Image only	1 (1)	Yes	18 (20)
Emojis	1 (1)	**Exemption granted by relevant ethics committee**	3 (4)
Multiple sample types	9 (10)		
Sample size, median (range)			
Posts	588 (8–291443)		
Images	361 (229–493)		
Videos	31 (1–126)		

online ethnography, and grounded theory (n = 7; 8%) [44, 64, 66, 87, 106, 108, 117]. Critical realism [71] and interpretive phenomenology analysis [89] were also mentioned in one record each.

Records that mentioned grounded theory as the underpinning methodology have described data analysis using content, thematic or discourse analysis. And records that mentioned ethnography have described data analysis using content, textual, narrative, and critical discourse analysis. Out of the 13 records that have used ethnography, nine reported the use of a digital form of ethnography, with four of them mentioning Netnography [61, 72, 73, 130]—a term coined by Kozinets [134] who developed an adaptation of traditional ethnography to suit the context of online communities, specifically in marketing research. However, it is unclear whether these records have followed the principles of Netnography as described by Kozinets. Even though most records did not adequately or appropriately report the methodological approach being used in their research, the analysis of SM data relating to mourning was described in varying degrees of detail and approached in a variety of ways.

A total of 20 different approaches to data analysis were identified and represented in Tables 2–5. Of the 89 records, 70 (79%) were qualitative, 10 were mixed methods (11%), and nine were quantitative records (10%). Those that employed a qualitative research approach used
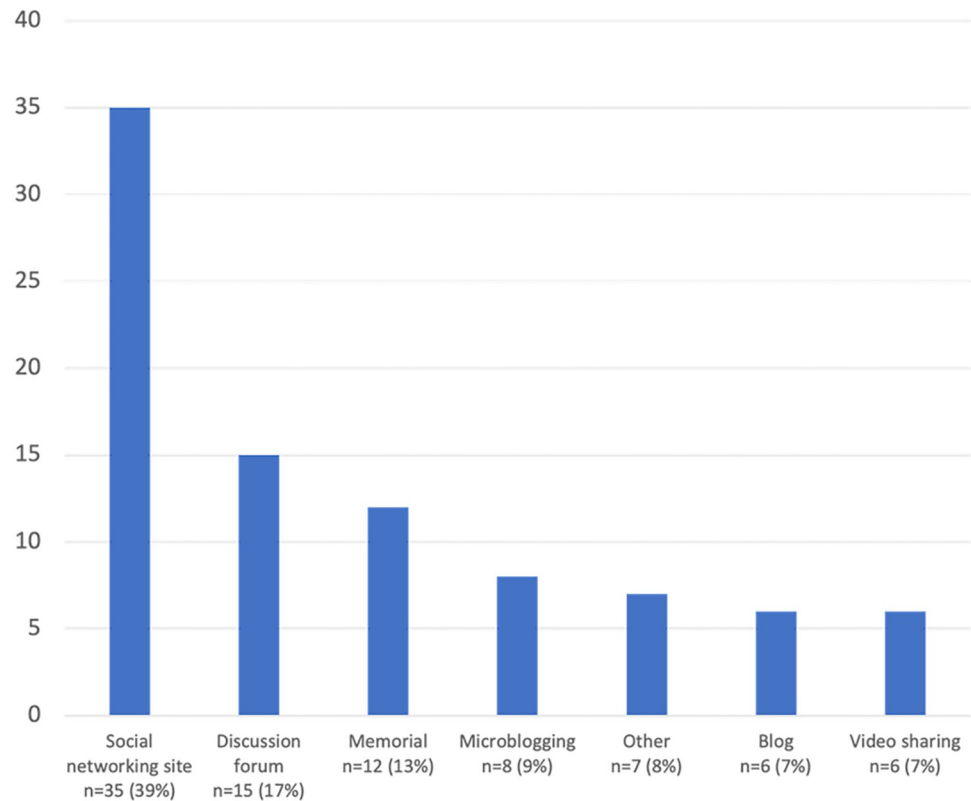
Fig 2. Social media platforms used for data collection.

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primarily content analysis (n = 21; 24%), coding (n = 12; 14%), and thematic analysis (n = 11; 12%). The most frequently combined approaches to data analysis in the mixed methods records were thematic analysis and descriptive statistical analysis (n = 3; 4%) to interpret and represent the data. In the quantitative records data were analyzed predominantly using sentiment analysis [70, 75, 84, 93, 94, 114–116]. A large variety of topics were investigated and reported in the included records. These have been identified and divided into four categories to facilitate the representation of data in a meaningful way (Fig 3).

Categories and the allocation of topics were determined by how the authors described the expressions of grief and the reviewers' perception of the data. A table for each category was developed to map the study designs used for data analysis, the year of publication, the country of the first author, the type of data used, the type of SM platform where data were collected, as well as ethics approval by Institutional Review Board (Tables 2–5).

Type of data collected and analyzed

Most included records used natural data in their analysis (n = 83; 94%). Four records (4%) [83, 85, 90, 125] used generated data, where authors were, or had been, active in the setting where the data was collected. In one (1%) [120] record, it was not possible to determine if the researcher had any influence on the generation of data, and one (1%) [135] record reported the use of both natural data and generated data.

Most mixed methods and quantitative records used natural data. The four records that used generated data, as well as the record where the data source was ambiguous, were qualitative in nature.

Table 2. Death of a loved one.

Death of a loved one n = 32 (36%) Approach to data analysis		Unspecified loved one n = 8 (9%)	Own child n = 8 (9%)	Friend n = 7 (8%)	Miscarriage, perinatal loss, and stillbirth n = 5 (6%)	Other n = 4 (4%)
Qualitative	Content Analysis	Wittenberg-Lyles et al. 2015 (USA) SNS, GD Keskinen, Kaunonen & Aho 2019 (Finland) SNS, ND Selman et al. 2021 (UK)† MB, ND	Aho, Paavilainen & Kaunonen 2012 (USA) F, U Musambira, Hastings & Hoover 2006 (USA) F, ND	Bouc, Han & Pennington 2016 (USA) NSN, ND Bousso et al. 2014 (Brazil)† SNS, ND	Bakker & Paris 2013 (USA) F, ND Sawicka 2017 (Poland) O, ND	
	Narrative Analysis		Frizzo, Bousso, De Faria & De Sa 2017 (Brazil)† B, ND	Giaxoglou 2015 (UK) SNS, ND		Spouse n = 2 (3%) Frizzo et al. 2017 (Brazil)† SNS, ND McDonald-Kenworthy 2012 (USA) F, GD
	Coding			Cesare & Branstad 2018 (USA) MB, ND		
	Thematic Analysis				Hayman, Chamberlain & Hopner 2018 (New Zealand)† SNS, ND	
	Textual Analysis		Finlay & Krueger 2011 (USA) M, ND			
	Discourse Analysis	DeGroot 2009 (USA) SNS, ND Pawelczyk 2013 (Poland) M, ND				
	Rhetorical Critical Approach		DeGroot & Carmack 2013 (USA) B, ND			
	Contrapuntal Analysis					Sibling n = 1 (1%) Halliwell & Franken 2016 (USA) F, ND
	Generative Rhetorical Analysis			Brooks 2014 (USA) SNS, GD		
	Unclear		Christensen et al. 2017 (Denmark) O, ND			
Quantitative	Sentiment Analysis	Han et al. 2021 (China)† MB, ND	Liu et al. 2019 (China)† MB, ND	Brubaker, Kivran-Swaine, Taber & Hayes 2012 (USA) SNS, ND		
	Content Analysis	Doveling 2015 (Germany) SNS, ND				
Mixed Methods	Thematic Analysis and Descriptive Statistics		Hastings, Musambira & Hoover 2007 (USA) F, ND	Brubaker & Hayes 2011 (USA) SNS, ND		
	Textual Analysis and Sentiment Analysis	Gray 2019 (USA) SNS, ND				
	Thematic Analysis and Latent Dirichlet Allocation				Cesare et al. 2020 (USA) MB, ND	
	Coding and Descriptive Statistics					Mother n = 1 (1%) Nager & de Vries 2004 (USA) M, ND
	Qualitative unclear and Descriptive Statistics				Sani, Dimanche & Bacque 2019 (France) VS, ND	

Notes

† Article stated ethics approval by Institutional Review Board. Type of platform: B, Blog; F, Forum; M, Memorial; MB, Microblogging; O, Other; SNS, Social network site; VS, Video sharing. Type of data: ND (Natural data); GD (Generated data), U, (Unclear).

Table 3. Grief.

Approach to data analysis		Grief n = 23 (25%) Disenfranchised Grief n = 15 (17%)			The experience or grief itself n = 8 (9%)
		Suicide n = 9 (10%)	Death of pet n = 3 (3%)	Other n = 3 (3%)	
Qualitative	Content Analysis	Schotanus-Dijkstra et al. 2014 (the Netherlands) F, ND			Children, adolescents' and young adult's grief n = 2 (3%)
					Doveling 2015 (Germany) SNS, ND
					Peruzzo 2007 (Brazil)† SNS, ND
					Communicating Grief n = 1 (1%)
					Eriksson Krutrok 2021 (Sweden) MB, ND
	Coding	Pritchard & Buckle 2018 (Canada)† F, ND			Athlete's concussion n = 1 (1%)
					Cassilo & Sanderson 2019 (USA) B, ND
					Death of adolescent peer n = 1 (1%)
					Williams & Merten 2009 (USA) SNS, ND
	Thematic Analysis	Krysinska & Andriessen 2015 (Australia) M, ND	Vitak et al. 2017 (USA)† SNS, ND	Traumatic birth n = 1 (1%)	Being a mother with cancer n = 1 (1%)
		Krysinska, Andriessen & Corveleyn 2014 (Australia) M, ND	Laing & Maylea 2018 (Australia) B, ND	DeGroot & Vik 2017 (USA) SNS, ND	Croson & Keim-Malpass 2016 (USA) B, ND
		Scott 2012 (UK)† M, ND			
	Textual Analysis			Abortion n = 1(1%)	Death of employer n = 1 (1%)
				Heathcote 2014 (Australia)† O, GD	Babis 2020 (Israel) SNS, ND
	Unclear	Hagstrom 2017 (Sweden) F, ND			
		Hagstrom 2017 (Sweden) F, ND			
Quantitative	Sentiment Analysis	Lester 2012 (USA) M, ND	Lyons et al. 2020 (UK) F, ND		Communicating Grief n = 1 (1%)
		Scourfield et al. 2019 (UK) SNS, ND			Getty et al. 2011 (Canada) SNS, ND
Mixed Methods	Thematic Analysis and Descriptive Statistics			AIDS n = 1 (1%)	
				Blando, Graves-Ferrick & Goecke 2004 (USA) M, ND	

Notes

† Article stated ethics approval by Institutional Review Board. Type of platform: B, Blog; F, Forum; M, Memorial; MB, Microblogging; O, Other; SNS, Social network site; VS, Video sharing. Type of data: ND (Natural data); GD, (Generated data), U, (Unclear).

General aims of included records

Even though the aims of included records were not encompassed in our research questions, during data extraction, it became clear that gaining insight into the overall purpose of studies

Table 4. Unspecified death.

Approach to data analysis		Unspecified death n = 18 (20%)
Qualitative	Content Analysis	Carroll & Landry 2010 (USA) SNS, ND
		De Vries & Rutherford 2004 (USA) M, ND
		Forman, Kerr & Gil-Egui 2012 (USA) SNS, ND
		Irwin 2015 (USA) SNS, ND
		Hasting, Hoover & Musambira 2005 (USA) F, ND
	Coding	DeGroot 2014 (USA) SNS, ND
		Dinning-Brinkmann 2010 (USA) VS, ND
		Giaxoglou 2014 (UK) SNS, ND
		Gibson 2016 (Australia) VS, ND
		Karkar & Burke 2020 (Australia)[†] B, ND
		Roberts & Vidal 2000 (USA) M, ND
	Textual Analysis	Keye 2017 (USA) SNS, ND
		Willis & Ferrucci 2017 (USA) SNS, ND
	Discourse Analysis	Paulus & Varga 2015 (USA)[†] F, ND
		Varga & Paulus 2014 (USA) F, ND
	Qualitative Document Analysis	Kasket 2012 (UK)[†] SNS, ND
	Unclear	Huberman 2017 (USA) M, ND
Quantitative	Sentiment Analysis	Xu, Manrique & Pereira Nunes 2021 (Australia) MB, ND

Notes

[†] Article stated ethics approval by Institutional Review Board. Type of platform: B, Blog; F, Forum; M, Memorial; MB, Microblogging; O, Other; SNS, Social network site; VS, Video sharing. Type of data: ND, (Natural data); GD, (Generated data), U, (Unclear).

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would add depth to the results of this review. Authors have described that their objectives involved the investigation of the ongoing engagement of survivors with the online presence of the deceased [74, 87, 92, 93, 102, 136, 137], the understanding of how people use SM to make sense of death [87, 90, 112, 136], the role of virtual interaction in mourning [46, 62, 109, 110], as well as the role of social support in online mourning [79]. Researchers have also been motivated by the opportunity to gain insight into people's reasons for mourning online [129], as well as the phenomenon of mourning among strangers [61, 78]. While the findings of the records are not the focus of this review, understanding why researchers conducted their studies contributes to the mapping of the use of SM data in research about the experience of mourning.

Two records, both from 2021, reported on research conducted using data from SM related to COVID-19. Han et al. [114] explored the impact of the COVID-19 pandemic on the bereaved, finding that the bereaved due to COVID-19 were more preoccupied with their grief, but displayed lower depression scores, compared to non-COVID-19 bereaved individuals. Selman et al. [71] explored the views and experiences of SM users resulting from knowing that someone they care about died without a family member or friend present and discussed the specific sadness of not being able to say goodbye. Both records collected data from microblogging platforms and obtained ethics approval.

Reporting of ethical considerations

Ethics approval from an Institutional Review Board (IRB) was not reported in the majority of records (n = 71; 80%), with many justifying this by stating that the data is considered public [19, 43, 45, 46, 60, 63, 86, 88, 104, 108, 112]. The authors of 21 studies applied for ethics

Table 5. Mediatized death.

Mediatized Death n = 16 (18%)	Famous people n = 11 (12%)	Non-famous people n = 5 (6%)
Approach to data analysis		
Qualitative — **Content Analysis**	Bingaman 2020 (USA) SNS, ND	Klastrup 2015 (Denmark) SNS, ND
		Pearce 2020 (USA) SNS, ND
Coding	Klastrup 2018 (Denmark) SNS, ND	
	Radford & Bloch 2012 (Canada) F, ND	
Thematic Analysis	Akhter & Tetteh 2021 (USA) MB, ND	
	DeGroot & Leith 2018 (USA) SNS, ND	
	Sanderson & Cheong 2010 (USA) MULT, ND	
Textual Analysis	Campbell & Smith 2015 (USA) M, ND	
Discourse Analysis	Pattwell 2017 (USA) O, ND	Scott 2017 (UK) VS, ND
Critical Discourse Analysis	Harju 2015 (Finland) VS, ND	
Unclear		Foot, Warnick & Schneider 2005 (USA) O, ND
Mixed Methods — **Textual Analysis and Natural Language Processing**		Patton et al. 2018 (USA) MB, ND
Coding and Sentiment Analysis	Stone & Pennebaker 2002 (USA) O, ND	
Coding and Descriptive Statistics	Alemi, Pazoki & Rezanejad 2021 (Iran) SNS, ND & GD	

Notes: [†] Article stated ethics approval by Institutional Review Board. Type of platform: B, Blog; F, Forum; M, Memorial; MB, Microblogging; O, Other; SNS, Social network site; VS, Video sharing. Type of data: ND, (Natural data); GD, (Generated data), U, (Unclear).

approval; 18 had their applications approved and three were provided with an exemption by their IRB with the justification that SM data are considered public domain and therefore consent is not required [19, 124]. In disciplines related to health sciences 60% of records reported approval by an IRB, and 17% from disciplines related to social sciences.

Of the 18 (20%) [69, 71, 74, 77, 79, 83, 87, 90, 95, 114, 117, 119, 121, 131] records that obtained ethics approval, 16 were published after 2012, the year that the Association of Internet Researchers (AoIR) published updated recommendations for ethical conduct of online research [30]. Sixteen of these 18 records were qualitative in nature, and two were quantitative [114, 116]. None of the mixed methods records reported obtaining ethics approval. Informed consent from participants was reported in six records, four that used natural data [69, 71, 119, 122], one that used generated data [90], and one where the type of data was unclear [120]. The AoIR guidelines are mentioned in 5 (6%) of the records that obtained ethics approval [19, 69, 77, 121, 131].

Regarding the protection of the identity of SM posters, 36 (40%) records described measures to protect the anonymity of posters [20, 21, 44, 59, 62, 66, 67, 71–74, 76, 77, 80–82, 89–91, 95, 96, 101, 114, 116, 117, 119, 121, 123, 126, 129–131, 133, 138–140], by changing their
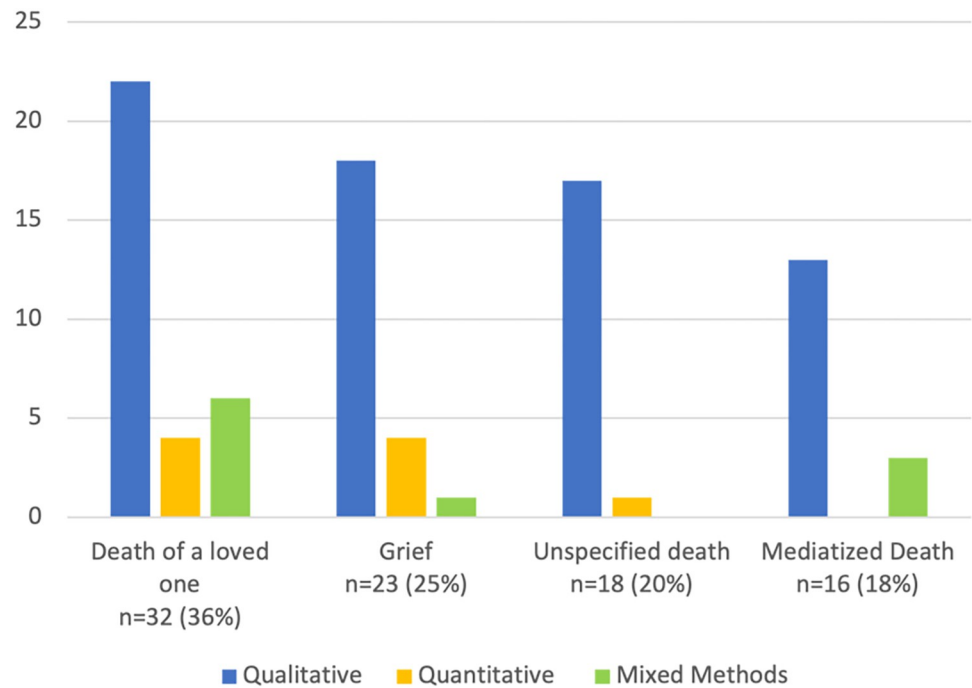
Fig 3. **Research approach by category.**

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profile names to pseudonyms, and/or not publishing any identifying information to protect posters' privacy. However, 50 (56%) records did not include any statement outlining considerations regarding users' privacy or other ethical considerations.

Discussion

This scoping review explored how SM data are used to research the experience of mourning. Specifically, it has identified the topics related to mourning being explored using SM data, the study designs employed by researchers, the type of data used to research the experience of mourning (natural data or generated), and the ethical aspects considered in published research.

After an extensive search of the literature, 89 records were included in this review. From these records, it is evident that the use of SM data has become an increasingly popular avenue to explore the phenomenon of mourning. A wide range of topics have been researched using data from SM platforms. The loss of a loved one was a frequently investigated topic, representing over 30% of the included records. Another significant area of investigation was grief: the experience of grief itself and disenfranchised grief.

When mourners have their right to grieve denied, or the legitimacy of their grief questioned, be it for reasons related to the way someone grieves, the nature of the loss or the nature of the relationship, their grief is referred to as disenfranchised grief [141]. In this review, it was found that SM platforms offered users who experience disenfranchised grief the opportunity to form community. This was evident in people who have lost a loved one to suicide [67, 69, 70, 72, 73, 80, 81, 115, 117] or to AIDS [142]; women who have had an abortion [83]; those mourning the death of their pets [75, 82, 95] and; women who have experienced a traumatic birth [108].

It is interesting to note that the topics explored using SM data have become more specific over time. Earlier publications investigated grief and mourning related to death more generally. Topics have since become much more tailored to include, for example, grief related to being a mother with cancer [124], and the phenomenon of mediatized death–the intense publicizing of someone's death on SM–which many times leads to parasocial grieving–public mourning for someone not personally known [64, 65, 96, 107]. Access to data from SM appears to have facilitated a deeper understanding of areas of mourning that would not be easily researched using more traditional methods of data collection.

Natural data were used in 94% of the records. These data included text, images, audio, or video materials produced without the influence of a researcher but collected by a researcher with the intention of analyzing them in a research project. Data were researcher-generated in 4% of records. In these studies, the researcher had some influence in the generation of data, such as being a poster in an online forum where the data were collected [90] or analyzing data from a Facebook page created by the researcher [125]. The proportion of included records that sought natural data is indicative of a seismic shift in research; a shift that will no doubt continue to have impact as SM platforms are used to mine data that documents the human experience.

A wide range of approaches were used to research mourning using SM, with content analysis being the most prevalent among the qualitative records, and sentiment analysis among the quantitative records. Many records described details of the process of data collection and analysis; however, most did not explicitly report a methodology. For example, Doveling [46] described how the data were collected, and DeGroot [107] described how the coding of Facebook data was undertaken. Liu [116] described how a web-crawler was designed and deployed to download information from the selected SM platform, the process of data selection and collection, as well as the methodology for text analysis. While a comprehensive description of the process of data collection and analysis would increase transparency and academic rigor, there is the need to protect SM users' privacy, especially when details of threads and hashtags are published with direct quotes from users. Bruns [143] discusses academic scholarship in the analysis of large data sets collected online, highlighting the need for full documentation of methods in this emerging area of SM research where methods and tools are frequently being adapted and created to suit the context of online research.

One of the discrepancies noted in the included records relates to ethics, and specifically, whether review by and Institutional Review Board (IRB) and consent from SM users were sought. Two significant questions arise when considering ethics in social media research: 'Are researchers handling primary data from human subjects or can the data collected from SM platforms be considered secondary data?', and 'Are these data public or private?' There is currently no consensus to these questions and answers will ultimately guide the requirements for ethical research practice and determine what measures are needed to protect privacy and anonymity in SM research going forward.

The involvement of human participants in research has traditionally been the criteria to determine whether a project needs ethics approval from an IRB [30]. However, if researchers consider the data collected from SM to be publicly available secondary data–data previously collected (in a SM platform) for a purpose other than the current purpose (analysis for research)–this would traditionally justify an exemption from an IRB [144].

Researchers with a background related to biomedical sciences are very familiar with the ethical principles guiding human research outlined in the Belmont Report [145] namely: respect for persons, beneficence, and justice, and therefore likely default to considering SM research to involve human subjects. Whereas researchers from a background in social science disciplines may consider SM research to involve only secondary data and therefore not seek review

from an IRB. In this review the difference between reporting application to an IRB in health sciences and social sciences was significant, with 60% of records from health sciences reporting ethics approval, compared to only 17% in social sciences.

Prior to the internet, and specifically SM, the use of secondary data in research posed little risk to the person whose information was used, as it would be impossible to connect a quote to a person if correct data management strategies had been used, such as anonymizing data sets. But as researchers increasingly use SM data and publish quotes in their papers, the possibility of re-identification of online data leading back to the poster becomes an ethical concern [146]. This concern escalates where content from vulnerable people is being used in research without their consent [31].

Over the last decade, as well as an increase in the overall volume of publications using SM data to explore the experience of mourning, there has been an increase in applications for ethical review to IRBs, particularly after 2012. In 2012 the Association of Internet Researchers (AoIR) published the updated version of the guidelines for ethical conduct of research, in which it was recommended that researchers consider the risk of harm to participants when conducting research using online data [30]. Whether the publication of the AoIR guidelines led authors to consider the ethical aspects of using secondary data from SM platforms, or if the increase in IRB applications reflects a broader recognition of the risks related to SM data is hard to determine. Nonetheless, appropriate guidelines that reflect the changing landscape of electronic data availability are required.

The AoIR 2020 guidelines state that while all research conducted using data from SM must employ strategies to protect users' privacy, the responsibility of the research community is greater when research involves vulnerable people such as minors, minorities, and, among others mentioned in the guidelines: those who are grieving. Anonymity online cannot be guaranteed, and depending on how much information is available, it is possible to identify the original poster from any given post (Gerrard 2020). If a direct quote is published, it can be tracked back to the poster, exposing them to harm. In research involving sensitive topics such as abortion [83] or self-harm [23], risking the exposure of the identity of the original poster may bring significant personal risk to individuals. For this reason, the NHMRC recommends that even if research is being conducted using secondary data, informed consent and protection of participants are necessary considerations.

The 2007 Australian Code for the Responsible Conduct of Research [147] and the 2015 update of the National Statement [148] did not explicitly identify ethical considerations regarding the use of secondary data. However, the current guidelines, published in 2018, state that consent and respect for privacy should be considered in research using secondary data, specifying that even though consent may be impracticable in this context, the risk associated with the use and publication of secondary data needs to be considered. The recommendation is that consent from posters is gained, or the absence of informed consent is sanctioned by an IRB.

The 2018 update also addressed the issue of the expectation of privacy online. Are the data private or public? The guidelines differentiate the information based on intent or expectation, stating that information available online ranges from what is fully public, such as books or newspapers, to information that, while it is available publicly–such as SM platforms–'the individuals who have made it public may consider it to be private, to information that is fully private in character'[p36]. Some information is clearly public domain, while others belong to the private domain. But what if information is publicly available, but the poster intended it for a specific audience? An example of this would be research using written posts from a publicly available online forum for parents who experienced perinatal loss [138]. In this case, even

though consent was not sought from posters, raw secondary data was used, and quotes were published verbatim as data was considered public.

While exploring SM users' views on ethical conduct in SM research, researchers found that 80% of Twitter users expected to be asked prior to a researcher using content produced by them in research, and approximately 90% expected their anonymity to be protected by researches [149]. These results show a clear discrepancy in how researchers may consider SM data–as public secondary data–and users consider their content–as private expression. The NHMRC guidelines state that when the access and use of information by a researcher does not match the expectation of individuals for the use of said information, privacy concerns should be raised [150].

It is important to note that this inclusion of ethical guidelines around secondary data into a guideline of ethical conduct of human research is very recent. Many records included in this review reported their secondary data as publicly available and therefore ethics approval or consent to use data were unnecessary. As researchers understand more about the use of data from social media in Mourning 2.0, the risks associated with the re-identification of posts, as well as respect for intent and expectations of posters, strategies, protocols, and standards will be required to protect SM users.

Implications for future research

This review has highlighted the changing landscape of research relating to grief and mourning resulting from the burgeoning use of SM. It was not the purpose or intention of the review to recommend changes in policies or practice relating to research using data from SM, but rather to map how this unique area of research has been developing over the last 20 years. Findings of this review may be useful for those wanting to undertake research that investigates grief and mourning using SM data and in the ongoing review and development of frameworks and policies that seek to provide protection to participants and strive to ensure transparency in research conduct.

Limitations

SM terminology has changed considerably since inception, resulting in significant variation in indexing terms. Consequently, despite a comprehensive search of the literature, it is possible that not all records that met inclusion criteria were captured in this review. No critical appraisal was performed in this review in line with the recommendations underpinning a Scoping Review methodology and only records in English and Portuguese were included. Although the data extraction was piloted with the three reviewers, and quality checks were undertaken, most of the data extraction was conducted by the lead reviewer.

Conclusions

This Scoping Review has provided insight into how SM data are used to research the experience of mourning. Through the analysis of eighty-nine records, this review has addressed four questions:

a) 'Which topics related to mourning are being studied using SM data?'; b) 'What study designs have been employed in the analysis of SM data about the experience of mourning?'; c) 'What type of data (natural or generated) have been predominantly used in SM research about the experience of mourning?' and d) 'How are ethical aspects considered in the published research?'.

The findings of this review highlighted the diversity of topics investigated using SM data, which range from the death of a loved one to grief related to life experiences. There was

significant variability in approaches to data analysis, with most records using natural data and employing qualitative approaches to analyse said data, particularly content analysis. This variability likely reflects the novelty of this approach to data collection, and consequently how researchers are experimenting with different methods of data analysis. What has become evident in this review is that, even though most records did not obtain ethics approval, researchers' perceptions of the ethical implications intrinsic to SM research have evolved over the last 10 years and will likely continue to do so as more is understood about the complexities involved in the use of secondary data from SM platforms, in research about mourning, and in other vulnerable populations. This is an emerging and rapidly changing field of research, and as such offers new opportunities to explore the social phenomenon of mourning.

Supporting information

S1 Appendix. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.
(DOCX)

S2 Appendix. Search strategy for CINAHL.
(DOCX)

S3 Appendix.
(XLSX)

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Chapter 5: Discussion

The use of SM as a place for expression of thoughts and emotions has grown significantly over the last 20 years, as has the use of data from SM by researchers seeking to understand social phenomena from different perspectives. As this is an emerging field of research, with studies being undertaken in diverse disciplines and with a variety of research methodologies and approaches to data analysis, a scoping review was undertaken. The primary question for this review was 'How are social media data being used to research the experience of mourning?'. This question was intentionally broad, to capture the extent and breadth of literature relating to the central topic. Four sub-questions were considered and included: a) 'Which topics related to mourning are being studied using SM data?'; b) 'What study designs have been employed in the analysis of SM data about the experience of mourning?'; c) 'What type of data (natural or generated) have been predominantly used in SM research about the experience of mourning?'; and d) 'How are ethical aspects considered in the published research?'. These were constructed to provide focus for the exploration of the included studies and to provide guidance for data extraction and analysis. Findings from the review provide insight into what is being researched using data from SM and how these data have been used, with emphasis on attitudes and approaches to the ethical complexities that surround the use of such data. As the research output about mourning online has increased, it was necessary to understand how studies were being conducted for two main reasons: to inform future research, particularly in using SM data posted by vulnerable populations, and to report and discuss the ethical challenges inherent to the use of natural data from SM platforms.

A scoping review methodology was selected as the most suitable, as it is ideal for addressing broad research questions and is particularly useful to explore the breadth and depth of the literature on a particular topic, to map and summarise evidence, and to inform the direction of future research (Arksey & O'Malley 2005; Munn et al. 2018; Peters et al. 2020; Peters et al. 2015; Tricco et al. 2016).

Within the different methodological descriptions of scoping reviews, the JBI guidelines were selected, as they outline the most detailed and rigorous approach available (Aromataris & Munn 2020).

A preliminary literature search informed a review protocol, which was developed and registered prospectively with Open Science Framework (https://osf.io/a2udy/ - Appendix B). With the assistance of an academic librarian, search strategies for eight different databases were designed, with the intent of capturing published and unpublished literature in the area. The database search resulted in 3418 records. After duplicate removal and title and abstract screening, 95 full text records were assessed for eligibility. Of these, sixteen were excluded as they did not focus on mourning; six were excluded as the analysis of SM content was negligible and two were excluded as they did not report primary research projects. An additional 22 records that met the eligibility criteria were identified through pearling the included records. In total, 89 records met the eligibility criteria. The search was completed in September 2021.

The results of this review revealed that a variety of reasons for mourning have been investigated by researchers using SM data; these can be grouped under two higher level categories: mourning related to death, and grief in the absence of death. The methodological approaches used to answer research questions were primarily qualitative in nature, with qualitative content analysis predominantly selected. Most records included in the review collected natural data and did not seek prior approval from an Institutional Review Board or equivalent. A detailed discussion of the results of the review is provided in the published report included in Chapter 4 of this thesis. What follows is a broader discussion of the implications of the findings, a description of the strengths and weaknesses of the project and a concluding summary.

During the preliminary scoping of the literature, conducted to inform the protocol, it was noted that a variety of approaches to data analysis were used by researchers. This was mapped in this review, and the diversity of approaches was even greater than expected. While some traditional methodologies, such as grounded theory (Cesare & Branstad 2018; DeGroot & Vik 2017) and

phenomenology (Gray 2019) were adopted by researchers, others opted to adapt methodologies to the context of online research, for example in the use of netnography (Harju 2015; Radford & Bloch 2012). As this is a novel area of exploration of social phenomena, it is not unreasonable to expect that methodologies will be adapted and approaches to data analysis further developed as this unique area of research expands.

When the protocol was written for this review, it was based on the preliminary search of the literature, with the four review questions weighted equally: none was considered more important than the other. However, through the process of data extraction and analysis, the complexity and implications of the ethical issues surrounding the use of natural data, particularly when vulnerable populations are involved, became a prominent topic of exploration and discussion. While it is timely to provide a comprehensive summary of topics investigated and approaches to data analysis over the last 20 years, these are not as critical as the broader community discussion regarding ethical issues in the context of social media research using natural data. This review contributes to this important ongoing discussion.

As described in the scoping review report provided in chapter four, the use of data from SM presents challenges to ethics codes and guidelines developed prior to the era of SM (Vitak, Shilton & Ashktorab 2016). The Belmont report, the foundation to most ethical conduct guidelines in research, was published in 1979 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and identified the three core ethical principles for research involving human subjects: respect for persons, beneficence, and justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978). The use of natural data in research using data from SM presents challenges to these three principles. Challenges related to *respect for persons* are linked to the barriers to informed consent in SM platforms, as well as the broader discussion of the need for consent in the case of publicly available SM platforms (Markham & Buchanan 2012, 2015). The main challenge to *beneficence* is in the possibility of reidentification of SM users from their published content which means that they could inadvertently be subjected to

harm because of an action of a researcher they have never had contact with and did not knowing provide data to (Ohm 2009). There are several documented instances where researchers either underestimated the possibility of reidentification of users from the data, or breached SM users' privacy by publishing private information (Pagoto & Nebeker 2019).

Written content published in publicly available media outlets has traditionally been considered secondary data, and therefore, in the past, have been exempt from ethics approval (U.S. Department of Health & Human Services 2018). This is starting to change because of the increased awareness of the risk associated with publishing direct quotes or any other information that can be tracked back to the original SM user (Franzke et al. 2020; Townsend & Wallace 2016; Williams, Burnap & Sloan 2017). The Association of Internet Researchers (AoIR) published their first ethical guidelines for internet research in 2002 (Ess), with further updates published in 2012 (Markham & Buchanan) and 2019 (Franzke et al.). These guidelines provide the research community with prompts to guide ethical decision making. They are a starting point for researchers to inductively apply overarching ethical principles to their individual projects. While these are very useful in the ethical design and conduct of research, they do not provide or recommend practical measures.

Townsend and Wallace (2017) were the first authors of a framework to guide researchers in the ethical conduct of research using data from the internet, and in particular, from social media. They recommend that data be fully anonymized, and if there is a need to publish a *verbatim* quote from a platform (for example to illustrate a theme) then the user be contacted for consent. This practice was successfully employed by Selman et al. (2021) when conducting a thematic content analysis of Twitter data from COVID-19 bereaved family members and friends. Prior to publishing direct quotes from Twitter, they gained consent from the authors of each Tweet. If consent was denied or the original author could not be contacted, the authors of the article paraphrased or omitted the quote.

As the different approaches to ethics were mapped in this review, it was identified that authors are becoming progressively more aware of the ethical challenges of using data from SM. Not only is the

need to protect the identity of SM users being considered (Ayers et al. 2018), but discussion is expanding to involve the respect for users' intent when posting (Eriksson Krutrök 2021; Kasket 2012). The line between private and public data in SM is not clear, and this complexity is increasingly being considered by researchers (Williams et al. 2017).

Implications for future research

The findings and discussion in this review may be useful to those entering this area of research using not only data from SM in the context of grief and mourning, but also SM data related to other social phenomena. It was not the intent of this review to provide recommendations for changes in policy or practice, but rather to add to the research community's discussion regarding the diversity of topics and approaches to data analysis, as well as the ethical challenges related to the use of these data in research. As this research progresses it would be useful to have consensus regarding definitions of terms related to SM research. This would add clarity in this area and promote a more accurate process for the indexing of terms.

Strengths of the project

This project provides a comprehensive map of how social media data are used to research experiences of mourning. This is an emerging area of research that, unsurprisingly, has become increasingly popular. However, despite the numerous articles published using data from SM in online mourning, this project is the first to summarise and publish a map of topics investigated, approaches to data analysis, type of data collected and ethical approaches to the use of SM data in this area of research.

Trends were observed and reported. The overwhelming use of natural data, the diversity of approaches to data analysis and the wide range of topics explored using these data, were identified, and discussed. Significant changes have occurred in this dynamic area of research over the last 20 years, such as the move from a focus on general mourning online (De Vries & Rutherford 2004; Hastings, Hoover & Musambira 2005) to more specific reasons for mourning (Babis 2020; Cassilo & Sanderson 2019). This project has highlighted the importance of SM research to gain insight into

collective social phenomena such as parasocial grief (Bingaman 2020), and sensitive phenomena such as disenfranchised grief (DeGroot & Vik 2017). The ethical progression of the research community in online mourning was described and discussed. Significant shifts in how the research community applies ethical principles were highlighted and discussed.

This review was conducted rigorously and transparently in accordance with well established guidelines for conducting scoping reviews and was reported in adherence to reporting guidelines for scoping reviews (Aromataris & Munn 2020; Page et al. 2021; Tricco et al. 2018). It was an appropriately selected methodology for exploring the review questions, and as a result the findings were explored comprehensively and meaningfully.

Limitations of the project

SM terminology has changed considerably since inception 1997, resulting in significant variation in indexing terms. Consequently, despite a comprehensive search of the literature, it is possible that not all records that met inclusion criteria were captured in the review included in this thesis. Although the data extraction was piloted with the three reviewers, and quality checks were undertaken, most of the data extraction was conducted by the lead reviewer. Only records in English and Portuguese were included in this project. The inclusion of records in other languages, and from other cultural perspectives, could have added to the results and discussion.

Conclusion

The unique review included in this thesis provides insight into what is being researched using data from SM and how these data have been used to research experiences of mourning. Through the data extraction and analysis of eighty-nine records, the review has addressed four questions: a) 'Which topics related to mourning are being studied using SM data?'; b) 'What study designs have been employed in the analysis of SM data about the experience of mourning?'; c) 'What type of data (natural or generated) have been predominantly used in SM research about the experience of mourning?' and d) 'How are ethical aspects considered in the research?'.

The findings of the review highlighted the diversity of topics investigated using SM data, and approaches to data analysis, with most records using natural data and employing qualitative approaches to analysis, particularly content analysis. Considering the novelty of this avenue for data collection, researchers are both adapting traditional research approaches and experimenting with different methods of data analysis. Highlighted in this project was the fact that even though most records did not obtain ethics approval, researchers' perceptions of the ethical implications intrinsic to SM research have evolved over the last 20 years and will likely continue to do so as more is understood about the complexities involved in the use of data from SM platforms, in research about mourning, and in the exploration of other social phenomena. This is an emerging and rapidly changing field of research, and as such offers new opportunities to explore the social phenomenon of mourning.

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Appendix A: PRISMA for Scoping Reviews Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE
TITLE			
Title	1	Identify the report as a scoping review.	2
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4-7
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	7-8
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	8
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	8
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	8-9
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Available in Multimedia Appendix 2

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	9
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	10
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	9-10
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not Applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	11
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	11
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	11-22
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	11-22
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	11-22
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	23-27

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE
Limitations	20	Discuss the limitations of the scoping review process.	27
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	27
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Not applicable (no funding for the review)

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

Appendix B: Review Protocol

How social media is being used to research the experience of mourning: A scoping review protocol

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Introduction

Social media and research

Social Media platforms are used worldwide. As of January 2020, 5.1 billion of the 7.7 billion people in the world had access to the internet and 3.8 billion are active SoMe users (an increase of 9.2% since January 2019).[1] The definition of SoMe has developed over the last 10 years and will continue to do so as society evolves.[2] After reviewing several definitions of SoMe, McCay-Peet and Quan-Haase[3] have proposed that "Social media are web based services that allow individuals, communities, and organizations to collaborate, connect, interact, and build community by enabling them to create, co-create, modify, share, and engage with user-generated content that is easily accessible".[3(p17)] While SoMe platforms may differ in purpose, they are all internet-based forms of communication of User Generated Content (UGC).[3] The UGC is created and exchanged by consumers who interact through online platforms.

Research has shown that there is an increased level of disclosure in social media platforms when compared with face to face interactions.[4,5] Online, it is possible to feel less restrained to express opinions and emotions that one would not necessarily share in face to face interactions. This has been described by Suler[6] as the online disinhibition effect, which is motivated mainly by the invisibility and anonymity that SoMe platforms can afford.[6,7] Invisibility online is represented by the ability to be physically invisible, which is possible in text driven environments. It eliminates the need to worry about physical appearance, tone of voice and body language when delivering a message, as well as the reactions of the recipient when receiving said message.[6] Physical signs of disapproval, such as a frown, a shaking head, or a bored expression can curb what one is willing to express; this inhibition is removed by invisibility.[6] Anonymity is represented by the possibility of hiding the true self from others and it provides the users with a sense that their actions online have no impact on their real lives.[6] Both invisibility and anonymity contribute to a greater levels of disclosure online, but they are not the reason people share personal information online. Researchers have found that disclosing stressful or sensitive information in SoMe has enhanced individuals' sense of wellbeing, by allowing them to connect with people with whom they can identify with. Andalibi[8], when analysing posts and pictures linked to #Depression on Instagram found clear evidence of social support and a sense of community. This was also confirmed by Zhang[9] when investigating the role of SoMe on university students' mental health. He found that self-disclosure on SoMe was higher during stressful life events, and was positively associated with life satisfaction and reduced incidence of depression. People disclose more on SoMe because of anonymity and invisibility, but they use SoMe for self-disclosure because it has the potential to improve their well-being through social connection.[10]

The dynamic nature of SoMe data, the availability of large amounts of UGC, and the high level of self-disclosure have drawn the attention of researchers. In 2004, Donath and Boyd[11], pioneered research about SoMe discussing public displays of connection and how the online environment is used as a space for self-representation. Clarke and Van Amerom[12] were among the first authors to utilise data from SoMe to gain understanding of social phenomenon. Since then, several disciplines have used data from SoMe to inform decisions and understand trends, including marketing[13], journalism[14] and health.[15] The access that researchers can potentially have to large amounts of data, paired to the level of disclosure that is demonstrated on SoMe platforms, offers the opportunity to investigate social phenomena in a way that would not be possible utilising traditional methods of research.[16]

Researchers are utilising data from SoMe to gain further insight into grief and its expression in the digital era. DeGroot and Carmack[17] employed an instrumental case study approach with data from a blog to describe parental grief; Brubaker[18] et al. utilized automated coding when examining bereaved individuals' distressed messages on SoMe; and Moore[19] et al. employed grounded theory to explore how people grieve on SoMe. These authors have published both interactive and observational research.

Interactive research interprets researcher generated data, which according to Moreno[20], is used when the researcher wishes to access content that is not publicly available, as well as when the researcher participates in the generation of data. This could take the form of a 'friendship request' or following someone on Twitter in order to gain access to the desired information, as well as when the researcher contacts potential participants asking them to create content.[16] This approach has been successfully employed by Caplan[21], who analyzed personal accounts of poverty posted on Reddit in response to an anonymous question from the researcher. Observational research, in turn, focusses on naturally occurring data as demonstrated by Hilton[22], who analyzed posts from Twitter to investigate self-harm.

Observational SoMe research has been very effective in deepening researchers' understanding of sensitive topics, such as miscarriage[23], eating disorders[24], and even to identify shifts from mental health discourse to suicidal ideation.[25] While observational research of SoMe data can be useful in the quest to understand social phenomena, it raises the issue of privacy and ethical conduct in research. Are data from SoMe private or public? Do SoMe users know (and would they agree if they did) their posts may be used in research? These are pertinent questions that have been raised in the research community[20,26,27], as well as from SoMe users.[28]

Social media and the experience of mourning

Death has and always will be part of life, from pre-modern societies, where death by illness was a constant threat, to the post-modern world where death invades our daily lives via televisions, radios, tablets and mobile phones. It is almost impossible to be unaware of a celebrity's death, or the occurrence of a natural disaster on the other side of the world.[29] This, combined with personal loss,

means that it is inevitable that we will all experience grief (the intense emotion that follows a loss) and mourning (the expression of grief) at some point in our lifetime.[30,31]

According to Walter et al.[29], death in pre-modern societies produced a bereaved community. Families lived together or in close proximity; neighbors knew and depended on each other for survival. When someone in a community died, all members of that community experienced loss, and would mourn together through rituals designed to memorialize the deceased.

Modern societies, on the other hand, produced bereaved individuals. Urban developments accompanied by geographical mobility resulted in a reduced sense of community, which meant dying and mourning became an increasingly private experience.[32] This coincides with the idea of sequestration of the dying and the dead.[29] Death became something to be hidden from everyday life, particularly in the western world, and relegated to places such as hospitals, hospices and nursing homes.[29] Likewise, grief became private, with survivors expected to continue on with everyday life and to move on.

Walter[29] et al. suggest that in the post-modern society, with the advent of the internet, we are offered the opportunity to grieve as a community once again. This is possible because of the internet, where those who have suffered similar losses (for example the death of a loved one, someone's suicide, a loss of income, etc.) can connect. The internet has allowed for the return of the community, but instead of a bereaved community of the pre-modern era, we have a community of the bereaved. Online communities provide a space for connection and public expression of grief and as such, represent a profound change in how people mourn, when compared to mourning in the pre internet era.[29]

Expressions of grief online have become so commonplace that a new term has been coined to represent mourning online: 'Mourning 2.0'. This term alludes to web 2.0 (the web of interaction and sharing of information, as opposed to web 1.0 where information was available without interaction) and defines how mourning has expanded from the private sphere to the public arena.[33] There are numerous support groups available for grievers on Social Media (SoMe), particularly on Facebook. The social support offered to individuals on SoMe contributes to the recognition of their grief, through the acknowledgement of their loss and validation of their feelings.[29]

While SoMe research about the experience of mourning has aided in understanding the post modern expression of grief, particularly in generations Y and Z (70% of SoMe users[1]), no study has been conducted providing a comprehensive map of the topics, study designs, type of data and ethical considerations involved in SoMe research about mourning. This is what this scoping review proposes to do.

There is value in mapping how SoMe data is being used in research because the internet has changed the way we mourn, with an increasing number of people not only turning to SoMe to express their grief,

but also disclosing more information than they would in face to face interactions. Researchers have identified that SoMe is an essential domain for research about the experience of mourning, and are exploring this important aspect of life using SoMe data. However, as the research output about the experience of mourning online increases, it is necessary to understand how these studies are being conducted, with the purpose of informing further research not only in the experience of mourning but also in the use of data from SoMe.

A preliminary search of Open Science Framework, PubMed, the Cochrane Database of Systematic Reviews and Google Scholar was conducted on 10th March 2020, and no current or underway scoping reviews or systematic reviews on the topic were identified.

This protocol, and subsequent review, aims to map topics, study designs, type of data and ethical considerations involved in SoMe research about the experience of mourning.

Review question

How is social media being used to research the experience of mourning?

Sub-questions:

Which topics related to mourning are being studied using Social Media data?

What study designs have been employed in the analysis of Social Media data about the experience of mourning?

What type of data (naturally occurring or researcher generated) have been predominantly used in SoMe research about the experience of mourning?

How are ethical aspects considered in the published research?

Inclusion criteria

Participants

The participants of this review will be people that have posted about their experience of mourning on SoMe platforms. Many studies that analyze SoMe data do not specify the number of people that participated in the study by posting on SoMe, rather, they disclose the number of entries in a specific period of time.

Concept

This review will consider studies that describe primary research that have analyzed SoMe data to

explore the experience of mourning. For the purpose of this review we define grief as the intense emotion that follows a loss, and mourning as the expression of grief, as defined by Ayers[30] et al. and Lofland.[31] Studies that utilize SoMe data, in full or in part, will be included in this review. Studies that use SoMe to recruit participants but do not collect data from SoMe will be excluded.

Context

This review will consider studies within any discipline, in which the data come totally or in part from SoMe. All geographical contexts will be included.

Types of sources

This scoping review will consider all methodological designs for inclusion. Articles published in English and Portuguese will be included. All years of publication will be included, as the analysis of data from Social Media for research purposes is a recent phenomenon, and therefore chronologically self-limited.

Methods

The proposed scoping review will be conducted in accordance with the Joanna Briggs Institute methodology for scoping reviews.[34]

Search strategy

The search strategy will aim to locate both published and unpublished primary studies. An initial limited search of MEDLINE and CINAHL was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for CINAHL (see Appendix 1). The search strategy, including all identified keywords and index terms will be adapted for each included information source. The reference lists of articles selected for full text review will be screened for additional papers.

Information sources

The databases to be searched for both published and unpublished literature include: CINAHL (EBSCO), Scopus (Elsevier), PubMed (NCBI), Embase (Elsevier), PsycINFO(APA), LILACS (BIREME), OpenGrey (INIST-CNRS) and ProQuest Dissertations and Theses Global (ProQuest).

Study selection

Following the search, all identified citations will be collated and uploaded into EndNote reference management system (Clarivate Analytics, PA, USA) and duplicates removed. Titles and abstracts will then be screened by the lead researcher for inclusion against the review's inclusion criteria. Potentially relevant studies will be retrieved in full, as well as studies for which a decision cannot be made based on title and abstract alone. The full text of selected studies will be assessed in detail against the inclusion

and exclusion criteria for the review. Each full text will then be screened independently by 2 reviewers. Reasons for exclusion of full text studies that do not meet the inclusion criteria will be recorded and provided in the final report of the review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion, or with a third reviewer. The results of the search will be reported in full in the final scoping review, and presented in a PRISMA flow diagram. The report will follow the guidelines and checklist published by Tricco[35] et al.

Data extraction

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed for this review (Appendix II). The data extracted will include specific details about the topic investigated, sample, study design, type of data, and ethical considerations for data extraction. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Authors of included papers will be contacted to request missing or additional data, where required.

Data presentation

The extracted data will be presented in diagrammatic and tabulated form in a manner that aligns with the objective of this scoping review, namely mapping how SoMe research about the experience of mourning is being conducted. A data presentation table has been drafted for this review and will be further developed during the review process. A narrative summary will accompany the tabulated and diagrammatic results and will describe how the results relate to the reviews objective and question.

Conflicts of interest

The authors declare no conflict of interest.

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Appendix I: Search strategy

CINAHL (EBSCO)

Search conducted on February 2020

Search	Query	Records retrieved
#1	MH Bereavement+ OR TI grief OR TI bereavement OR TI mourning OR AB grief OR AB bereavement OR AB mourning	15714
#2	MH "social media+" OR TI "web 2.0" OR TI "social media" OR TI internet OR TI online OR TI facebook OR TI myspace OR TI twitter OR TI instagram OR TI "social networking" OR TI YouTube OR TI blog OR AB "social media" OR AB internet OR AB online OR AB facebook OR AB myspace OR AB twitter OR AB instagram OR AB "social networking" OR AB YouTube OR AB blog	97087
#3	#1 AND #2	363
No limits		

Appendix II: Data extraction instrument

Scoping Review Details	
Scoping Review Title	
Review objective/s	
Review question/s	
Inclusion/Exclusion Criteria	
Population	
Concept	
Context	
Types of Study	
Study Details and Characteristics	
Study citation details (e.g. author/s, date, title, journal, volume, issue, pages)	
Country	
Social Media Platform/s	
Focus of study and research question	
Total number of Posts/Entries analyzed	
Details/Results extracted from study (in relation to the concept of the scoping review)	
Type of data	
Study design	
Ethical considerations	

Appendix C: Search Strategy CINAHL

Search platform: CINAHL	
Limits: none	
Search terms:	
Mourning	Social Media
MH Bereavement+	MH "social media+"
OR	OR
TI grief	TI "web 2.0"
OR	OR
TI bereavement	TI "social media"
OR	OR
TI mourning	TI internet
OR	OR
AB grief	TI online
OR	OR
AB bereavement	TI Facebook
OR	OR
AB mourning	TI myspace
	OR
	TI Twitter
	OR
	TI Instagram
	OR
	TI "social networking"
	OR
	TI YouTube
	OR
	TI blog
	OR
	AB "social media"
	OR

	AB internet
	OR
	AB online
	OR
	AB Facebook
	OR
	AB myspace
	OR
	AB Twitter
	OR
	AB Instagram
	OR
	AB "social networking"
	OR
	AB YouTube
	OR
	AB blog

(MH Bereavement+ OR TI grief OR TI bereavement OR TI mourning OR AB grief OR AB bereavement OR AB mourning) AND (MH "social media+" OR TI "web 2.0" OR TI "social media" OR TI internet OR TI online OR TI Facebook OR TI myspace OR TI Twitter OR TI Instagram OR TI "social networking" OR TI YouTube OR TI blog OR AB "social media" OR AB internet OR AB online OR AB Facebook OR AB myspace OR AB Twitter OR AB Instagram OR AB "social networking" OR AB YouTube OR AB blog)

Appendix D: Data Extraction Tool

Scoping Review Details	
Scoping Review Title	How social media data are being used to research the experience of mourning
Review objective	To explore how social media data are being used to research the experience of mourning.
Review question/s	How are social media data being used to research the experience of mourning? Sub-questions: a) Which topics related to mourning are being studied? b) What study designs have been used to analyse SM data? c) What type of data (natural or generated) have been used? d) How are ethical decisions being considered?

Inclusion/Exclusion Criteria	
Population	People that have posted about their experience of mourning on social media platforms.
Concept	Primary research that analysed social media data to explore the experience of mourning.
Context	Studies within any discipline, in which the data came totally or in part from social media. All geographical contexts will be included.
Types of Study	All methodological designs for inclusion; English and Portuguese; All years of publication.

Study Details and Characteristics	Possible responses
Study citation details	Reference (Vancouver)
Country	Free text
Region	Free text
Year of publication	Free text
Language	Free text
Type of publication	Free text
Academic discipline	Free text
Focus (Category)	Free text
How data was obtained	Manual or automated
Methodology underpinning data analysis	Free text
Approach to data analysis	Free text
Type of social media/Platform	Free text
Platform name	Free text
Units of analysis	Free text
Type of content analysed	Free text
Type of data	Natural or generated
Ethical review	Reported or not reported
Protection of SM users	Free text