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

Julia Muller Spiti¹*, Ellen Davies¹,², Paul McLiesh¹, Janet Kelly¹

¹ Adelaide Nursing School, Faculty of Health and Medical Sciences, University of Adelaide, Adelaide, Australia, ² Adelaide Health Simulation, Faculty of Health and Medical Sciences, University of Adelaide, Adelaide, Australia

* Julia.MullerSpiti@adelaide.edu.au

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—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 post-modern 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.

https://doi.org/10.1371/journal.pone.0271034.g001
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
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—a term coined by Kozinets—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

| 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)              |                         |                         |

https://doi.org/10.1371/journal.pone.0271034.t001

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.
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.

| Approach to data analysis | Death of a loved one n = 32 (36%) | 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                         | Aho, Paavilainen & Kaunonen 2012 (USA) | Bouc, Han & Pennington 2016 (USA) | Bakker & Paris 2013 (USA) | F, ND |
|                          | Keskinen, Kaunonen & Aho 2019 (Finland) | SNS, ND                        | Musambira, Hastings & Hoover 2006 (USA) | Bouss et al. 2014 (Brazil) | Sawicka 2017 (Poland) | O, ND |
|                          | Selman et al. 2021 (UK)†            | MB, ND                          |                     |                 |                                               |                 |
| **Narrative Analysis**    | Fritzo, Bouso, De Faria & De So 2017 (Brazil) | R, ND                           | Girzglou 2015 (UK) |                 |                                               |                 |
| **Coding**                |                                   |                                 |                     |                 |                                               |                 |
| **Thematic Analysis**     |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Textual Analysis**      |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Discourse Analysis**    |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Rhetorical Critical Approach** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Contrapuntal Analysis** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Generative Rhetorical Analysis** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Unclear**               |                                   |                                 |                     |                 |                                               |                 |
| **Quantitative**          |                                   |                                 |                     |                 |                                               |                 |
| **Sentiment Analysis**    |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Content Analysis**      |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Mixed Methods**         |                                   |                                 |                     |                 |                                               |                 |
| **Thematic Analysis and Descriptive Statistics** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Textual Analysis and Sentiment Analysis** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Thematic Analysis and Latent Dirichlet Allocation** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Coding and Descriptive Statistics** |                                   |                                 |                     |                 |                                               |                 |
|                          |                                   |                                 |                     |                 |                                               |                 |
| **Qualitative unclear and Descriptive Statistics** |                                   |                                 |                     |                 |                                               |                 |

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).

https://doi.org/10.1371/journal.pone.0271034.t002
**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...
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 approval.
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

Table 5. Mediatized death.

| Approach to data analysis | Mediatized Death n = 16 (18%) | Famous people n = 11 (12%) | Non-famous people n = 5 (6%) |
|---------------------------|-------------------------------|-----------------------------|-----------------------------|
| 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).

https://doi.org/10.1371/journal.pone.0271034.t005
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 an 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 researchers [149]. These results show a clear discrepancy in how researchers may consider SM data—public secondary data—and users consider their content—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.

S2 Appendix. Search strategy for CINAHL.

S3 Appendix.

Acknowledgments

We would like to thank Vikki Langton, Research Librarian, for her assistance with the search strategy.

We also thank Dr. Vitor Parola, Adjunct Professor at The University Fernando Pessoa, Porto, Portugal, for his assistance with full text screening of records in Portuguese.

Author Contributions

Conceptualization: Julia Muller Spiti, Paul McLiesh, Janet Kelly.

Data curation: Julia Muller Spiti, Paul McLiesh, Janet Kelly.

Formal analysis: Julia Muller Spiti, Ellen Davies, Paul McLiesh, Janet Kelly.

Investigation: Julia Muller Spiti, Ellen Davies.

Methodology: Julia Muller Spiti, Paul McLiesh, Janet Kelly.

Project administration: Julia Muller Spiti.

Resources: Julia Muller Spiti.

Supervision: Ellen Davies, Paul McLiesh, Janet Kelly.

Writing – original draft: Julia Muller Spiti, Ellen Davies.

Writing – review & editing: Julia Muller Spiti, Ellen Davies, Paul McLiesh, Janet Kelly.

References

1. Kemp S. Global Digital Report: We are Social; 2021 [cited 2021 3 July]. Available from: https://wecareasocial.com/digital-2021.  
2. Donath J, Boyd D. Public Displays of Connection. BT Technology Journal. 2004; 22(4):71–82. https://doi.org/10.1023/B:BTJT.0000047585.06264.cc
3. Clarke J, Van Amerom G. A comparison of blogs by depressed men and women. Issues in Mental Health Nursing. 2008; 29(3):243–64. https://doi.org/10.1080/01612840701869403 PMID: 18340611

4. McCarthy J, Rowley J, Ashworth CJ, Pioch E. Managing brand presence through social media: The case of UK football clubs. Internet Research. 2014; 24(2):181–204. https://doi.org/10.1108/IntR-08-2012-0154

5. Lewis SC, Molyneux L. A decade of research on social media and journalism: Assumptions, blind spots, and a way forward. Media and Communication. 2018; 6(4):11–23. https://doi.org/10.17645/mac.v6i4.1562

6. Greaves F, Laverty AA, Ramirez Cano D, Moilanen K, Pulman S, Darzi A, et al. Tweets about hospital quality: A mixed methods study. BMJ Quality and Safety. 2014; 23(10):838–46. https://doi.org/10.1136/bmjqs-2014-002875 PMID: 24748372

7. Lafferty NT, Manca A. Perspectives on social media in and as research: A synthetic review. International Review of Psychiatry. 2015; 27(2):85–96. https://doi.org/10.3109/09540261.2015.1009419 PMID: 25742363

8. Papacharissi Z. We Have Always Been Social. Social Media + Society. 2015; 1(1):1–10. https://doi.org/10.1177/2056305115581185

9. McCay-Peet L, Quan-Haase A. What is social media and what questions can social media research help us answer? In: Sloan L, Quan-Haase A, editors. The sage handbook of social media research methods. London: SAGE; 2017.

10. Suler J. The Online Disinhibition Effect. CyberPsychology & Behavior. 2004; 7(3):321–6. https://doi.org/10.1089/1094931041291295 PMID: 15257832

11. Andalibi N, Marcu G, Moesgen T, Forte A, Mullin R, editors. Not alone: Designing for self-disclosure and social support exchange after pregnancy loss. Conference on Human Factors in Computing Systems—Proceedings; 2018.

12. Andalibi N, Morris ME, Forte A. Testing waters, sending clues: Indirect disclosures of socially stigmatized experiences on social media. Proceedings of the ACM on Human-Computer Interaction. 2018; 2(CSCW). https://doi.org/10.1145/3274288

13. Andalibi N, Ozturk P, Forte A. Depression-related imagery on Instagram. Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW. 2015:231–4. https://doi.org/10.1145/2685553.2699014

14. Zhang R. The stress-buffering effect of self-disclosure on Facebook: An examination of stressful life events, social support, and mental health among college students. Computers in Human Behavior. 2017; 75:527–37. https://doi.org/10.1016/j.chb.2017.05.043

15. Clark JL, Algese SB, Green MC. Social Network Sites and Well-Being: The Role of Social Connection. Current Directions in Psychological Science. 2018; 27(1):32–7. https://doi.org/10.1177/0963721417730833

16. Giannoulakis S, Tsapatsoulis N. Evaluating the descriptive power of Instagram hashtags. Journal of Innovation in Digital Ecosystems. 2016; 3(2):114–29.

17. Statista. Distribution of YouTube users worldwide as of January 2022, by age group and gender: Statista Research Department; 2022 [14th April]. Available from: https://www.statista.com/statistics/1287137/youtube-global-users-age-gender-distribution/.

18. Statista. Distribution of Snapchat users worldwide as of January 2022, by age and gender: Statista Research Department; 2022 [14th April]. Available from: https://www.statista.com/statistics/933948/snapchat-global-user-age-distribution/.

19. Varga MA, Paulus TM. Grieving online: Newcomers’ constructions of grief in an online support group. Death Studies. 2014; 38(7):443–9. https://doi.org/10.1080/07481187.2013.780112 PMID: 24758214

20. Sani L, Dimanche ACL, Bacque MF. Angels in the Clouds: Stillbirth and Virtual Cemeteries on 50 YouTube Videos. Omega (Westport). 2019. Epub 2019/01/30. https://doi.org/10.1177/0963721417730833

21. Cesare N, Oladeji O, Ferryman K, Wijaya D, Hendricks-Munoz KD, Ward A, et al. Discussions of miscarriage and preterm births on Twitter. Paediatr Perinat Epidemiol. 2020. Epub 2020/01/09. https://doi.org/10.1111/ppe.12622 PMID: 31912544.

22. Zhou T. Representative methods of computational socioeconomics. Journal of Physics: Complexity. 2021; 2(3). https://doi.org/10.1088/2632-072X/ac2072

23. Hilton CE. Unveiling self-harm behaviour: what can social media site Twitter tell us about self-harm? A qualitative exploration. Journal of Clinical Nursing. 2017; 26(11/12):1690–704. https://doi.org/10.1111/jocn.13575 PMID: 27604049.

24. Pater JA, Haimson OL, Andalibi N, Mynatt ED. “Hunger Hurts but Starving Works” Characterizing the Presentation of Eating Disorders Online. Proceedings of the 19th ACM Conference on Computer-
25. De Choudhury M, Kiciman E, Dredze M, Coppersmith G, Kumar M. Discovering shifts to suicidal ideation from mental health content in social media. Conference on Human Factors in Computing Systems —Proceedings. 2016:2098–110. https://doi.org/10.1145/2858036.2858207

26. Moreno M, Goniu N, Moreno P, Diekema D. Ethics of Social Media Research: Common Concerns and Practical Considerations. CyberPsychology, Behavior & Social Networking. 2013; 16(9):708–13. https://doi.org/10.1089/cyber.2012.0334 PMID: 23679571

27. Caplan MA, Purser G, Kindle PA. Personal Accounts of Poverty: A Thematic Analysis of Social Media. Journal of Evidence-Informed Social Work. 2017; 14(6):433–56. https://doi.org/10.1080/23761407.2017.1380547 PMID: 29140758

28. Elgesem D. What is special about the ethical issues in online research? Ethics and Information Technology. 2002; 4(3):195–203. https://doi.org/10.1023/a:1021320510186 PMID: 15977360

29. Ess C. Ethical decision-making and Internet research: Recommendations from the AoIR ethics working committee 2002 [cited 2021 1 October]. Available from: http://aoir.org/reports/ethics.pdf.

30. Markham A, Buchanan E. Ethical decision-making and internet research: Version 2.0. recommendations from the AoIR ethics working committee. Available online: aoir.org/reports/ethics2.pdf. 2012.

31. Franzke A, Bechmann A, Zimmer M, Ess C. Internet research: ethical guidelines 3.0 association of internet researchers. 2020.

32. De Montjoye Y-A, Radaelli L, Singh VK, Pentland AS. Unique in the shopping mall: On the reidentifiability of credit card metadata. Science. 2015; 347(6221):536–9.

33. de Montjoye YA, Hidalgo CA, Verleysen M, Blondel VD. Unique in the Crowd: The privacy bounds of human mobility. Sci Rep. 2013; 3:1376. https://doi.org/10.1038/srep01376 PMID: 23524645

34. Townsend L, Wallace C. Social media research: A guide to ethics. University of Aberdeen. 2016.

35. Myles D, Cherba M, Millerand F. Situating Ethics in Online Mourning Research: A Scoping Review of Empirical Studies. Qualitative Inquiry. 2019; 25(3):289–99. https://doi.org/10.1177/1077800418806599

36. Ayers JW, Caputi TL, Nebeker C, Dredze M. Don’t quote me: reverse identification of research participants in social media studies. NPJ Digit Med. 2018; 1:30. https://doi.org/10.1038/s41746-018-0036-2 PMID: 31304312

37. Maddrell A. Mapping grief. A conceptual framework for understanding the spatial dimensions of bereavement, mourning and remembrance. Social and Cultural Geography. 2016; 17(2):166–88. https://doi.org/10.1080/14649365.2015.1075579

38. Walter T. New mourners, old mourners: Online memorial culture as a chapter in the history of mourning. New Review of Hypermedia and Multimedia. 2015; 21(1–2):10–24. https://doi.org/10.1080/13614568.2014.983555

39. Lofland LH. The Social Shaping of Emotion: The Case of Grief. Symbolic Interaction. 1985; 8(2):171–90. https://doi.org/10.1525/si.1985.8.2.171

40. Walter T. Communication media and the dead: from the Stone Age to Facebook. Mortality. 2015; 20(3):215–32. https://doi.org/10.1080/13576275.2014.993598 PMID: 26549977

41. Walter T, Hourizi R, Moncur W, Pitsillides S. Does the internet change how we die and mourn? Overview and analysis. Omega: Journal of Death and Dying. 2011; 64(4):275–302. https://doi.org/10.2190/om.64.4.a PMID: 22530294

42. Kellehear A. A Social History of Dying. Cambridge : Cambridge University Press; 2007. ISBN: 9780521694292.

43. Irwin MD. Mourning 2.0—Continuing Bonds Between the Living and the Dead on Facebook. Omega (Westport, United States). 2015; 72(2):119–50. https://doi.org/10.1177/0030222815574830 PMID: 27132379

44. Cesare N, Branstad J. Mourning and memory in the twittersphere. Mortality. 2018; 23(1):82–97. https://doi.org/10.1080/13576275.2017.1319349

45. DeGroot JM, Carmack HJ. "It may not be pretty, but it's honest": examining parental grief on the Callapitter blog. Death Stud. 2013; 37(5):448–70. https://doi.org/10.1080/07481187.2011.649940 PMID: 24517565

46. Döveling K. "Help me. I am so alone." Online emotional self-disclosure in shared coping-processes of children and adolescents on social networking platforms. Communications. 2015; 40(4):403–23. https://doi.org/10.1515/commun-2015-0018
47. Tricco AC, Lillie E, Zarin W, O'Brien K, Colquhoun H, Kastner M, et al. A scoping review on the conduct and reporting of scoping reviews. BMC medical research methodology. 2016; 16(1):15. https://doi.org/10.1186/s12874-016-0116-4 PMID: 26857112

48. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International journal of social research methodology. 2005; 8(1):19–32. ISSN: 1364-5579

49. Peters MD, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evidence Synthesis. 2020; 18(10):2119–26. https://doi.org/10.11124/JBIES-20-00167 PMID: 33038124

50. Aromataris E, Munn Z, editors. JBI Manual for Evidence Synthesis. JBI, 2020. Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-01

51. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Medical Research Methodology. 2018; 18(1). https://doi.org/10.1186/s12874-018-0611-x PMID: 30453902

52. Taylor J, Pagliari C. Comprehensive scoping review of health research using social media data. BMJ Open. 2018; 8(12). https://doi.org/10.1136/bmjopen-2018-022931 PMID: 30552260

53. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier L, et al. Scoping reviews: Time for clarity in definition, methods, and reporting. Journal of Clinical Epidemiology. 2014; 67(12):1291–4. https://doi.org/10.1016/j.jclinepi.2014.03.013 PMID: 25034198

54. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implementation Science. 2010; 5(1):69. https://doi.org/10.1186/1748-5908-5-69 PMID: 20854677

55. Daudt HM, van Mossel C, Scott SJ. Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. BMC medical research methodology. 2013; 13(1):1–9. https://doi.org/10.1186/1741-2288-13-48 PMID: 23522333

56. Pollock D, Davies EL, Peters MDJ, Tricco AC, Alexander L, McInerney P, et al. Undertaking a scoping review: A practical guide for nursing and midwifery students, clinicians, researchers, and academics. Journal of Advanced Nursing. 2021; 77(4):2102–13. https://doi.org/10.1111/jan.14743 PMID: 33543511

57. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. Annals of Internal Medicine. 2018; 169(7):467–73. https://doi.org/10.7326/M18-0850 PMID: 30178033

58. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. PLoS Med. 2021; 18(3):e1003583. Epub 2021/03/30. https://doi.org/10.1371/journal.pmed.1003583 PMID: 33780438

59. Giaxoglou K. ‘RIP man–you are missed and loved by many’: entextualising moments of mourning on a Facebook Rest in Peace group site. Thanatos. 2014; 3(1):10–28.

60. Giaxoglou K. Entextualising mourning on Facebook: Stories of grief as acts of sharing. New Review of Hypermedia and Multimedia. 2015; 21(1–2):87–105. https://doi.org/10.1080/13614568.2014.983560

61. Harju A. Socially shared mourning: Construction and consumption of collective memory. New Review of Hypermedia and Multimedia. 2015; 21(1–2):123–45. https://doi.org/10.1080/13614568.2014.983562

62. Döveling K. Emotion regulation in bereavement: Searching for and finding emotional support in social network sites. New Review of Hypermedia and Multimedia. 2015; 21(1–2):106–22. https://doi.org/10.1080/13614568.2014.983558

63. Keskinen N, Kaunonen M, Aho AL. How Loved Ones Express Grief After the Death of a Child by Sharing Photographs on Facebook. Journal of Loss & Trauma. 2019; 24(7):609–24. https://doi.org/10.1080/15325024.2019.16314568.2014.983564

64. Klastrup L. “i didn’t know her, but.”: Parasocial mourning of mediated deaths on Facebook RIP pages. New Review of Hypermedia and Multimedia. 2015; 21(1–2):146–64. https://doi.org/10.1080/13614568.2014.983564

65. Klastrup L. Death and Communal Mass-Mourning: Vin Diesel and the Remembrance of Paul Walker. Social Media and Society. 2018; 4(1). https://doi.org/10.1177/2056305117751383

66. Sawicka M. Searching for a narrative of loss: Interactional ordering of ambiguous grief. Symbolic Interaction. 2017; 40(2):229–46. http://dx.doi.org/https://10.1002/symb.270.

67. Schotanus-Dijkstra M, Havinga P, van Ballegooijen W, Delfosse L, Mokkenstom J, Boon B. What do the bereaved by suicide communicate in online support groups? A content analysis. Crisis. 2014; 35(1):27–35. Epub 2013/09/27. https://doi.org/10.1027/0227-5910/a000225 PMID: 24067249.

68. Scott SAQ. Social media memorialising and the public death event [Ph.D.]. Ann Arbor: Queen Mary University of London (United Kingdom); 2017.
69. Scott SL. Living in the shadow of a suicide: the narrative of an online internet memorial site created by a survivor of bereavement by suicide—a biographical study. University of Southampton; 2012.

70. Scourfield J, Evans R, Colombo G, Burrows D, Jacob N, Williams M, et al. Are youth suicide memorial sites on Facebook different from those for other sudden deaths? Death Studies. 2019; No-Specified. https://doi.org/10.1080/07481187.2019.1614109 PMID: 31094663

71. Selman LE, Chamberlain C, Bowden R, Chao D, Selman D, Taubert M, et al. Sadness, despair and anger when a patient dies alone from COVID-19: A thematic content analysis of Twitter data from bereaved family members and friends. Palliative Medicine. 2021; 35(7):1267–76. https://doi.org/10.1177/02692163211017026 PMID: 34016005

72. Silvén Hagström A. ‘Suicide stigma’ renegotiated: Storytelling, social support and resistance in an Internet-based community for the young suicide-bereaved. Qualitative Social Work. 2017; 16(6):775–92. https://doi.org/10.1177/1473325016644039

73. Silvén Hagström A. Breaking the silence: parentally suicide-bereaved youths’ self-disclosure on the internet and the social responses of others related to stigma. Journal of Youth Studies. 2017; 20(8):1077–92. https://doi.org/10.1080/13676261.2017.1307330

74. Kasket E. Continuing bonds in the age of social networking: Facebook as a modern-day medium. Bereavement Care. 2012; 31(2):62–9. https://doi.org/10.1080/02682621.2012.710493

75. Lyons M, Ford K, McCray H, Peddie C, Spurdle K, Trusty A, et al. Expressions of Grief in online Discussion Forums—Linguistic Similarities and Differences in Pet and Human Bereavement. OMEGA-Journal of Death and Dying. 2020;003022280914678. https://doi.org/10.1177/0030222820914678 PMID: 32249671

76. Pawelczyk J. Coping online with loss: Implications for offline clinical contexts. Language@ Internet. 2013; 10(8). ISSN 1860–2029.

77. Eriksson Krutrok M. Algorithmic Closeness in Mourning: Vernaculars of the Hashtag #grief on TikTok. Social Media and Society. 2021; 7(3). https://doi.org/10.1177/20563051211042396

78. Gibson M. YouTube and bereavement vlogging: Emotional exchange between strangers. Journal of Sociology. 2016; 52(4):631–45. https://doi.org/10.1177/1440783315573613

79. Hayman J, Chamberlain K, Hopner V. Disembodied social life: the ongoing social presence of the born-still on Facebook. Mortality. 2018; 23(1):65–81.

80. Krysinska K, Andriessen K. Online memorialization and grief after suicide: An analysis of suicide memorials on the Internet. Omega: Journal of Death and Dying. 2015; 71(1):19–47. https://doi.org/10.1177/0030222814568276 PMID: 26152025

81. Krysinska K, Andriessen K, Corveleyn J. Religion and spirituality in online suicide bereavement: An analysis of online memorials. Crisis. 2014; 35(5):349–56. https://doi.org/10.1027/0227-5910/a000270 PMID: 25189112

82. Laing M, Maylea C. “They burn brightly, but only for a short time”: The role of social workers in companion animal grief and loss. Anthrozoos. 2018; 31(2):221–32. https://doi.org/10.1080/08927936.2018.1434062

83. Heathcote A. A grief that cannot be shared: Continuing relationships with aborted fetuses in contemporary Vietnam. Thanatos. 2014; 3(1):2945. ISSN: 2242-6280

84. Xu X, Manrique R, Pereira Nunes B, editors. #RIP Emojis and Words to Contextualize Mourning on Twitter. HT 2021—Proceedings of the 32nd ACM Conference on Hypertext and Social Media; 2021.

85. Brooks LL. Letters to an absent friend: A generative rhetorical analysis of Facebook memorial pages [M.A.]. Ann Arbor: San Diego State University; 2014.

86. Keye WA. #RIP: Social Media and the Changing Experience of Life and Death [M.S.]. Ann Arbor: University of Oregon; 2017.

87. DeGroot JM. Reconnecting with the dead via Facebook: Examining transcorporeal communication as a way to maintain relationships: Ohio University; 2009.

88. Dinning-Bri nkmann R. Memorializing on youtube: An ethnographic study about the phenomenon of video memorials. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2010; 71(6-A):1852.

89. Gray MR. Grieving among Friends: Using Social Media during the First Year of Grieving [Ph.D.]. Ann Arbor: Fielding Graduate University; 2019.

90. McDonald-Kenworthy N. How to be a widow: Performing identity in grief narratives of an online community [Ph.D.]. Ann Arbor: The Ohio State University; 2012.

91. Pattwell AB. Celebrity ghosts in the machine: Mourning the famous online. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2017; 78(3-A(E)):No Pagination Specified.
92. Brubaker JR, Hayes GR. We will never forget you [online]: An empirical investigation of post-mortem MySpace comments. Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW. 2011:123–32. https://doi.org/10.1145/1958824.1958843

93. Brubaker JR, Kivran-Swaine F, Taber L, Hayes GR. Grief-stricken in a crowd: The language of bereavement and distress in social media. ICWSM 2012—Proceedings of the 6th International AAAI Conference on Weblogs and Social Media. 2012:42–9.

94. Getty E, Cobb J, Gabeler M, Nelson C, Weng E, Hancock JT. I said your name in an empty room: Grieving and continuing bonds on Facebook. Conference on Human Factors in Computing Systems—Proceedings. 2011:997–1000. https://doi.org/10.1145/1978942.1979091

95. Vitak J, Wisniewski P, Ashktorab Z, Badillo-Urquiola K, editors. Benefits and drawbacks of using social media to grieve following the loss of pet. ACM Conference on Human Factors in Computing Systems—Proceeding Series; 2017.

96. Akhther N, Tetteh DA. Global Mediatized Death and Emotion: Parasocial Grieving-Mourning #stephenhawking on Twitter. Omega (Westport). 2021:30228211014775. https://doi.org/10.1177/00302228211014775 PMID: 34018436

97. Bingaman J. “Dude I’ve Never Felt This Way Towards a Celebrity Death”: Parasocial Grieving and the Collective Mourning of Kobe Bryant on Reddit. Omega (United States). 2020. https://doi.org/10.1177/0030222820971531 PMID: 33115332

98. Bouc A, Han S-H, Pennington N. “Why are they commenting on his page?”: Using Facebook profile pages to continue connections with the deceased. Computers in Human Behavior. 2016; 62:635–43. http://dx.doi.org/10.1016/j.chb.2016.04.027.

99. Christensen DR, af Segerstad YH, Kasperowski D, Sandvik K. Bereaved parents’ online grief communities: De-tabooing practices or relation-building grief-ghettos? Journal of Broadcasting & Electronic Media. 2017; 61(1):58–72.

100. Campbell K, Smith K. Cybermourning frames and collective memory: Remembering comedian Robin Williams on Legacy.com. Campbell, K, & Smith, K. 2015.

101. Sanderson J, Cheong P. Tweeting prayers and communicating grief over Michael Jackson online. Bulletin of science, technology & society. 2010; 30(5):328–40.

102. Hastings SO, Hoover JD, Musambira GW. “In my heart for eternity”: Normalizing messages to the deceased. Storytelling, Self, Society. 2005; 1(2):11–25.

103. Hastings SO, Musambira GW, Hoover JD. Community as a key to healing after the death of a child. Communication & Medicine. 2007; 4(2):153–63. https://doi.org/10.1515/CAM.2007.019 PMID: 18052815

104. Cassilo D, Sanderson J. From Social Isolation to Becoming an Advocate: Exploring Athletes’ Grief Discourse About Lived Concussion Experiences in Online Forums. Communication and Sport. 2019; 7(5):678–96. https://doi.org/10.1177/2167479518790039

105. Forman AE, Kern R, Gil-Egui G. Death and mourning as sources of community participation in online social networks: RIP pages in Facebook. First Monday. 2012.

106. DeGroot JM. “For whom the bell tolls”: emotional rubbernecking in Facebook memorial groups. Death Stud. 2014; 38(1–5):79–84. Epub 2014/02/13. https://doi.org/10.1080/07481187.2012.725450 PMID: 24517705.

107. DeGroot JM, Leith AP. R.I.P. Kutner: Parasocial Grief Following the Death of a Television Character. Omega: Journal of Death & Dying. 2018; 77(3):199–216. https://doi.org/10.1080/07481187.2017.13490828. Language: English. Entry Date: 20180713. Revision Date: 20180713. Publication Type: Article. Journal Subset: Biomedical.

108. DeGroot JM, Vik TA. Disenfranchised Grief Following a Traumatic Birth. Journal of Loss & Trauma. 2017; 22(4):346–56. Language: English. Entry Date: 20170421. Revision Date: 0190329. Publication Type: Article.

109. Finlay C, Krueger G. A space for mothers: Grief as identity construction on memorial websites created by SIDS parents. Omega: Journal of Death and Dying. 2011; 63(1):21–44. https://doi.org/10.2190/OM.63.1b PMID: 21748920

110. Foot K, Warnick B, Schneider SM. Web-based memorializing after September 11: Toward a conceptual framework. Journal of Computer-Mediated Communication. 2005; 11(1):72–96.

111. Carroll B, Landry K. Logging on and letting out: Using online social networks to grieve and to mourn. Bulletin of Science, Technology & Society. 2010; 30(5):341–9.

112. Halliwell D, Franken N. “He was supposed to be with me for the rest of my life”: Meaning-making in bereaved siblings’ online stories. Journal of Family Communication. 2016; 16(4):337–54. http://dx.doi.org/10.1080/15267431.2016.1194841.

113. Musambira GW, Hastings SO, Hoover JD. Bereavement, gender, and cyberspace: a content analysis of parents’ memorials to their children. Omega: Journal of Death & Dying. 2006; 54(4):263–79. PMID:
114. Han N, Chen G, Li S, Huang F, Wang X, Ren X, et al. Impacts of the COVID-19 pandemic on the bereaved: A study of bereaved weibo users. Healthcare (Switzerland). 2021; 9(6). https://doi.org/10.3390/healthcare9060724 PMID: 34204707

115. Lester D. Bereavement after suicide: a study of memorials on the Internet. Omega (Westport). 2012; 65(3):189–94. Epub 2012/10/13. https://doi.org/10.2190/OM.65.3.b PMID: 23057244.

116. Liu M, Liu T, Wang X, Zhao N, Xue J, Zhu T. A linguistic study of chinese weibo users who lost their only child. Death Studies. 2019:No-Specified. https://doi.org/10.1080/07481187.2019.1686088 PMID: 31709924

117. Pritchard TR, Buckle JL. Meaning-making after partner suicide: A narrative exploration using the meaning of loss codebook. Death Studies. 2018; 42(1):35–44. https://doi.org/10.1080/07481187.2017.1334007 PMID: 28541774

118. Stone LD, Pennebaker JW. Trauma in real time: Talking and avoiding online conversations about the death of Princess Diana. Basic and Applied Social Psychology. 2002; 24(3):173–83. http://dx.doi.org/10.1207/153248302760179101.

119. Karkar AJ, Burke LM. "It's your loss": Making loss one's own through blog narrative practices. Death Studies. 2020; 44(4):210–22. https://doi.org/10.1080/07481187.2018.1531087 PMID: 30574837.

120. Aho AL, Paavilainen E, Kaunonen M. Mothers’ experiences of peer support via an internet discussion forum after the death of a child. Scandinavian Journal of Caring Sciences. 2012; 26(3):417–26. https://doi.org/10.1111/j.1471-6712.2011.00929.x PMID: 21985396.

121. Bousso RS, Ramos D, Frizzo HCF, dos Santos MR, Bousso F. Facebook: A new locus for the manifestation of a significant loss. Psicologia USP. 2014; 25(2):172–9. https://doi.org/10.1590/0103-656420130002.

122. Frizzo HCF, Bousso RS, Borghi CA, Pedro WJA. A expressão de pesar e luto na internet: um estudo de caso mediante o processo de adoecimento e morte de um cônjuge. Rev Kairós. 2017; 20(4):207–31.

123. Babić D. Digital mourning on Facebook: the case of Filipino migrant worker live-in caregivers in Israel. Media, Culture and Society. 2020. https://doi.org/10.1177/0163443720957550.

124. Croson E, Keim-Malpass J. Grief and Gracefulness Regarding Cancer Experiences Among Young Women. Oncology Nursing Forum. 2016; 43(6):747–54. https://doi.org/10.1188/16.ONF.747-753 PMID: 27768132.

125. Wittenberg-Lyles E, Washington K, Oliver DP, Shaunfield S, Gage LA, Mooney M, et al. "It is the 'starting over' part that is so hard": Using an online group to support hospice bereavement. Palliat Support Care. 2015; 13(2):351–7. Epub 2014/02/25. https://doi.org/10.1017/S1478951513001235 PMID: 24559689; PubMed Central PMCID: PMC4143489.

126. Babić D. Digital mourning on Facebook: the case of Filipino migrant worker live-in caregivers in Israel. Media, Culture and Society. 2020. https://doi.org/10.1177/0163443720957550.

127. Pearce JS. Lafayette Strong: A Content Analysis of Grief and Support Online Following a Theater Shooting. Illness, Crisis & Loss. 2020; 28(4):299–320. Language: English. Entry Date: 20201004. Publication Type: Article.

128. Babić D. Digital mourning on Facebook: the case of Filipino migrant worker live-in caregivers in Israel. Media, Culture and Society. 2020. https://doi.org/10.1177/0163443720957550.

129. Radford SK, Bloch PH. Grief, commiseration, and consumption following the death of a celebrity. Journal of Consumer Culture. 2012; 12(2):137–55. http://dx.doi.org/10.1177/0303072216688284 PMID: 28077011.

130. Willis E, Ferrucci P. Mourning and Grief on Facebook: An Examination of Motivations for Interacting With the Deceased. Omega (Westport). 2017; 76(2):122–40. Epub 2017/01/13. https://doi.org/10.1177/003022816688284 PMID: 28077011.

131. Nager EA, de Vries B. Memorializing on The World Wide Web: Patterns of Grief and Attachment in Adult Daughters of Deceased Mothers. Omega: Journal of Death and Dying. 2004; 49(1):43–56. http://dx.doi.org/10.2190/WA9E-AKSL-2P2G-1QP1.

132. Patton DU, MacBeth J, Schoenebeck S, Shear K, McKeown K. Accommodating Grief on Twitter: An Analysis of Expressions of Grief Among Gang Involved Youth on Twitter Using Qualitative Analysis.
133. Kozinets RV. The field behind the screen: Using netnography for marketing research in online communities. Journal of Marketing Research. 2002; 39(1):61–72. https://doi.org/10.1509/jmkr.39.1.61.18935

134. Alemi M, Pazoki Moakhar N, Rezanejad A. A cross-cultural study of condolence strategies in computer-mediated social network. Russian Journal of Linguistics. 2021; 25(2):417–42. https://doi.org/10.22363/2687-0088-2021-25-2-417-442

135. DeGroot JM. Maintaining relational continuity with the deceased on facebook. Omega (United States). 2012; 65(3):195–212. https://doi.org/10.2190/OM.65.3.c PMID: 23057245

136. Huberman J. Dearly departed: Communicating with the dead in the digital age. Social Analysis. 2017; 61(3):91–107. https://doi.org/10.3167/sa.2017.610306

137. Bakker JK, Paris J. Bereavement and religion online: Stillbirth, neonatal loss, and parental religiosity. Journal for the Scientific Study of Religion. 2013; 52(4):657–74.

138. Peruzzo AS, Jung BMG, Soares T, Scarparo HBK. A expressão e a elaboração do luto por adolescentes e adultos jovens através da internet. Estudos e Pesquisas em Psicologia. 2007; 7:0-.

139. Williams AL, Merten MJ. Adolescents’ online networking following the death of a peer. Journal of Adolescent Research. 2009; 24(1):67–90. http://dx.doi.org/10.1177/0743558408328440.

140. Doka KJ. Disenfranchised grief: new directions, challenges, and strategies for practice. USA: Research Press Publishers; 2002.

141. Blando JA, Graves-Ferrick K, Goecke J. Relationship differences in AIDS memorials. OMEGA-Journal of Death and Dying. 2004; 49(1):27–42.

142. Bruns A. Faster than the speed of print: Reconciling ‘big data’social media analysis and academic scholarship. First Monday. 2013; 18(10):1–5.

143. U.S. Department of Health & Human Services. Basic Health and Human Services Policy for Protection of Human Research Subjects. United States of America: 2018.

144. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research B, Md. The Belmont report: Ethical principles and guidelines for the protection of human subjects of research: Superintendent of Documents; 1978.

145. Gerrard Y. What’s in a (pseudo)name? Ethical conundrums for the principles of anonymisation in social media research. Qualitative Research. 2020;1468794120922070. https://doi.org/10.1177/1468794120922070

146. NHMRC A. National statement on ethical conduct in human research. Canberra, NHMRC. 2007.

147. NHMRC A. National statement on ethical conduct in human research. Canberra, NHMRC. 2015.

148. Williams ML, Burnap P, Sloan L, Jessop C, Lepps H. Users’ views of ethics in social media research: Informed consent, anonymity, and harm. The ethics of online research: Emerald Publishing Limited; 2017.

149. NHMRC A. National statement on ethical conduct in human research. Canberra, NHMRC. 2018.