



## Social media as a recruitment method to reach a diverse sample of bereaved parents



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### ABSTRACT

**Background:** Recruiting a diverse group of parents who are grieving the loss of a child into research is challenging. Social media users represent all demographic groups in the United States. Online platforms, such as Facebook and Twitter, may be one potential method to reach and recruit a diverse group of bereaved parents. To our knowledge, this is the first known article to describe social media as a recruitment mechanism for bereaved parents.

**Purpose:** The purpose of this paper is to describe 1) how the social media platforms of Facebook and Twitter were used to recruit bereaved parents into a cross-sectional, online survey, and 2) the effectiveness of social media as a recruitment tool for this population.

**Conclusions:** Social media has the potential to be an effective recruitment tool to reach a diverse group of users. More research is needed, however, to determine the best methods to reach fathers as well as racial and ethnic minorities.

### 1. Introduction

Recruiting bereaved parents to participate in research remains difficult. Despite many ethical and practical challenges (Butler, Hall, & Copnell, 2017), findings in previous studies suggested parents who choose to participate in bereavement research had an overall positive experience (Akard et al., 2014; Butler, Hall, & Copnell, 2018; Dyregrov, 2004; Hynson, Aroni, Bauld, & Sawyer, 2006). Social media may be one novel way to reach individuals grieving the loss of a child to participate in research. The details and effectiveness of recruiting these individuals through social media have not yet been well described.

#### 1.1. Background

Theoretical models of parental grief have traditionally been based on the perspectives of mothers (Phares, Fields, Kamboukos, & Lopez, 2005) and the culture of Anglo-Americans (R. Davies, 2004). Bereavement outcomes may be influenced by multiple factors such as parental gender, cultural norms and beliefs, time since loss, and nature of death (Waugh, Kiemle, & Slade, 2018). Before investigators can develop culturally relevant interventions to address grief-related needs of

diverse individuals who have lost a child, participants that represent diverse cultural views must be included in descriptive research studies. Methods to recruit a more diverse population of grieving parents, such as fathers, racial minorities, and those from lower socioeconomic groups, must be expanded. The recruitment of a more diverse sample of parents, including fathers, into a qualitative study has been previously described (Currie, Roche, Christian, Bakitas, & Meneses, 2016). Little information, however, is available on how to recruit diverse individuals grieving the loss of a child in a community-based setting into quantitative or mixed methods studies which require a larger sample.

Above and beyond traditional clinic and community-based settings, social media, including Twitter and Facebook, is a new way bereaved parents can be reached and recruited to participate in studies. Social media has been successfully used to recruit other difficult to reach populations (O'Connor, Jackson, Goldsmith, & Skirton, 2014). A report in 2018 found Facebook to be the most widely used social media platform for American adults. Overall, 68% of American adults are Facebook users with approximately 75% of those users accessing the platform on a daily basis (Smith & Anderson, 2018). Twitter reaches fewer people but 24% of all adults in America use Twitter (Smith & Anderson, 2018).

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Social media is accessed and used by a diverse group of individuals. The Pew Research Center detailed social media use according to demographic groups. In the United States, 62% of men and 74% of women use Facebook. Users are racially diverse, with 70% of Black Americans and 73% of those who identify as Hispanic using Facebook. Additionally, social media reaches a geographically diverse population with 58% of rural dwellers and 67% of suburban dwellers using Facebook. Many age ranges are active on Facebook. The majority of Americans who are most likely to have a child under the age of 18 are active Facebook users: 18–24 (80%), 25–29 (82%), 30–49 (78%), and 50–64 (65%). Twitter has a younger user base (< 29 years) and but reaches a similarly diverse group of users likely to have children under the age of 18 (Smith & Anderson, 2018).

## 1.2. Purpose

The purpose of this paper is to describe the methodological process of using social media to recruit individuals grieving the loss of a minor child into an online survey. First, we describe the methodological details of the recruitment plan, which used Twitter and Facebook, as a primary means of reaching bereaved individuals. Second, we describe the diversity of the sample who participated in our study so the sample can be compared to the overall diversity of social media users. To our knowledge, this is the first known methodological description of using social media to recruit individuals grieving the loss of a minor child.

## 2. Overview of the study

The exploratory survey was designed to gather information about what digital bereavement tools individuals access (including technology devices, websites, and smartphone applications) and how the use of digital bereavement tools may be associated with psychological and physical outcomes of grief. The initial phase of recruitment took place over 6 months in 2018. The information for this manuscript was gathered in team meetings during recruitment. Analysis of primary and secondary study outcomes are in progress and will be described elsewhere.

### 2.1. Study participant enrollment criteria

Due to the focus on digital bereavement support tools, a sample of participants who were active users of technology were sought. To participate in the survey, participants had to be at least 18 years old and be grieving the loss of a child from birth to the 18th birthday. Prenatal loss was excluded.

### 2.2. Data collection and management

Study data were collected and managed using REDCap electronic data capture tools hosted at East Carolina University (Harris et al., 2009). REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. REDCap generated a hyperlink to the survey that could be used on multiple social media platforms.

## 3. Screening and recruitment

When potential participants accessed the survey, inclusion and exclusion criteria questions were displayed to first establish eligibility. The online consent form was then displayed for eligible participants. Because bereavement is a sensitive topic, the following language was included on each page of the survey: If you have suicidal thoughts or

feelings please contact the National Suicide Prevention Lifeline at 1–800–273–8255 (toll free). Social media was the primary method of recruitment for this study. Two platforms, Twitter and Facebook, were chosen.

### 3.1. Using Twitter as a recruitment mechanism

First, a Twitter account was created using study-specific, university-issued email addresses. The Twitter account included a professional photo of the investigator along with a short biographical description and the investigator's university-issued email address. The Twitter account followed 22 other Twitter accounts that focused on pediatric grief and loss. These other accounts represented international, national, and regional/local organizations. Every effort was made to recruit a sample representative of the United States. Regional and local organizations were not specific to investigator locations. The identified accounts were asked to follow the study-related Twitter account, but only five did so.

Investigators worked closely with the IRB to develop Tweets, which are up to 280 characters, which would be appropriate to use for a sensitive topic such as bereavement. The Twitter account “Tweeted” the approved language which included a hyperlink to the online survey. Tweets included hashtags (written with a # symbol) to index keywords related to pediatric grief and loss so that Twitter users could find the Tweets by using the Twitter search function. Investigators conducted an extensive search using the Twitter search function to identify hashtags commonly used by adults grieving the loss of a child. The hashtags used for this study included #grief, #loss, #bereavement, #bereaved, and #deathofachild. The study Twitter account began to send out Tweets after other pages had been followed and investigators asked the other accounts to ‘retweet’ the study information. Tweets were sent out every two to 3 days for 14 days. Due to low access and enrollment numbers an amendment was submitted to the IRB to expand recruitment to Facebook.

### 3.2. Using Facebook as a mechanism of recruitment

A public Facebook page was created using a university-issued email address. A Facebook banner graphic was created using photographs of the two investigators and university affiliation information. IRB approved language was used to create Facebook posts about the study and each post included the hyperlink to the REDCap survey. The first recruitment strategy was to share the approved posts directly to the Facebook page (Table 1).

### 3.3. Contacting infant and child loss Facebook groups

In an effort to bolster recruitment for the survey, investigators sought partnerships with public groups on Facebook dedicated to pediatric grief and loss. Private pediatric grief and loss groups, which require someone to request access to the group, were not contacted. Both national and regional public groups were considered. The

**Table 1**  
Steps to recruiting on social media.

1. Establish a university or organization affiliated email address
2. Select the most appropriate social media platform and create an account
3. Establish legitimacy
  - a. Post professional investigator photos
  - b. Provide links to university or organization profiles
  - c. Provide university or organization affiliated email addresses
4. Identify relevant groups
  - a. Search for and identify topic specific public groups or pages
5. Contact group or page moderators and leaders
  - a. Establish collaborative relationships with stakeholders
6. Provide relevant study information to social media groups
  - a. Answer study related questions
  - b. Provide relevant documentation, such as IRB approval

investigators used the Facebook search feature to identify relevant groups. The following search phrases were used: *child loss*, *infant loss*, and *parent grief support*. A standardized message was created that introduced the investigators, gave a brief description of the research study, and inquired about collaborating to recruit for the study. The investigators answered any questions the page moderators had about the study and provided documentation of IRB approval if requested.

### 3.4. Contacting general grief and loss Facebook groups

Investigators decided to search for and contact general grief and loss public Facebook pages to improve recruitment. The Facebook search feature was used to search for the following terms: *grief and loss*, *bereavement*, *grief support*, *death of a loved one*. Public groups with the largest number of followers were prioritized for contact. The same standardized message was used to contact page moderators of these groups. Investigators answered questions about the study and provided IRB approval documentation.

## 4. Results

### 4.1. Twitter results

Investigators noted the majority of Twitter pages for grief and loss of a child are for infant and prenatal loss. Prenatal loss was excluded from the study, making relevant pages more difficult to identify. Only five accounts followed the study Twitter page. This fact substantially limited the reach of the study information on Twitter and we did not achieve a snowball effect using the Tweet/retweet method. At the end of 14 days, only five people had accessed the survey and only three people completed the survey.

### 4.2. Facebook results

In a one-month time period, six posts were made directly to the page. Facebook analytics show that these posts were shared a total of 29 times and reached a total of 2455 people. At the end of 1 month, no new participants had completed the pediatric grief and loss survey.

### 4.3. Facebook results for child and infant loss groups

Four groups with a large number of followers were initially identified from the search. Two groups contacted by the investigators never responded to the inquiry. The two groups that did respond engaged with the investigators but did not post the study information to their pages.

### 4.4. Facebook results for general grief and loss groups

Three groups with a large number of followers were identified by investigators. The first group contacted declined to post the study information because the page was reserved to promote their own grief and loss resources. The second group gave the investigators permission to post about the study in the comments section of the page but declined to post the study information as though it was endorsed by the page. The third group agreed to post the study related information. Based on this one post, 46 potential participants accessed the pediatric survey and 24 participants completed the survey over the next 3 months.

### 4.5. Diversity of recruited sample

The mean age of participants who completed the survey was 43.2 (SD  $\pm$  10.2), 100% were female, 96% ( $n = 23$ ) were White, and 42% ( $n = 10$ ) had an income  $<$  \$30,000. The top three causes of death identified were accidents (30%,  $n = 9$ ), congenital malformations

(16.7%,  $n = 5$ ), and cancer (6.7%,  $n = 2$ ).

## 5. Discussion

Though there is enormous potential to reach a diverse sample using social media our study only partially met that goal. The majority of participants were female and White, which is typical of previous studies examining grief and loss of a child (Davies, 2004; Phares et al., 2005). It may be that women are more likely than men to seek large online support systems or that it is culturally more acceptable for women to publicly grieve. Many reasons could potentially explain the minimal racial and ethnic diversity in the sample including cultural components of grief and loss or a distrust of the research and medical community. A different approach to recruiting fathers and racial and ethnic minorities is needed. Future strategies might include contacting Facebook or Twitter pages specific to fathers and racial and ethnic minorities.

Where our study did succeed was in recruiting those with a lower socioeconomic status and including many types of child loss. With a larger sample it may be possible to examine parental grief and loss outcomes by the nature of death. Furthermore, income was distributed relatively evenly in the pediatric arm of the survey which reflects the demographics of social media users.

Losing a child remains a relatively uncommon experience for parents and rates of child mortality have been declining for last several decades (*Infant, child, and teen mortality*, 2018). Because of this, grieving parents can be difficult to locate and contact through more traditionally used recruitment methods, such as medical records and medical institution databases. Medical records and databases are often limited to one institution or institutional system and may not identify parents who had a child die outside of a medical system, such as a loss due to suicide. Moreover, recruiting from one type clinical area may significantly limit the age range of children who have died whose parents are included in the study. For example, recruiting from the Neonatal Intensive Care Unit would limit the sample to those grieving the loss of an infant.

Parents of older children, such as teenagers, may have a very different grieving experience and need different grief support resources than parents who experience the loss of an infant (Davies, 2001; Morris, Fletcher, & Goldstein, 2018; Wilcox, Mittendorfer-Rutz, Kjeldgård, Alexanderson, & Runeson, 2015). One study suggests parents grieving the loss of a younger child may have an increased wish to be dead compared to parents grieving the loss of an older child, but analysis was limited by a small sample size (Zetumer et al., 2015). Large-scale, quantitative, descriptive studies are needed to further identify potential differences in how individuals grieve the loss of a child based on age of the child and nature of the death. Social media provides a platform to reach parents who have lost children from birth to age 18 as well as parents who have lost children for many reasons including illness, accidental injury, or suicide.

An unfortunate consequence of having so few individuals grieving the loss of a child is there are often few readily available supports in both the community setting or from healthcare providers with up to 60% of individuals grieving a child reporting it is too difficult to find help (Lichtenthal et al., 2015). This lack of basic resources for grieving a child is further compounded by the relative lack of diversity among those recruited into bereavement research (Currie et al., 2016; Davies, 2004; Phares et al., 2005). Without inclusive samples representing racial and ethnic, geographical, socioeconomic, and language diversity, the few available resources will continue to not be relevant for many individuals.

Recruitment using social media is still a relatively new phenomenon that is increasingly complicated by the number of popular social media platforms available to the public. Social media, however, has a diverse group of users and may be one avenue for researchers to begin to locate and recruit a more diverse sample of grieving parents. Additional research is needed to determine the appropriateness of social media

recruitment in a population of individuals grieving the loss of a child. Researchers also need to further examine which social media platforms are best suited for this type of research. Because evidence on parental preference for recruitment methods is limited, investigators should consider adding a few additional questions to bereavement studies to examine the acceptability and feasibility of the methods used for recruitment.

## 6. Conclusion

Bereaved parents have positive experiences when participating in research but a diverse sample can be difficult to reach for a variety of reasons. Social media users are a diverse group of individuals that represent many different demographics in the United States. Social media has the potential to reach a diverse sample of individuals grieving the loss of a child but further development and implementation of the methods are needed for it to be a viable means of recruitment for this population.

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## Declaration of competing interest

The authors have no disclosures.

## References

- Akard, T. F., Gilmer, M. J., Miller, K., Steele, A. C., Hancock, K., Barrera, M., & Gerhardt, C. A. (2014). Factors affecting recruitment and participation of bereaved parents and siblings in grief research. *Progress in Palliative Care*, 22(2), 75–79. <https://doi.org/10.1179/1743291X13Y.0000000071>.
- Butler, A. E., Hall, H., & Copnell, B. (2017). Ethical and practical realities of using letters for recruitment in bereavement research. *Research in Nursing & Health*, 40(4), 372–377. <https://doi.org/10.1002/nur.21800>.
- Butler, A. E., Hall, H., & Copnell, B. (2018). Bereaved parents' experiences of research participation. *BMC Palliative Care*, 17(1), 122. <https://doi.org/10.1186/s12904-018-0375-4>.
- Currie, E. R., Roche, C., Christian, B. J., Bakitas, M., & Meneses, K. (2016). Recruiting bereaved parents for research after infant death in the neonatal intensive care unit. *Applied Nursing Research: ANR*, 32, 281–285. <https://doi.org/10.1016/j.apnr.2016.08.012>.
- Davies, A. M. (2001). Death of adolescents: Parental grief and coping strategies. *British Journal of Nursing*, 10(20), 1332–1342. <https://doi.org/10.12968/bjon.2001.10.20.9365>.
- Davies, P. (2004). New understandings of parental grief: Literature review. *Journal of Advanced Nursing*, 46(5), 506–513. <https://doi.org/10.1111/j.1365-2648.2004.03024.x>.
- Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science & Medicine*, 58(2), 391–400.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>.
- Hynson, J. L., Aroni, R., Bauld, C., & Sawyer, S. M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine*, 20(8), 805–811. <https://doi.org/10.1177/0269216306072349>.
- Infant, child, and teen mortality. Retrieved from <https://www.childtrends.org/indicators/infant-child-and-teen-mortality>.
- Lichtenthal, W. G., Corner, G. W., Sweeney, C. R., Wiener, L., Roberts, K. E., Baser, R. E., & Prigerson, H. G. (2015). Mental health services for parents who lost a child to cancer: If we build them, will they come? *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 33(20), 2246–2253. <https://doi.org/10.1200/JCO.2014.59.0406>.
- Morris, S., Fletcher, K., & Goldstein, R. (2018). The grief of parents after the death of a young child. *Journal of Clinical Psychology in Medical Settings*. <https://doi.org/10.1007/s10880-018-9590-7>.
- O'Connor, A., Jackson, L., Goldsmith, L., & Skirton, H. (2014). Can I get a retweet please? Health research recruitment and the twittersphere. *Journal of Advanced Nursing*, 70(3), 599–609. <https://doi.org/10.1111/jan.12222>.
- Phares, V., Fields, S., Kamboukos, D., & Lopez, E. (2005). Still looking for poppa. *The American Psychologist*, 60(7), 735–736. <https://doi.org/10.1037/0003-066X.60.7.735>.
- Smith, A., & Anderson, M. (2018). Social media use 2018: Demographics and statistics | pew research center. Retrieved from <http://www.pewinternet.org/2018/03/01/social-media-use-in-2018/>.
- Waugh, A., Kiemle, G., & Slade, P. (2018). What aspects of post-traumatic growth are experienced by bereaved parents? A systematic review. *European Journal of Psychotraumatology*, 9(1), 1506230. <https://doi.org/10.1080/20008198.2018.1506230>.
- Wilcox, H. C., Mittendorfer-Rutz, E., Kjeldgård, L., Alexanderson, K., & Runeson, B. (2015). Functional impairment due to bereavement after the death of adolescent or young adult offspring in a national population study of 1,051,515 parents. *Social Psychiatry and Psychiatric Epidemiology*, 50(8), 1249–1256. <https://doi.org/10.1007/s00127-014-0997-7>.
- Zetumer, S., Young, I., Shear, M. K., Skritskaya, N., Lebowitz, B., Simon, N., & Zisook, S. (2015). The impact of losing a child on the clinical presentation of complicated grief. *Journal of Affective Disorders*, 170, 15–21. <https://doi.org/10.1016/j.jad.2014.08.021>.