The worldwide surge in the use of social media, especially during the COVID-19 pandemic (Pennycook et al., 2020), has sparked an increase in its use for research (Wilson et al., 2012). Despite this increased use, a dearth of information on best methodological practices in this area exists, especially for certain types of qualitative methods—like visual methods (Snelson, 2016). Given this gap, and the recent push to embrace new online methodological opportunities during the COVID-19 pandemic (Kobakhidze et al., 2021; Lobe et al., 2020), identifying lessons learned using social media for qualitative work is essential.

Debates abound regarding the pros and cons of Facebook for personal use and in research (Majeed et al., 2020). Nonetheless, its use in qualitative research is common, given how much of people’s social lives are described and recorded via the platform (Franz et al., 2019; Snelson, 2016). While scholarly analysis of Facebook-based qualitative research is limited, a small body of relevant literature has emerged. A few scholars have written about the challenges associated with Facebook-based qualitative research, specifically regarding ethical issues such as access to technology (Weiner et al., 2017) and participant privacy (Franz et al., 2019). Others have described the use of Facebook as an ethnographic site (de Jong, 2015; Tunçalp & Lê, 2014), as a tool for recruiting hard-to-reach groups (Weiner et al., 2017), and as a platform for conducting focus groups (Lijadi & van Schalkwyk, 2015). The published literature on Facebook as a platform for visual qualitative research—particularly for research on interventions that incorporate visual imagery—is decidedly limited. For exceptions, see the following: Groot et al. (2021), Haines-Saah et al. (2015), and Struik and Baskerville (2014). Growing use of Facebook as a qualitative research tool suggests that the field would benefit from more methodological descriptions and dissemination of lessons learned (Franz et al., 2019).

To that end, in this commentary, we describe our use of Facebook as a platform for the delivery and testing of Caregiver Speaks, a U.S.-based storytelling intervention that uses photo-elicitation to support caregivers of persons living with dementia. We describe the intervention and share our successes and challenges using Facebook as an intervention and data collection site for images and text. While beyond the scope of this commentary, additional information on the intervention and its ongoing clinical trial is available elsewhere (Rolbiecki et al., 2021).

Description of Caregiver Speaks

Caregiver Speaks (CS) is a technologically mediated storytelling intervention that utilizes photo-elicitation (Harper, 2002) and social networking via Facebook to help active and bereaved caregivers of persons living with dementia (PLWD) make meaning of their caregiving and bereavement experiences. This meaning-centered intervention is informed by Park and Folkman’s meaning-making model of stress and coping (Park & Folkman, 1997), which posits that when individuals can make sense of, or potentially find benefit in, their adverse life experiences (e.g., caregiving and bereavement), they are better able to make meaning of these experiences, which results in lower depression and anxiety. In CS, participants post photos to albums within their respective Facebook groups (either active caregiving or bereaved caregiving) and share stories with other caregivers about their experiences.
Our selection of Facebook as the platform for CS was motivated by a number of different factors. Perhaps most significantly, because Facebook is a free and widely available site with which many American adults are familiar, its use reduced numerous barriers to participation. Sharing and discussion of images and corresponding text, as is involved in the CS intervention, is easily accomplished on the site. In addition, features such as the ability to designate groups as hidden (not discoverable via search) and private (access restricted to approved group members), greatly enhanced participant privacy.

Summary of CS intervention participation: Upon providing consent to participate, caregivers are given a brief orientation to the CS intervention, including a discussion regarding privacy concerns and, if needed, technical assistance with Facebook (e.g., how to set-up profile and navigate the platform). During this time, the study’s primary interventionist (i.e., the person who actively facilitates the Facebook group for the research study) also discusses elements of the caregiving journey with newly enrolled participants and asks them to describe any images they may wish to feature in their photo-elicitation process. Once orientation activities are complete, the interventionist enrolls participants in the active caregiver Facebook group. Caregivers participate in this group until the PLWD dies, at which time they transition (1 month later) into a bereavement-focused group. The bereavement group includes the same components, but the focus of the photos and conversation are on bereavement.

Photos are the primary vehicle for delivering participants’ stories. Participants share their stories by posting and describing photos that capture their experience providing daily care for PLWD, or their journey through bereavement, in group albums, which are themed according to the study’s guiding meaning-making theory. Themes begin by laying a foundation for the caregiving experience by identifying significant points in participants’ timelines and continue through sharing challenges, strengths, and experiences of ambiguous loss, self-care, hope, and caregiving identity. For example, caregivers may share photos that capture their daily activities caring for their family member or reveal their perceptions of themselves and their interpersonal relationships, including how these changed when they assumed the caregiver role. As a result, discussions about how caregiving affects their views of the world and their future may occur. Caregivers who enter the bereavement group follow the same approach but are asked to share photographs that capture their experiences and perceptions as bereaved individuals (e.g., how their sense of self has changed in bereavement, re-examined priorities for life, relationships with the living and continued bonds with the dead, and how their views of the world and future have changed).

Benefits of Using Facebook to Facilitate Caregiver Speaks

Nearly 70% of Americans report using social media, and Facebook is the most common platform (Pew Research Center, 2021). As such, many caregivers of PLWD have existing Facebook profiles and are familiar with how to navigate the platform. This makes supporting caregivers of PLWD via Facebook a practical and natural extension of current social media usage. With these points in mind, we briefly summarize some of the benefits and successes we have experienced utilizing the Facebook platform to facilitate the CS intervention.

Facebook’s primary intention is to create social networks for its users. The caregiver burden literature suggests that social support plays an important role in reducing the burden associated with caring for PLWD (Xu et al., 2021). Given this, our intention for using FB to deliver CS was to reach a population that is vulnerable to becoming socially isolated as a result of increased caregiving demands (Xu et al., 2021). In our prior work, we found that it is highly feasible to deliver an intervention aimed building connection via shared experience through Facebook (Robbiecki et al., 2018, 2019). Preliminary results from our current CS study reveal that caregivers value the connections they have made with others in the group over shared experiences of caregiving and bereavement. “[What] really struck me [about participating in CS] was [that] it was supportive and nurturing…people who had been [in the group] for a while would reach out to new [members]…it was very nice…it helped me get through my grieving process.” –CS Participant

Facebook is free and readily available to users at any time, day or night. For caregivers of PLWD, the round-the-clock availability of Facebook is particularly useful given their limited availability to attend in-person or regularly scheduled support or therapeutic groups (Xu et al., 2021). Caregivers can access their CS group from the comfort of their own homes, at any time of day, as there are no time specifications for when stories need to be posted.

Facebook features for sharing photos are user-friendly. In many cases, individuals can upload photos to their respective group/album directly from their phone, which makes participating in CS seamless.

Availability of Facebook as a mobile phone app additionally increases the ease with which participants can engage in CS. Most CS participants take photos with their mobile phones. The real-time capture and sharing of photos on Facebook allows for more immediate exchange, support, and validation of experiences.

Mere exposure to a community of people caring for PLWD at the end of life and into bereavement is impactful. Using Facebook to deliver CS helps facilitate a shared connection over a common experience for caregivers of PLWD.

Participants in the CS intervention are encouraged to participate, but not required. Those who do not actively participate by posting photos or text to the group have been identified as passive participants in that they continue to be exposed to information, posts, pictures, and experiences of their fellow participants.
Challenges with Utilizing Facebook to Facilitate Caregiver Speaks

While there are benefits to utilizing Facebook to facilitate CS, challenges do exist. Preliminarily speaking, six (n = 6) of our currently enrolled participants (n = 122) have withdrawn from the study explicitly citing that they prefer not to use the Facebook platform. We have made adjustments to our inclusion criteria and recruitment procedures to address this moving forward. Additional challenges with using Facebook to deliver CS are described below.

Facebook privacy breaches (Isaak & Hanna, 2018; Kozlowska, 2018; Wagner, 2021) and questionable corporate practices may cause participant concerns. We have found that if participants feel confidentiality is at risk via their participation, they are less likely to engage in the group. Recent allegations of unethical corporate behavior (Timberg, 2021) may cause additional participant concerns.

There are varying degrees of comfort when tangibly using the platform, despite it being familiar. Some participants may feel familiar with the platform for general use but are unfamiliar with engaging in a private group setting or using specific tools and features within the platform. We have found it helpful to provide a technical assistance call to every CS participant, independent of their stated comfort with Facebook, which can be time- and resource-intensive.

Participant privacy settings and notification settings are unique to that user and need to be identified prior to engaging in the CS intervention. Privacy settings that do not allow the interventionist to easily locate the prospective participant within the platform, send an invitation to the private group, or allow participants to be notified of activity within the group are identified as challenges within determining each participant’s privacy settings.

Building rapport with participants via social media platform can be challenging. The CS intervention asks participants to disclose vulnerabilities, and the extent to which rapport has been established with the group facilitator and other members can influence the depth and richness of the intervention experience. Meaningfully expressing authenticity and empathy—key elements of rapport-building—can be challenging via technology.

Variability in the number of participants present in the Facebook group can challenge the level of engagement. During times where study enrollment is slow, activity within the group often decreases and fewer images and stories are exchanged.

Ethical considerations of the CS intervention present some challenges. Participants share photos of their experiences, and although not required, some participants choose to share photographs of the PLWD for whom they provide care. As is often the case for PLWD at end of life, the incapacity to make decisions about sharing pictures via social media presents a consideration of the ethics in doing so. At this point, participants are asked to consider the wishes of the PLWD and, as their caregiver, determine the appropriateness of sharing pictures or personal information about the PLWD’s diagnosis, illness, and disease progression.

Conclusion

As the COVID-19 pandemic continues, it is reasonable to assume that more qualitative scholars will use Facebook as a tool for conducting research, particularly those who are studying visual qualitative methods and/or those who are conducting intervention research. With this in mind, an in-depth awareness of the benefits and challenges of conducting visual qualitative intervention research via Facebook is needed. As noted in this commentary, it is feasible to use Facebook as a tool for delivering visually based interventions, yet important benefits and challenges must be considered.

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