

Understanding the experiences of survivors of a loss by suicide: A photovoice study

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Abstract:

Suicide is a devastating loss that leaves behind many survivors who are left to cope with unique obstacles such as isolation, stigma, and the question of why the death occurred. All of these aspects can lead to negative mental health consequences and make it difficult to express the grief experience verbally. Words may not provide the fullest description of the experience, but photographs may provide survivors the opportunity to share their experience on a deeper level. In this study, the researchers used photovoice methodology to explore the experience of survivors. The result included seven themes with a total of 15 photos. These enriching photographs not only give voice to survivors of suicide, but also bring the survivors' voices out of isolation and provide other individuals within the survivors' community with a powerful message of their grief experiences.

Keywords: Photovoice | suicide | loss | grief | counseling | creativity in counseling

Article:

According to the American Foundation for Suicide Prevention (AFSP), suicide is the 10th leading cause of death in the US, with roughly 44,193 Americans who die by suicide each year (American Foundation for Suicide Prevention [AFSP], 2017). Suicide impacts everyone within the community, especially the loved ones left behind to deal with the aftermath. For every one suicide, between six and 28 survivors of suicide loss are severely affected by grief (Knieper, 1999). For these survivors, the grief process may have negative consequences, with the risk of both physical and mental health ramifications being magnified (Dyregrov, 2002; Erlangsen et al., 2017; Jordan, 2001; Mcmenamy, Jordan, & Mitchell, 2008; Schneider, Grebner, Schnabel, & Georgi, 2011). These consequences include shock, anger, guilt, depression, isolation, anxiety,

shame, self-blame, post-traumatic stress, and other physical complications (Groos & Shakespeare-Finch, 2013; Hunt & Hertlein, 2015; Van Dongen, 1990, 1991).

Magnifications of the aforementioned negative consequences can arise given the complications of grief for survivors of suicide loss. The survivors may question why the person took their life, wish to isolate themselves from others and from the stigma attached to being a suicide loss survivor (Van der Wal, 1990). Indeed, the agonizing question of why the suicide occurred does not always have an obvious answer. While this unanswered question does not make the grief process more difficult for some survivors (Van der Wal, 1990), others feel the loss more keenly due to the lack of understanding why the suicide took place (Currier, Holland, & Neimeyer, 2006). The change in socialization and stigma for survivors of suicide loss can also be difficult to cope with, causing isolation (Jordan, 2001). This isolation can be due to individuals, including family members, not knowing how to respond to a survivor following the suicidal death, further preventing them from communicating with others (Mcmenamy et al., 2008) and experiencing feelings of rejection and uneasiness due to other's discomfort (Peters, Cunningham, Murphy, & Jackson, 2016). This stigma, which differs for survivors of suicide loss than for losses from natural causes (Feigelman, Jordan, & Gorman, 2011), additionally prevents survivors from seeking support from professionals (Bailey, Bell, & Kennedy, 2015; Wilson & Marshall, 2010).

The difficulty that arises from this isolation is the loss of opportunity for survivors to share their narrative, decreasing the ability to make new meaning and adjust to a new reality (Currier et al., 2006; Groos & Shakespeare-Finch, 2013). Sharing one's narrative around suicide loss has been shown to have positive effects. Specifically, Dyregrov, Dieserud, Hjelmeland, Straiton, Rasmussen, Knizek, and Leenaars (2011) found that sharing one's story about loss helped survivors gain insight and assist others by encouraging them to seek support. Yet, while sharing one's narrative has been found to be helpful, many survivors report they silence their voice or avoid talking about their feelings because of the stigma surrounding suicide and the influence this stigma has on interactions with others (Maple, Edwards, Plummer, & Minichiello, 2009; Peters et al., 2016). The ability to share one's story may be even more important for survivors of suicide loss since many questions exist around the loved one's actions. Neimeyer (2006) indicated that a loss by suicide is considered traumatic and does not easily transfer into a comprehensible story, making it difficult to incorporate the loss into a survivors' narrative. Given the difficulties in expressing one's story directly to others due to stigma associated with suicide, and with the difficulties in finding words that communicate internal experiences, a need exists for more outlets to allow survivors to describe what they want others to know.

While qualitative interviews have been successful in providing insight into the experiences, not all survivors of suicide loss are able to verbally express their experience. Previous interviews have provided some idea of the following: (a) experienced isolation and stigma; (b) the need for different types of support; (c) the difference in this grief experience compared to other losses; (d) the complete change in routine; and (e) the question of why (Bailey et al., 2015; Peters et al., 2016; Van Dongen, 1990). Given the need to better understand this population's experience, and to explore if other aspects of their narrative emerge when survivors of suicide loss can use a different non-verbal modality, the researchers of the current study used photographs to help survivors communicate their stories. The researchers believe this study is needed in order to inform mental health counselors of the experience of survivors of suicide loss, in addition to

providing a voice for clients who have experienced a loss by suicide, so they may communicate their lived experience to others. The following research questions were addressed: (a) What are the experiences of survivors of suicide? and (b) what do these survivors want others to know about this experience?

Methods

Photovoice methodology

Photovoice was used because it acknowledges that individuals are the experts in their experience and provides a way for them to communicate their experience visually (Wang, 2003). Photovoice is a qualitative participatory action methodology and is designed to offer participants the opportunity to acknowledge and represent their experience through photographs (Wang, Yuan, & Feng, 1996), construct meaning out of their experience (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009), and communicate to others their internal experience (Wang & Redwood-Jones, 2001). Photovoice is often applied to populations that are vulnerable or marginalized because it provides an opportunity to actively share their voice that may or may not be heard within their community (Wang, 2003). This method is effective at providing visual pictures to facilitate community understanding of participants' experiences, particularly when words are not available to describe or explain a particular circumstance. The strengths of this methodology include the empowerment of participants by acknowledging their experience and advocating for changes in treatment, knowledge, or policies through the communication of their experiences (Wang, 2003).

Participants

One loss by suicide support group at a local hospice setting was selected. To be a member of this group, individuals needed to have experienced the loss of a loved one by suicide and be 18 years of age or older. The final sample consisted of five participants (two males; three females), the majority of which self-identified as White/Caucasian ($n = 3$), with two participants not reporting racial/ethnic demographics. The ages of participants included 29, 40, and 62 years of age (two did not specify age). The type of suicide loss consisted of the loss of a sibling or child. The amount of time since the loss of a loved one by suicide ranged between 18 and 32 months.

Procedures

Once the Institutional Review Board at the researcher's organization approved this project, each member of the loss by suicide support group ($n = 10$) was informed of the study. Seven out of the ten invited participants agreed to take part in the study (70% initial response rate). Reasons for not participating in the study included not feeling ready to partake in this activity at their current stage of grief. Other group members were not able to make the scheduled day and time of the photovoice focus group where data analysis would occur. Of the seven agreeing to participate in the group process, one participant did not consent to his pictures being included in the study. Another participant arrived at the end of the focus group, which did not allow enough time for the participant's pictures to be discussed by the group. Therefore, only five participants' pictures were included in the final results and analysis (50% final response rate). In total, there were 18

photos discussed and analyzed by the group. While the final themes are represented by all 18 photos, quotes and photos for one participant are not included due to dissenting to the research study.

Participants interested in the study were instructed to take photos during the three-week time frame between the recruitment and the photovoice focus group process. Each participant received additional instructions including: (a) to use their phone or camera to take at least three pictures that represented what they would like others to know about experiencing the loss of a loved one by suicide; and (b) to not include pictures of faces or identifying information due to confidentiality of others. Participants were asked to print out or email the pictures to the researcher prior to the photovoice focus group. In the focus group, each participant took turns sharing their interpretation of their pictures including the picture caption and the meaning behind the picture. While participants were instructed to use the SHOWED method in order to structure the interpretation of the photographs (Wang & Burris, 1997; Wang & Redwood-Jones, 2001), some of the participants ventured off from this method of interpretation and communicated the meaning within their photos more generally. The SHOWED interpretation method has been used in many research studies and provides a concise way of constructing meaning to the photographs. SHOWED is a mnemonic device consisting of six questions: (a) What do you See here?; (b) What's really Happening here?; (c) How does this relate to Our lives?; (d) Why does this situation, concern, or strength exist?; (e) How could this image Educate others?, and (f) What can we Do about it?). Ultimately, SHOWED is used as a tool for participants to easily describe their pictures. The opportunity to ask questions or comment on each other's pictures was also provided for the group. Finally, participants processed and analyzed their photographs in the photovoice focus group process, which took 1.5 hours (the typical length of the regular suicide support group).

Data analysis

The initial data analysis was conducted by the participants in the 1.5-hour group session. After each participant had the opportunity to share their photographs, the group placed all the photographs on a table in order to have a clear view of all pictures and physically manipulate them. The first step in the analysis process involved the group members sorting all the photos into themes and labeling the themes as they emerged. The themes reflected the message members wanted others in the community to know about their experience as survivors of suicide loss. While every theme does not contain a picture from each group member, group members came to consensus on the necessity of sharing these themes with individuals who have not experienced a suicide loss. In an effort to reduce the emotional distress of participants, the researcher, as well as the clinical group leader (i.e., employee of the community agency, not associated with the research study) were present in case of needed support. After the conclusion of the group experience, the researcher transcribed all the notes and quotes from the group members. This process provided more depth and clarity of the themes that participants acknowledged.

Results

Seven themes emerged during the data analysis including: (a) Lonely Struggle; (b) Everything has Changed; (c) Everyone has a Story; (d) Changing Emotions; (e) Choices; (f) Beyond the Horizon; and (g) Unsettled Forever. Each of these themes are discussed. It should be noted that three of the themes (e.g., Lonely Struggle, Everything has Changed, and Everyone has a Story) seemed to represent photos and comments from all the group participants and were the most discussed themes. The four additional themes were unique to some of the survivors of suicide loss and did not represent photos and quotes provided by the entire group; however, group participants agreed that these four themes were important as each theme represented different parts of the experience for individuals, revealing the uniqueness of their stories. Each theme is discussed below.

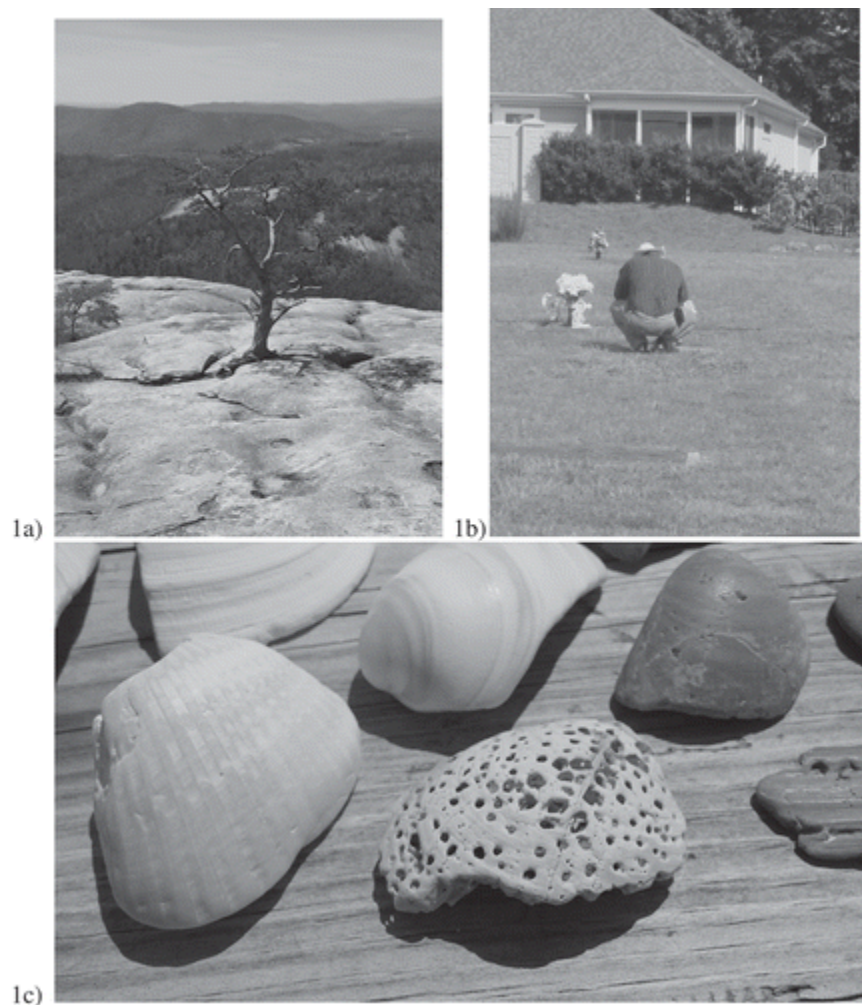


Figure 1. (a) The struggle, (b) Father daughter dance, and (c) Pieces of whales.

Lonely struggle

This theme developed from two pictures provided by two of the five group members. However, all group members came to a consensus that this was a relevant theme that existed in their lives. The “lonely struggle” encompasses the fight that both the victims of suicide and survivors of suicide loss face. John emphasized this theme by stating, “We are struggling to live and to get

along just like the person was. They felt lonely, isolated, and were struggling to do things in a difficult situation from their point of view.” A photograph of a tree standing alone in the middle of a rock cliff representing loneliness supplemented this quote (Figure 1a).

Participants discussed the difficulty they have admitting that their loved one felt this loneliness while also acknowledging a similar, and yet unwanted feeling, within themselves. The stigma of their suicide loss, combined with the complexity of their own grief, creates this loneliness. Susan discussed her own grief experience and the loneliness by voicing, “We have the fresh trail of grief always, and people we don’t know have forgotten and we have not forgotten. Our grief is still tight, other people are at different points.” Susan wanted to emphasize the fact that people around her have forgotten that she is grieving and that everyone who experiences a suicide loss is different and should not be put into one category. Both of these points that Susan emphasized contribute to the loneliness she feels and the disconnection she feels from others in her loss.

Everything has changed

Participants expressed that they believed experiencing a loss by suicide was a life-altering change. While life generally had changed, participants also recognized a need to reevaluate their priorities and their lives as a whole. All participants acknowledged that this theme was relevant in their lives. Three pictures, along with quotes, represented the “Everything has Changed” theme. Participants discussed that change had occurred at multiple levels within their lives. First and foremost, change occurred with the absence of their loved one, but it also occurred at a level including the smallest details such as keeping the house clean. Ultimately, the consensus was that their lives, and everything within it, from priorities to perceptions, to day to day living, was altered.

In reference to the loss of her daughter, Molly brought in a picture of a man squatting down in front of a grave marker. When commenting on the photo Molly said, “that is forever how he will visit his daughter and take care of his daughter. He goes and cleans the grave marker. That will forever be the two of them” (Figure 1b). Following the presentation of this photo, the group discussed how the overwhelming feeling resulting from a forced change, such as loss by suicide, did not allow for any preparation. This loss, combined with the lack of preparation, ultimately altered everything in their life resulting in changes, typically in undesired ways. The helpless feeling this change brought about led to difficulties in accepting the loss. This difficulty was explained by Susan’s reaction to a picture of a top hat that reminded her of celebrating the holidays. She stated, “I think people think that holidays are going to be like they used to be, and they aren’t. You need to give people who have lost someone some slack. Maybe I don’t have to smile about it [the holiday].”

While the majority of the discussion was about larger, holistic changes to one’s life, participants also discussed smaller changes. Examples included activities and behaviors that were originally considered a high priority before the suicide loss not mattering as much after. Susan described a picture of a dust bunny (n.b., picture not included) that she found on her floor and related this to her experience of this realization:

Things that used to be important to me, like a clean house, are not very important, and when [people] come to visit me, if I don't think it is important, I am not going to do it. My priorities have changed. Some things that I used to pride myself for, no longer seem relevant or important.

Everyone has a story

Participants noted their belief that everyone affected by suicide, including both the victims and the survivors, present a different story. Thus, the need to understand all the stories was noted as important. However, participants acknowledged the fact that due to victims of suicide no longer with being with us, we cannot truly know their full story. All participants stated their desire to “appear” to be managing well, but acknowledged this façade was merely masking what they were experiencing under the surface. Similar to the victims of suicide, the story of suicide survivors is not fully known either due to this façade. Throughout the group discussion, the majority of the group members prided their ability to pretend to be managing well after their loss but pointed out that “doing well” was only a surface representation.

Two pictures (taken by two different group members) were selected by the group to specifically represent the “Everyone has a story” theme. The first picture was a photograph of a tree stump with various cracks or splits in the wood. Reflecting on this picture, Susan commented on what was below her façade, “We had a solid family, like that big tree was, and now it's shattered and can't be put back together... and people need to realize that it was good when it was good and now it is not.” Group members discussed how other people are not aware of the struggles and healing of survivors of suicide. Therefore, it is not fair to make assumptions about their stories. In the second picture (Figure 1c), Rachel expressed an importance to remember that each survivor of suicide has their own unique story, even if it is below the surface:

All the shells are broken. Some are smoother than others and have clean cuts. We all have different stories, and some are not as bad as some others, and some are more tragic. Some are more smoothed out because they have had more time to heal. Everyone was weathered down in different ways that is a part of life and death. Keep yourself together and keep going on even with all the holes. All survivors are trying to be normal and cope with their own grief, but this is hard to do when things are not normal.

Changing of emotions

This theme (represented by three pictures and contributed by two group members) was described as the unpredictable and instantaneous change of emotions survivors of suicide loss face on a daily basis. Participants noted constantly experiencing emotions that not only linger, but also change drastically, and as a result of this fluctuation of both positive and negative emotions, each day felt new and uncharted. The following quote refers to a photograph of various clouds in a blue, peaceful sky:

For those left behind after the suicide, there are many storms of emotions. These storms are constant for quite a while, but as you heal, the clouds begin to break, and the sun begins to shine. But, without warning, as storms often do, the emotions rage again, and it

begins to rain [tears] or the thunder sounds [anger]. Our hope is that we eventually get to a place where the storm passes as quickly as it formed. I am personally not there yet, but my hope is that this place we long for, where the storms don't rage, will provide the sunshine of peace." [Molly]

This perceived instability of emotions can make suicide grief difficult to manage. Rachel, reflected on a picture of the ocean, which contrasted the brightness of the sky and gloominess of the ocean (Figure 2c):

One second, it can be bright and sunny, and one second you could be drowning, and they can go back and forth because they are so blended together. Acknowledge the feelings and feel them and try not to get too consumed by them because one second you can be up here, and one second you can be down here.

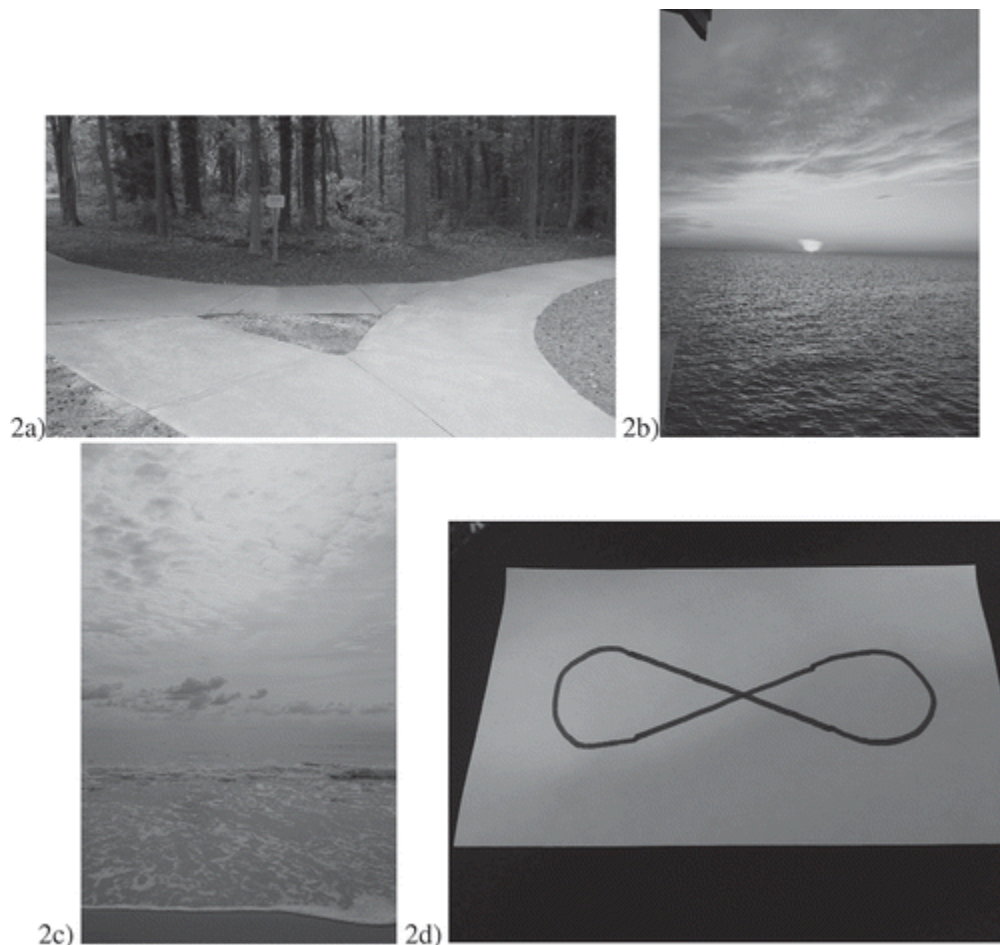


Figure 2. (a) Choice, (b) Slipping away, (c) Waves, and (d) Grief doesn't have an ending.

Choices

This theme refers to the choice that survivors of suicide loss have to make every day about whether to stay in their grief or to move forward. Participants discussed choosing to confront their grief head on or to find a way around it. Two pictures from two of five group members

were selected to represent this theme. Molly described her photograph of a long train blocking a crossroad as a representation of the daily choice she makes to push through her grief. She interpreted this as “Suicide is much like a road block. It stops you in your tracks. Afterwards, we often have to reload to get through our day, a refueling of sorts.” While making these daily choices is difficult, the survivors in the focus group indicated they were choosing to move forward, which required them to find a path through grief each day. Rachel related this meaning to her photograph of a split in the sidewalk that represents two choices when it comes to confronting her own grief: moving through it or standing still (Figure 2a):

You can stay still and stand there with these two options in front of you and go to the dark side or to the light side. You can always turn around and come back and go the other way or walk around in a big circle. You have choices you can pick a path or stand still.

Beyond the horizon

This theme consisted of two pictures provided by one of the five group members. This theme focuses on the victims of the suicide death and the survivors’ awareness of their situation. Participants noted when their loved ones were alive, they were slipping away from everyone, and it is as if one little thing can cause them to be lost forever. John provided a photograph of the sun setting over the ocean. This image of the sun slipping away from people’s sight provided a visual for the core of this theme (Figure 2b). As a result of slipping away, participants felt their loved ones were beyond the horizon and difficult to reach because they could not prevent their suicidal act. John felt that, for his son, “it was dangerous situation he was in, and that it was similar to always being close to the edge of being ok and not being ok.” John wished he could have been “aware that his son was in this situation and nudge him away from the edge even though he seems to be right back at it.” John used a second photograph of a waterfall with a sharp drop off to represent this reflection. Participants within the group emphasized the importance of looking back and knowing the signs and the ability to recognize suicidal acts before they happen because it is important to open your eyes to see what is really going on. However, they also noted that it was a helpless feeling because it is not always easy to see the signs, and even less so when people do not know what to look for.

Unsettled forever

This theme only consisted of one photograph contributed by one group member. While group members had difficulty coming up with a theme for this picture, all members conceded that it needed to be separate because it did not fit in with the other themes, but acknowledged the photo was important. This theme illustrates the permanent and lasting feeling of grief caused by the suicidal loss of a loved one. The grief and aftermath of a loss by suicide was described as “unstable and familiar.” The instability refers to the random triggers that cause a relapse back to the reality of the loss as soon as the survivor is managing their grief well. This theme was represented by a photograph of an infinity sign to explain the continued grief (Figure 2d):

Don’t beat yourself up looking for the day it used to be, because it’s never going to [be]. The community doesn’t have to pat me on the back and tell me, “it’s going to be ok.” I

want the community to know that it's not going to end, and you don't have to work on changing me. [David]

The unsettling consequence of grief resulting from a suicide loss was described as the fact that survivors feel they have to tread lightly around others because survivors have the potential to become irritable or angry at any moment. People can unintentionally provoke survivors of suicide and are ill-prepared to deal with the consequences of this reaction.

Discussion

Suicide is a loss that is associated with feelings of isolation and stigma. It is also considered complex in that it leads to both physical and mental health consequences, which results in complicated grief (Dyregrov, 2002; Jordan, 2001; Mcmenamy et al., 2008; Schneider et al., 2011). This study provided powerful photos that conveyed meaning and insight concerning what the grief experience is like for survivors of suicide loss. Several of the results from this study aligned with previous research. The theme of isolation seems to echo some of the unique aspects of suicide loss including social isolation and stigmatization, which make it difficult for survivors to cope (Jordan, 2001). Survivors experience a great amount of loneliness, which is to be expected when they are compared to individuals who have experienced a loss by natural causes (Groos & Shakespeare-Finch, 2013). However, the agonizing question of why the suicide death occurred was not reflected in the themes of this current study, which may be due to the fact that this group of survivors had been participating in the group for a significant period of time and could have been in a different stage of their healing process. More so what emerged among group participants was the importance of recognizing the signs of suicide and feeling their loved one was beyond their reach prior to their death (as evidenced in the theme "Beyond the Horizon").

While supporting previous findings, the results from this study also add to what is already known about the experience of suicide survivors. Specifically, an important theme that was conveyed is the idea that everyone has a different story and handles their grief differently. Furthermore, there is an importance in refraining from seeing all survivors of suicide as the same and to understand that interacting with one individual may not be the same as the next. The theme "Everyone has a Story" also communicates the need for these individuals' voices to be heard and for opportunities to be provided for them to do this. Another theme added through photographs in this study, included "Beyond the Horizon." This theme differs from previous themes in that it found survivors of suicide loss experienced self-blame, judgment, and rejection (Trimble, Hannigan, & Gaffney, 2012). In the current study, participants conveyed they did not place blame on themselves, but felt their loved ones were beyond their reach. This may also be due to the length of time since the loss of their loved ones, with the possibility that the survivors in the current study had moved passed this initial self-blame stage. Finally, this group of survivors wanted the community to understand that their life will never be normal again. Indeed, they will not be able to go back to what was normal, and in fact, they may need to embrace a "new normal." The new normal was more unsettling and undesired, and resulted in constantly changing emotions. It takes effort to grieve and continued choice and energy to continue to move forward, which is something people may not see on the immediate surface given that their true stories are hidden beneath the surface and will potentially remain unshared.

Implications and limitations

The photos and quotes that resulted from this study provide practitioners with a better understanding of a survivor's experience. Knowing survivors of suicide loss struggle each day to make a choice to continue moving forward, can get bombarded with emotions that are unexpected, and feel constantly alone is important to know to provide the best care possible. Based on these themes, it is important to prepare survivors of suicide for the continued waves of emotions that may emerge, along with helping them learn how to reach out and communicate to others. Indeed, communication was a struggle that the majority of participants noted in the current study. Additionally, while there may be a commonality of grief across survivors of suicide loss, each story is unique, and counselors should approach each client as such. Given the need for a "new normal," a continued rollercoaster of emotions, and various difficulties in communicating, it is important to check beneath the immediate surface and explore what a survivor of suicide loss may not be telling you or others even when they present as "doing well" on the outside. Helping survivors cultivate a toolbox of available coping strategies for when emotions rage in quick and unexpected ways may be helpful so clients can prepare for triggers and sudden changes in emotions.

Photographs can be utilized, as a tool, by practitioners in their clinical work when working with survivors of suicide, especially since photographs have the ability to highlight the uniqueness of each survivor's story and visually bring these stories to the forefront. Using these transformational images can be useful to convey a narrative when words do not suffice, promoting movement towards more insight (Neimeyer, 1999). Photographs can be used as an expressive arts activity in individual or group settings to help individuals present their unique stories, for which they have no words or may be uncomfortable sharing verbally. Photographs can provide mental health professionals and others a better understanding of the client's lived experience as a survivor.

While there are important implications in this study for mental health counselors, they should be taken in context with the limitations of the study, as well. First, given the qualitative nature and the small number of participants, all experiences among survivors of suicide loss may not be represented. Additionally, the results from this study cannot be generalized to the larger population; however, it should be noted some of the themes found in this study support findings from previous researchers, thus increasing the ability to transfer this knowledge and explore the potential for these experiences among other clients. Finally, the participants in this study may differ from other survivors of suicide given most were older adults who had lost a child or sibling to suicide more than a year ago and had been attending the group for a significant amount of time. These demographic factors could have influenced the themes that were of importance to this group and may be different for other survivors of suicide. In addition, the lack of diversity in the sample can be a limitation in this study as there are many cultural considerations that can influence the grief experience.

Conclusion

The unique approach to this study using photovoice allowed new themes to emerge among survivors of suicide that have not been found in previous studies, thus practitioners can use photovoice as a technique or intervention tool in counseling to help survivors of suicide loss tell their story in ways that may not require the use of words. Additionally, photographs can be used by other survivors as reassurance that they are not alone. Photographs may help decrease the sense of social isolation. Conversations can be started in the counseling room by having survivors present photographs, which in turn, can be shared with other clients who have experienced a suicide loss and help normalize their experience. Photovoice methodology can also be used in advocacy at a larger community or societal level. Indeed, suicide is a problem not only for survivors, but for society at large. Using photographs taken by survivors of suicide loss can increase the potential understanding of family members and individuals within the community of the impact suicide loss can have. This understanding not only has the potential to decrease social isolation for survivors of suicide loss, but also may speak to individuals considering suicide as they may have a better understanding of the impact suicide may have on the family and friends they leave behind.

Disclosure statement

No potential conflict of interest was reported by the authors.

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