

Australian Social Work



Date: 14 July 2017, At: 04:29

ISSN: 0312-407X (Print) 1447-0748 (Online) Journal homepage: http://www.tandfonline.com/loi/rasw20

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To cite this article: Kate Wakelin & Annette F. Street (2015) An Online Expressive Writing Group for People Affected by Cancer: A Virtual Third Place, Australian Social Work, 68:2, 198-211, DOI: 10.1080/0312407X.2014.991336

To link to this article: http://dx.doi.org/10.1080/0312407X.2014.991336

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An Online Expressive Writing Group for People Affected by Cancer: A Virtual Third Place

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Abstract

This paper examines the experiences of members of an online expressive writing (EW) group for adults affected by cancer. An asynchronous online focus group was conducted over six months, with 10 participants providing 103 written responses. Findings revealed a complex relationship expressed between the process of EW for a selected online audience, the product (written work) itself, and the process of engaging with the reflections on this product and the products of others. Of particular interest was the evolution of a virtual third place, The Goat'n'Quill, where participants were able to transcend the limitations placed upon them as a result of their cancer experience. This study provides useful guidance for social work practice. It affirms the value of third places where community members can coconstruct the format and processes to meet their needs. It also confirms the usefulness of technology-based strategies to extend social and emotional care.

Keywords: Cancer; Expressive Writing; Psychosocial Support; Online Support; Cancer Support Groups; Metaphor; Third Place; Virtual Third Place

Living with cancer can be a difficult and isolating experience. Internationally there is clear evidence that many experience psychosocial distress in the shape of anxiety and depression, uncertainty, fear of death, decreased self-esteem, and disruptions to intimate, family, and social relationships (Wiljer et al., 2011). Opportunities to creatively express this distress are often limited. The rise of cancer support groups has met an important need for people to share experiences with others in a similar situation and has led to the development of cancer-specific online communities (Ussher, Kirsten, Butow, & Sandoval, 2006). Individuals write about the cancer experience and share these reflections online with a wider audience through blogs, forums, facilitated online support groups, and other forms of social media (Hong, Peña-Purcell, & Ory, 2012).

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The opportunity to write about experience is also the basis of expressive writing (EW) groups that have emerged as a strategy to reduce distress in those living with serious conditions and life-limiting illnesses (Bruera, Willey, Cohen, & Palmer, 2008; Henry, Schlegel, Talley, Molix, & Bettencourt, 2010; Laccetti, 2007). Such groups aim to marry the positive psychosocial outcomes gained from group support with the more specific benefits that can arise from EW (Gellaitry, Peters, Bloomfield, & Horne, 2010; Smyth & Pennebaker, 2008).

We conducted a study to explore the experiences of a group of people affected by cancer who participated in a Cancer Council facilitated online EW group that became a "virtual third place" (Ducheneaut, Moore, & Nickell, 2007; Moore, Gathman, & Ducheneaut, 2009). It has been argued that "third places" can provide social interaction outside home and work contacts for people with specific interests (Glover & Parry, 2009; Oldenburg & Brissett, 1982; Scott Rosenbaum & Smallwood, 2013) and virtual third places transcend the need for physical presence and shared locality to provide support to individuals (Soukup, 2006). In this instance the group instigated a metaphorical pub called The Goat'n'Quill, which became a shared place where members could post their writing, discuss each other's work, and offer mutual support. This paper examines the EW experience and the value of the virtual third place to 10 individuals who shared their writing and their views in an online focus group.

Background

EW involves participants writing about their deepest thoughts and feelings, related to a past upheaval (Seih, Chung, & Pennebaker, 2011). Popularised as a therapeutic tool (Pennebaker & Beall, 1986) EW programs generally provide participants with structured exercises, aiming to improve various psychological and physical health outcomes. Although the act of writing about stressful or traumatic events has been argued to improve physical and psychological health (Baikie & Wilhelm, 2005; Gellaitry et al., 2010; Morgan, Graves, Poggi, & Cheson, 2008; Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004), the form and structure of EW interventions vary greatly (Graham, Lobel, Glass, & Lokshina, 2008; Greenberg, Wortman, & Stone, 1996; Petrie, Fontanilla, Thomas, Booth, & Pennebaker, 2004). Outcome measures also vary and include physical wellbeing, clinical indicators, life satisfaction, mood, pain, and fatigue (Broderick, Junghaenel, & Schwartz, 2005; Creswell et al., 2007; Petrie et al., 2004; Weinman, Ebrecht, Scott, Walburn, & Dyson, 2008).

Meta-analyses generally support evidence of improved psychological health outcomes but contest the additional claims of physical health benefits (Meads & Nouwen, 2005; Merz, Fox, & Malcarne, 2014; Mogk, Otte, Reinhold-Hurly, & Kröner-Herwig, 2006), particularly with regard to preventative effects on further health problems. Nevertheless, the success of different forms of EW in patients with chronic illness and trauma has led therapists to use this strategy with people experiencing serious illnesses such as cancer (Craft, Davis, & Paulson, 2013).

Social workers have been pioneers in the development of online psychosocial care and use a range of digital media for communication, knowledge dissemination, and etherapy (Finn & Lavitt, 1994; Hunt, 2002; Ley, 2012). Oncology social workers have been early adopters of online therapies to manage geographic distance or hospitalisation during cancer treatments, support initial entry to therapy, and ensure anonymity when needed (Colon, 1996; Colon & Friedman, 2003; Weinberg, Schmale, Uken, & Wessel, 1995). Meta-analyses (Barak, Hen, Boniel-Nissim, & Shapira, 2008) and best practice research (Abbott, Klein, & Ciechomski, 2008) indicate that internet-based psychotherapeutic interventions are as effective as face-to-face therapies, provide greater accessibility, and foster empowerment (Barak, Boniel-Nissim, & Suler, 2008; Street, Wakelin, Hordern, Bruce, & Horey, 2012). A recent review indicated there is still little known about the value of online technologies for EW to assist those affected by cancer to express their feelings with others in a writing group (Merz et al., 2014).

The Cancer Council facilitated online EW group was an asynchronous group set up to provide choice about writing frequency, expressive styles, time of day, and volume, with the possibility to read and respond when not well enough to write. This flexibility enabled participants to structure what we recognised as a virtual third place.

The concept of third place was first described by Oldenburg and Brissett (1982) to describe places outside the home or workplace where social interactions occur, contributing to the development of broader and more meaningful and creative interactions (e.g., pubs, cafes, libraries, and parks). Some of the qualities of third places include: held on neutral ground, a social and economic leveller, easily accessible, conversation as the main activity, home away from home, available to regulars and casual visitors, and with playful mood (Oldenburg, 1989). Similarities in descriptive characteristics of third places have been identified between the virtual (online) and physical worlds. Moore et al. (2009) identified four features of virtual spaces critical to their success as a third place, namely accessibility (ease of discovery and navigation), social density (ratio of users to the size of the space), activity resources (resources available for supporting social activities), and hosts (options available to hosts for managing the space). Virtual places can transcend the limitations of physical spaces such as hospital beds or remote locations or local communities (Colon & Stern, 2010; Steinkuehler & Williams, 2006). When participants create a virtual third place they coconstruct a created and mediated symbolic virtual space where interactions take place in a mutually framed reality.

The Genesis of a Virtual Third Place: The Goat'n'Quill

Although the EW group began with a similar model to other facilitated online support groups, some differences emerged that suggested the participants were using the online space as a virtual third place. Early in the life of the EW group, a participant shared a humorous anecdote about her goat climbing onto the roof of a car. This anecdote initiated considerable online discussion about the positive

attributes of goats including adaptability, resilience, and defiance. The group decided to adopt the goat as a group mascot along with a writer's quill and the name The Goat'n'Quill was born as a virtual pub location for group interactions. It was variously described in terms of location (southern coast of Australia), interior (e.g., open fire, light of setting sun through bevelled window panes), and menu (e.g., slow cooked lamb, chocolate, and free supply of alcoholic beverages—many items which cannot be consumed in real life due to treatment side effects).

Method

The Cancer Council of Victoria established the online EW group in 2010. This group, open to people affected by cancer of any type, operates via the www.cancerconnec tions.com.au online community. This website is owned and moderated by Cancer Council NSW, incorporating a specific area for private online support groups. Group entry is based on self-referral, via the Cancer Council Helpline or other health professionals. Individuals referred to the group undergo an assessment telephone interview with the group facilitator. This is to assess suitability for the group, provide information about how the group operates, and provide referral to other support services.

The group interacts via a private shared blog (viewable only to group members). Conversations are asynchronous, enabling group members to engage and contribute at any time. Members use a pseudonym and there is no minimum level of interaction required for ongoing group membership. Group contributions are commonly in the form of poems, prose, and short stories, interspersed by more general updates and observations from members. Once a contribution has been published on the blog, other members are able to post comments. These may take the form of words of encouragement, personal reflection, or expressive contributions such as an additional verse.

Study Design

Online research methods bring their own ethical challenges in terms of confidentiality, self-determination and paternalism, informed consent, professional-client boundaries, and dual relationships (Reamer, 2012) but also are increasingly popular for diverse and vulnerable populations (Willis, 2012). Focus groups are widely used in social work research (Linhorst, 2002) with technologically-mediated focus groups increasing in use (Allen, 2014). Establishing this group as a professionally facilitated group enabled the careful attention to the ethical challenges by providing a safe, closed online environment that mirrored the EW group conditions. Individual confidentiality was maintained through the use of a pseudonym and self-determination was increased through the asynchronous structure enabling individuals to participate when and how it suited them.

Prior to the project, the Telephone and Internet Support Groups Program Manager (and group facilitator) discussed plans for the study with the members of the group via the blog, inviting discussion and participation. A few group members posted questions about the project and all posts welcomed the opportunity to reflect on their participation. Participants were included if they met the following criteria: were over 18 years, with a cancer diagnosis, and had participated in the online EW group, via the www.cancerconnections.com.au website.

Individuals who indicated interest were emailed an information sheet outlining the study, including aims, procedures involved, and potential risks or discomforts. Posting content within the online focus group was considered consent to participate. Group members were able to post writing when well enough and to "lurk" (observe without actively participating) on the site or make comments on the writing of others as they chose. At the conclusion of the study, all participants had an opportunity to review their contributions, and to withdraw any material they had shared from the study if they wished (no participants requested material to be withdrawn). The research study was granted ethical clearance by the Human Ethics Research Committees of the Cancer Councils in Victoria and New South Wales.

Data Collection: Online Focus Group

The EW group comprised 15 members active within the preceding 12 months. Of these, 10 opted to actively participate in the study. This group comprised eight females and two males, age range 35–79 (average age 50). The focus group participants were given the following conversation starters and asked to respond in writing in their own time.

- 1. What does the expressive writing process mean to you? Are you new to expressive writing or rediscovering writing?
- 2. How is this group different to other types of groups—what makes it helpful or special, which perhaps might not happen if it was not online? Is it more challenging?
- 3. How do you locate yourself in The Goat'n'Quill? Your place, your role, your identity.
- 4. What does keeping company with others in The Goat'n'Quill mean for you? How do you interact?

Participants were welcome to contribute as much or as little as they wished. They were also invited to share any of their own online postings that would provide more insight. Some of the participants also chose to submit some of their writing but this was not used in the analysis. The focus group was active for a period of six months with 103 written contributions from the 10 participants.

Data Analysis

The responses to the focus group questions were subject to a qualitative content analysis method (Graneheim & Lundman, 2004). Participants were allocated a number from P1 to P10 to differentiate their contributions and maintain anonymity.

The two researchers then coded the transcripts independently and identified 17 meaning units. Examples included: the venue, EW process, the rationale for writing, value of the group input, transcendence, life outside cancer, absence of "helpful outsiders", safe space, shared knowledge, being a whole person, and the use of humour. Meaning units were then condensed to reveal the manifest content including the elements of the creative process of writing about cancer, the aesthetics of the crafted product, and the place of metaphor. Finally they explored the latent content related to the key categories of interest focused on self-determination in the cocreation of the metaphoric virtual third place and its therapeutic impact.

Findings

There was an interesting relationship expressed between the process of writing creative poetry and prose for a selected online audience, the product (written work) itself, and the process of engaging with the reflections on this product and the products of others. The tension between the therapeutic and aesthetic process of writing, the value of crafted written product as a tangible expression of that creativity, and the group life that emerged through shared reflections and commitment were key themes that emerged from the analysis.

Creative Process

Participants reflected on the process and function of EW in the online support group context. Many spoke of the sense of urgency or compulsion to write about their experiences of cancer: "I think that I suffer from poetic cancerous diarrhoea!" (P8). There was also the sense of needing to capture the experience in order to assist the integration of this into the whole person: "Having the written word somehow made the experience real...even looking at the words as I wrote them provided some sort of confirmation. It stopped me being in a fog of denial... stopped me from feeling crazy" (P3).

The expression of emotion (without burdening family and friends) was seen as an important element; "paper is safe, it has no feelings, I can't hurt it or offend it or damage it's [sic] little ego" (P3). This was seen as very different to the level of inquiry demonstrated by the medical team: "I do recall my urgency to create something on a different level to the dialogue I was having with the doctors, nurses and empathetic friends. Something that would say to them: 'Here. THIS is how it is for me'" (P1). "When the oncologist asks, 'How are you?' my answer is concrete and misses all the deeply intricate nuances that he/she would find if she/he instead asked me to write a poem about how you are!" (P4).

The EW aspect of this group experience was seen to be particularly important, allowing a greater sense of connection and empathy, as one participant said:

This may take the form of writing that brings us to tears or allows us to laugh out loud. It is this sharing of experiences that for me is so important. I am not mad. There are others like me. (P5)

Expressing emotions in written form also allowed participants to further process their responses, as described by one participant who had had a poor experience with a medical professional: "I wrote a lot about that incompetent doctor then I realised how lucky I was to ditch him. I was angry but did not follow up on my anger as through my writing I decided to let it go" (P8).

For some participants, the process of writing was strongly tied to their sense of identity (and the regaining of this following the cancer experience): "For me, being able to jump off one rock onto another one, keeping ahead of the literal interpretation of what was happening to me, was important. It was a matter of survival. Survival of my identity" (P1).

The process of EW also allowed participants to explore and create meaning: "I have found it's easier to explore the meaning of this whole experience (and life in general) through the beautiful art of language arranged in a way that can be called poetry and narrative" (P4); "This group saved my sanity. It allowed me to express and delve into the layers of meaning of a cancer diagnosis" (P5). Participants also valued being able to add new insights (rather than just repeating what another person had said): "I tend not to post if someone makes a point that I had also thought of. I just leave it be in that situation" (P1).

As described in our previous research into online groups (Street & Wakelin, 2009; Street et al., 2012) humour was seen as an integral element in the life of this group: "The humour (sometimes black) that has also emerged from this site has helped me to piece together my life when it changed irrevocably" (P5).

Crafted Expression

The work produced was also important. It was clear that for some participants, EW helped provide a tangible record of their experiences: "They are like a poetic diary/journal of my cancer journey" (P8), while for others, this was less important: "I wasn't really interested in going through the chronology of what happened. I didn't feel any urge to write that down" (P1). While the need to record more concrete experiences was important, participants also valued the ability to delve into the: "deeper inner self that I am, the part that is real, the part that often I don't even know until the words are there on the page before me" (P4).

Participants found it beneficial to be able to look back over what they had written and see their progression over time (and the acknowledgement from group members of this growth): "When I read over some of it I realise what a dark place I was in for a while and how far I have come...people noticed the change in my tone...as I progressed in my recovery" (P5).

It was clear that decision-making processes extended beyond the considerations of what to write and how to write it, to decisions of whether to post the product online.

Although there was generalised agreement that the group was a safe space to share at times very raw and emotional writing, there was also acknowledgment that not all writing was appropriate to be shared: "[What] I ask myself often is 'what good thing will happen from saying or doing this?' I apply that to posts too, if I feel that no good will happen, I won't post" (P3). There was a sense of self-censorship regarding posting writing related to noncancer related situations: "I do write about it but not on this site as it is not relevant to this site" (P2).

Participants discussed in detail the ways in which the online group aspect contributed to their experiences of EW. For many, the ability to publish in a tangible form was important: "I can touch and see the written word. Sometimes I think that expressing in words makes them seem more real and somehow more valid and allowable" (P3). The immediacy and access of the online group space was also helpful: "I like the fact that I can 'talk' to others at any time on this site. There maybe someone else awake at strange hours of the night, who may respond to my thoughts" (P8).

Participants also appreciated the lack of other factors that may detract from, or prevent attendance at, face-to-face programs:

All we know about each other is the writing. There are no car keys, trams or trains, faces, parking spaces, and commencing times involved...I am aware that everyone will see what I write and nothing more. Unless I write it. (P1)

The freedom to participate at the level comfortable for the individual was also valued, reducing the social expectations sometimes experienced in face-to-face settings: "I like this group because I can write any time about anything. I like to 'lurk' too, especially when I am feeling unwell. I know that lurking is often a therapeutic exercise for me." (P8).

In exploring these aspects with the online focus group, participants strongly linked these outcomes with regaining a sense of control (that had been lost through the cancer experience). As one participant said: "Being able to write in a range of forms without derision or judgement and to be involved with the often lengthy conversations that ensued from a single post have assisted me in developing some control over the experience" (P5).

The Goat'n'Quill as a Third Place

The creation of The Goat'n'Quill as a virtual gathering place was seen as integral to the identity and function of the EW group. Participants described in great detail the physical location and appearance of this virtual pub: "When the sun sets, and casts its red light through the windows, it glows on the mahogany table, and there is a peaceful moment when it seems all is right with the world" (P4).

An aspect that was especially appreciated was the ability to visit The Goat'n'Quill, without feeling pressure to participate: "So...for a while, I will curl up on the window seat in the sun watching the breeze skip on the water and reassure myself that if I have been fortunate enough to survive the curse of 'c'[cancer]..." (P5). "And there are some mirrors on the wall past the bobbing heads and if I look in them the right way I can disappear from view and just watch and think for a while. And nobody minds" (P1).

In The Goat'n'Quill it was evident that participants engaged in online disinhibition (Suler, 2004) through the anonymity provided by the use of pseudonyms. They entered a shared world where they not only made up stories about their own avatars but imagined stories about others, transferring them into people they would like to know and confide in: "The other thing I like is being able to walk in and know everyone. It's amazing, but I have never walked into The Goat'n'Quill and not recognised everyone in there" (P1). "I love how everyone listens to the recitations and everyone nods when the poet finishes—and smiles, and nods again—because we all 'know'" (P4).

Visiting The Goat'n'Quill allowed participants to temporarily transcend the limitations placed upon them as a result of their cancer experience: "I love that I can taste the NZ Sauv Blanc without any contribution from metallic saliva and worn out liver" (P4). "We remove all those items [cancer related] to let go of our cancer.... so that we just become a group of friends who happen to have a few strange things happening in their lives" (P8).

For participants, The Goat'n'Quill had become a place of refuge and solace:

For although this great inn of both quill and goat,

Is a haven, a refuge, that offers rest and hope,

It is the people I meet here who provide the space,

Who allow me to rest and be at peace in this place. (P4)

As is frequently found in other support group environments (Ussher et al., 2006) participants highlighted the value of connecting with others who had been through similar experiences. And as is also common, this bridged practical and concrete information sharing, as well as allowing group members to form emotional connections: "I find it therapeutic and comforting to know that others with cancer have similar feelings... It is also good to find out incidental bits of cancer info that may be of help" (P8).

Another essential aspect was nonjudgemental response: "Most important is not censoring our words, just telling and listening, and lots and lots of laughter and a few tears too" (P3). This neutralising of status is fundamental to the third place and a common element of disinhibition (Barak, Boniel-Nissim, et al., 2008; Suler, 2004). It enabled individuals, who had not felt confident to share their writing previously, to do so: "being able to write and not be judged was critical for me. I have always wanted to write but never been a part of a forum that allowed this to happen without the writing being judged in some way" (P5). Others were encouraged to explore new forms of writing: "They [the group] are encouraging and not critical, which inspires me to try different forms of writing" (P8). This disinhibition enabled participants to

delve deeper into their inner selves without the distraction of adhering to form, or fear of critique: "The process of 'pen to paper' was extremely therapeutic in assisting me in making sense of what my world had become, without having to be overly concerned about the construction or even the content to some extent" (P5). Participants particularly enjoyed freedom from unsolicited suggestions from others (outside the group) regarding complementary and alternative therapies: "Apricot kernals [sic], wheat grass, dried clay extracts and linseed oil are banned from the (online) kitchen. The kernals are for the birds, wheat grass for rabbits and oil for the furniture" (P3).

The private aspect of the group space allowed group members to lower their defence mechanisms in the absence of "helpful" outsiders and connect to their emotions: "Sometimes I just simply want to be heard without judgement and without someone spouting off about how I should be grateful to be alive" (P3). For some, the site provided them with "the opportunity to deal with a huge backlog of stuff that was simmering away wanting to get out" (P2). "I doubt that I would have bared my soul so openly had I been face-to-face" (P5). Alongside this was the need to protect others (outside the group) from the raw reality of the cancer experience; "I wrote a lot about the pain and misery that was not appropriate to share; too much of a burden to place on people I loved" (P3). This was further enhanced by the ability to be anonymous: "Anonymity also allows for honesty (of individual feelings)" (P5).

Discussion

This study showed that an anonymous online asynchronous EW community, without set rules concerning time and structure provided a safe, self-determining virtual place for people living with cancer. As many others have found (Baikie & Wilhelm, 2005; Bruera et al., 2008; Craft et al., 2013; Laccetti, 2007; Low, Stanton, Bower, & Gyllenhammer, 2010; Pauley, Morman, & Floyd, 2011; Zakowski et al., 2004), engaging in the creative process of EW was therapeutic. EW functioned as an outlet for often deeply held thoughts and emotions, enabling participants to process traumatic events and move forward in their psychological recovery by integrating their cancer experiences into their sense of self (Street & Wakelin, 2009; Street et al., 2012; Ussher et al., 2006; Willig, 2009). Peer support fostered a safe and supportive environment for participants to use other group members' writing as a launch pad for their own explorations in an often humorous and playful manner, allowing participants to add layers of meaning to other's experiences as well as their own.

Seeing the words in black and white, published on-screen, validated experiences and enabled participants to gain greater insights. The instant nature of the online space meant that participants could publish at any time, allowing them to say what they wanted to say, when they wanted to say it, rather than needing to wait for an allocated meeting time. The online space also allowed participants to see their own (and others') progression over time. The text-based conversations stripped back some

of the distracting factors that might be present in other settings (Barak, Hen, et al., 2008; Colon & Stern, 2010).

In the absence of a physical space, early interactions to create connections led to a shared virtual third place that took shape as a virtual pub, The Goat'n'Quill. The rich, multilayered descriptions of the pub, and those who visited it, grounded their developing community in a virtual place with rules of their own making. This self-determination was enhanced by the process of disinhibition that led to disclosure on a neutral ground where the restrictions of cancer did not define them (Street & Wakelin, 2009). They ate and drank what they desired, there was no unwelcome advice, they could lurk and read the work of others when unwell, and they could imagine themselves well. EW was delivered to an imagined audience from their self-constructed web presence that functioned as an avatar. The freedom that this anonymity provided was liberating for people who were living with serious, life-limiting disease with its boundaries, rules, restrictions, treatments, complications, unwanted side effects, and lack of privacy. No longer an object of the medical and family gaze, they redefined themselves with an online identity and shared their EW in a virtual pub.

Limitations

This study was limited by its small size and the ability of participants to self-select into the process. EW groups cater for participants who have the interest, writing skill, time, and computer access to participate. Further studies are needed to ascertain whether online EW groups can be structured to become virtual third places. The development of such an imaginative virtual third place may not eventuate for other online EW groups, however the elements of third place are worth considering in the establishment of EW groups with therapeutic and empowerment intent.

Implications for Social Work Practice

The potential to intentionally support virtual third places could become an additional e-therapy strategy for social workers interested in developing client self-determination and social support through online communities in a time of increased need and scarce resources. A number of key elements to support this process were identified. Client anonymity and confidentiality were assured through pseudonyms (which participants transformed into avatars) and the use of a secure host website. "Group fit" was managed through assessment of prospective group members. The asynchronous structure enabled self-determined participation. Disinhibition was managed positively as participants used the distancing process of writing their experiences in poems or prose. Emotional connections were managed through the boundaries set by the group guidelines and processes. In an increasingly virtual world, social work training in the use of EW and e-therapy could provide competence and confidence to manage group transitions to virtual third places.

Acknowledgements

The authors wish to acknowledge the people who agreed to take part in this study at such an important time in their lives. We also want to thank the Cancer Councils of Victoria and New South Wales, especially Mr Felix Ratcliff, Coordinator of the Cancer Connections Program, for his support. Thanks also to Ms Melanie Jepson for her valuable contributions regarding virtual third place.

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