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To ring or not to ring: An interpretive description of cancer patients and caregivers exiting treatment

by Abigail Bridarolli, Jude Spiers, and Edith Pituskin

ABSTRACT

The “ringing of the bell” (RTB) ritual upon the completion of cancer treatment is a common tradition in many centres. There is a paucity of research investigating the impact of this experience on the cancer patient and their caregivers exiting treatment. The purpose of this study was to identify key concepts within the experiences of cancer patients and their caregivers related to the ritual of RTB. An interpretive description (ID) approach was used including open-ended interviews with two cancer patients and their two caregivers. All four participants perceived the experience of RTB as being a positive aspect in the transition out of active cancer treatment. Moreover, RTB created a sense of community and was an important milestone that was symbolic of returning back to “normal life” after cancer treatment. Future work should examine the effects of rituals such as ringing the bell among diverse patient populations and across the cancer transition continuum.

Key words: cancer treatment, ringing the bell, rituals, traditions, transition

Cancer is a disease process that affects nearly every household in Canada. Based on 2010 estimates, half of all Canadians will develop cancer in their lifetime, with an average of 565 Canadians being diagnosed with cancer every day (Canadian Cancer Society’s Advisory Committee, 2017). The empirical evidence has overwhelmingly indicated that patients with cancer suffer from a multitude of intense physical and psychological symptoms regardless of the stage of the disease (Naughton & Weaver, 2014). Over time, researchers have also illuminated methods of coping from their research on patients’ transitions through cancer. Rituals and traditions used to mark and celebrate the completion of cancer treatment are one example of this coping. One such tradition has been termed “ringing the bell” (RTB) and has become a widespread phenomenon in treatment centres across North America and the United Kingdom (University of Texas, 2011).

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The act of RTB signifies the completion of either chemotherapy or radiation therapy and is sometimes referred to as a “victory bell” (Gale, 2019). It involves a physical bell, typically a traditional brass bell or in some cases a gong, that is rung to represent victory obtained through successful treatment. The bell is often hung in the oncology unit or within the specific chemotherapy or radiation treatment suite where others may witness the bell being rung. RTB is a celebration that usually involves the patient, family, significant others and other patients. Frequently, this is a public event within the unit or hospital, so much so that it has created a subculture within cancer treatment centres that the bell will be rung by each patient as they depart from their last round of treatment.

LITERATURE REVIEW

In searching for empirical literature, a professional reference librarian assisted with a multiple database search, (CINAHL, DynaMed Plus, Ovid, and PubMed) using the search terms “Cancer treatment AND bell” and “Cancer treatment AND bell ringing” with no data limitations. The search was expanded using key terms of “rituals”, “traditions” and “cancer treatment”, conducted on October 9, 2017, and repeated in March 2019. There were two results, both anecdotal descriptions of RTB experiences. Kane and Kennedy Sheldon’s (2016) commentary highlighted the importance of RTB as a symbolic representation of the completion of cancer treatment, conceptualizing it as “wake-up call” for many patients. Conversely, Gale (2019) regarded ringing the loud brass “victory bell” near those with terminal conditions as unkind, and possibly unethical, in that it may convey negative psychological sequelae. He reported that some cancer centres in the U.S. are now replacing the victory bell with a certificate, or gift and card from the treatment team. Despite the lack of research, RTB is a topic of increasing conversation in social media. While there are many positive stories surrounding the “ringing of the bell” ceremony in the form of news stories and patient forum postings, there are also indications that not all RTB experiences are positive.

To date, there is no research examining effects of RTB ritual on the patient and caregivers transitioning from their treatment phase. Accordingly, we undertook a qualitative study, aiming to understand the first-person experience of ringing the bell.

METHODS AND PROCEDURES

Interpretive description (ID) was employed because it is orientated towards providing knowledge with the specific intent to inform nursing practice (Thorne, 2016). ID is best suited for research questions arising from complex concerns with the ultimate goal of yielding practical clinical applications. This study was reviewed and approved by the relevant academic and clinical ethical bodies (approval HREBA.CC-18-0129). The setting of this study was a large cancer centre located in Western Canada.

Sample

We used purposive sampling via invitational posters placed in the cancer centre chemotherapy and radiotherapy departments to recruit participants. Inclusion criteria included: patients or a caregiver aged 18 or older; receiving or have received anti-cancer treatments; have rung, or plan to ring the bell at the conclusion of their treatment; able to communicate adequately in English, and; able to understand and give informed consent. Patients were invited to identify a significant other (in whatever capacity) to accompany them as a co-participant in the interview. Patients and their caregivers were invited to contact the study team to learn more about the project. They provided individual written consent and we scheduled a private, mutually agreeable interview location in which to interview the patient and caregiver together.

Data generation and analysis

Following informed consent procedures, audio recorded semi-structured joint patient-caregiver interviews were guided by general trigger questions (Thorne, 2016) developed from the underlying key concepts of transition out of cancer treatment and clinical experience. It was important to have both patient and caregiver in the interview to enhance the possibility of stimulating memories and perceptions of the RTB experience that might not occur when interviewed alone. Topics included their cancer journey experience, experience of the RTB ritual, perceptions of how RTB represented meaning within the transition journey out of active treatment, and the positive and negative impacts of RTB on themselves and others. Interviews, conducted by both the first and third authors, lasted between 60 to 90 minutes.

Field notes were recorded and debriefing occurred with all researchers. Analysis co-occurred, using the approach outlined by Thorne (2016). There are three key components to the ID process, including finding patterns among the data pieces, sorting and organizing the pieces, and making sense of the pattern. The first author was the primary analyst, and the analysis process included iterative coding phases and labelling of any interesting section of text. As coding continued, labels evolved from *in vivo* codes, using the participants' own words or very descriptive labels, to more abstract subthemes that combined similar ideas. As analysis progressed, themes and subthemes were identified in the RTB experiences (Braun & Clarke, 2006). Finally, descriptions were written for each theme and its subthemes. The data coding, themes, subthemes and descriptions were frequently reviewed by the second author and interpretation was discussed in team meetings to ensure consistency and agreement in analysis. Analysis was managed using Quirkos®.

We used the credibility criteria outlined by Thorne (2016) of epistemological integrity, representative credibility, analytic logic, and interpretive authority. The complete lack of empirical research on RTB meant we needed a design and research strategies to allow for the most flexibility and openness to hearing what participants wanted to say. The research team consisted of a trainee (first author), an expert oncology Nurse Practitioner (EP) and expert qualitative researcher (JS). All research and analysis decisions were consensus based, especially the interpretation phase of themes that followed descriptive coding. Including both the patient and caregiver

perspectives ensured we could capture different perceptions of the experience, although the small sample serves primarily to identify potential concepts for further investigation.

RESULTS

Four participants were recruited, two middle-aged cancer patients (one female and one male) and their spouses. The participants with cancer had been diagnosed (breast and oral cancer respectively) within the last two years and had completed radiation therapy within the previous six months. Neither patient identified their stage of cancer at the time of the RTB. Both patient participants were well educated and held professional positions. No adverse events occurred during data collection; rather, both patients and their caregivers felt the opportunity to articulate their experiences was beneficial.

Overall, RTB was a positive experience for all four participants. The tradition provided a sense of community with others undergoing cancer treatment. RTB was an important milestone that was symbolic of their hopes for returning to "normal life" after cancer treatment. The patient participants further noted that this tradition provided a sense of determination in their cancer journey. The themes illustrated below include: 1) sense of community; 2) journey through cancer treatment; and 3) enabling/self-determination.

1. Sense of community

Ringling the bell created a unifying sense of community for all four participants. The ritual created a collective space for patients and caregivers in a hospital environment that, for many, is intimidating and full of uncertainty. Part of the RTB tradition is a system of language that gives both the cancer patients and their caregivers an alternative narrative to an experience that potentially had a negative tone. RTB was perceived as a "rite of passage...something you have in common" with other patients. As one patient said, "it's something you can talk to another cancer patient about. 'Did you ring the bell?' Instead of saying, 'Well, did you complete chemo and radiation?' It's the same... [chuckling] kind of something we have." The sense of community served as a form of informal support not only during the active treatment phase, but into recovery, as well. Friends made during treatment were regarded as important for RTB, as this participant's spouse described, along with the reaction of a friend whose treatment was continuing:

Everybody knew in advance. ... So they said, "I'm 10:15 [for radiation appointment] ... So I'm gonna be here too." ... There was a woman who had re-occurring breast cancer and she started to cry and saying, "What am I going to do when you're not here?" It was quite something. She says, "I wish you were here for the bell." ... I think there is power in the bell. There really is.

None of the participants recalled formally being introduced to the ritual, rather, it was something perceived as patient-led with little involvement from staff:

Well, it's actually patient-led ... because no one tells you about the bell. You read about it while you're sitting there. And then you see people ring it and are so elated. And I remember saying, "Look, there's the bell you can ring when you're done."

The participants described in detail their cancer journey and the fear they experienced when entering the oncology system for treatment. They described staff at the centre as supportive and kind. But the RTB ritual was central to forming an overall cohesive sense of being part of treatment, both personally and as a group of patients and caregivers. Learning about the ritual occurred through a mixture of observation, experience, and storytelling amongst patients and family, as this caregiver explains:

It's the power of – of stories. It's that sense of engagement. It's that sense of being cohesive, and being part of something that, while it's personal, it's bigger than you. [P1: Yeah] And it's – and it's almost a collective piece that one could bridge, in terms of having people say, "I can't wait to ring the bell." You know, instead of, "I'm so embarrassed. Or I just – I'm so uncomfortable – but this is something that I'm looking forward to." And by creating that, that pre-emptive energy and enthusiasm, that's really great.

The cancer experience was perceived as a journey, which is largely controlled while entering treatment, but the journey exiting treatment is unknown.

2. Journey through cancer

The cancer journey through treatment and transitioning to "normal life" was marked by milestones. Participants noted how RTB was a rite of passage, a pivotal moment in their journey, as a concrete and tangible experience in an otherwise turbulent time.

Ah, the ringing of the bell was significant for me. I think it kind of gave me hope, during the radiation, that there was that milestone, that bell to ring.

Cancer journeys commonly have major phases for those with early disease; namely diagnosis, the uncertainty waiting for treatment, and treatment (Adams, 1991). RTB creates a definitive point in time when the transition between one section or stage and the next occurs, and represented a rite of passage that patients exiting active treatment could share.

Just take a breath and be present. Be in that moment. Take some pictures. Be proud of the fact that it's just part of a long, long journey. You're not cured of cancer. You're not... and lots and lots of things are going to happen to you. But for that one five-minute window of your time, relish - enjoy it. Because that's what it is. And take some pictures, and celebrate. You may not feel the best at that very moment. But it will be an accomplishment that you'll be proud of in time.

RTB, as a symbolic event, was described using a variety of metaphors representing a tangible ritual of celebration and closure:

We talked about it being a marathon. It's always been the course of the journey. Ringing the bell is another signpost. A visual and auditory symbol of being able to move forward.

One caregiver saw RTB as one way to "walk the journey" together with staff who are supporting patients through the worst phases of treatment:

To me, ringing the bell is just like, you did it. You – you made it through. Watching the whole process from the outside,

being a spouse, it was so fascinating for me to ... watch, how they [clinicians] dealt with him [cancer patient] saying – I don't know if it was the 20th or 19th treatment - he says, "I'm not doing this anymore. I can't do this anymore." And he was really, really, really sick. I just remember watching as the oncologist says, "Okay, but let's see how you feel – we'll just hydrate you. You're clearly dehydrated." And he hadn't eaten in days and... "Let's see how you feel after this." Rather than saying, "Oh, you can't make that decision and this is what's gonna happen if you don't [continue treatment]." So, the way it was handled was just so brilliant to me. He's, "Okay, I'll try one more." And just that, one step at a time, so that when you do finally ring that bell, from where we started to where we got to, is just an amazing accomplishment. The [hospital] has such a brilliant way of getting patients involved and saying, "This is something that we're gonna do together. We're gonna walk this path together." [Pause] And really, hearing that bell over and over, that's a confirmation that that's exactly what they are doing.

The abruptness of treatment cessation, no matter how planned in advance, could be a shock, and RTB was perceived as a way to relieve some of the stress associated with closure and transition to survivorship:

I think sometimes folks feel numb with the process So all of a sudden, it [treatment] just kind of ends. But I think there are ways to personalize it, in terms of people's own narrative, that had a potential to relieve a piece of it.

3. Enabling and self-determination

Feeling both a sense of being enabled and a sense of self-determination were interdependent experiences for our participants. These worked in tandem to symbolize the sense of empowerment that cancer patients and their caregivers experienced. Ringing the bell allowed the cancer patient a sense of self-determination in a time otherwise marked by turbulence and lack of individual control.

Because if [only] people knew more about the power of the ritual. Because you have so little within your span of control. And so much of it is external to the participant.

Both cancer patients spoke to how the celebration provided them with a sense of "self." The two patient participants both spoke to the value they placed in being enabled to have a sense of control and how every individual "brings their own narrative to that ringing of the bell" and could conduct the tradition in a way that honoured their own personal journey, as one participant noted, "I knew that I wanted to do it my way."

However, participants also talked about the possibility of "jinxing" their recovery, as illustrated in the following quote by a participant who indicated her reluctance to talk about her future journey:

"I don't want to talk about it because I don't want to jinx it." I am not done. I rang the bell - I am done my radiation. But I'm not going to talk to you about it, because I am not cured.

The other patient believed in good luck and regarded RTB as a "lucky charm" that would continue to protect her. While

patient and caregiver participants were predominantly positive, they acknowledged that their experiences anticipating RTB were influenced by how treatment was going at the time. They were able to describe several examples of seeing or interacting with patients who did not have positive regard toward RTB ritual:

I remember seeing this young man who was angry. And he was with someone [a young woman] who was very supportive ... he went to the bell. I remember saying to her, I said, "Well, this is big. I'll take pictures. I will ... video this. Because this is important," and she said, "No. he's not feeling that good about it." And I said he should feel great about it. 'Cause this is one more step done. But that's my perspective on things.

DISCUSSION

This exploratory study has identified key concepts in patient and caregivers' experiences that characterize how RTB can be a supportive ritual for patients and caregivers and how RTB reflects that their lives have been irreversibly changed by cancer (Baker, Beesley, Fletcher, Ablett, Holcombe, & Salmon, 2016).

RTB is a ritual that is a part of the larger transition journey. Transitioning into and out of the phases of cancer care is an emerging topic of interest. To our knowledge, this study is the first to show that the RTB ritual has a clear connection with the overall transition experience, with positive implications for both cancer patients and their caregivers. Exiting treatment and recreating a life post treatment is known to be a challenging transition period for patients (Lewis, 2013). The need to live a "normal life" is defined in two distinct ways: continuity with the past with minimal disruption from cancer versus the future being changed or constrained by cancer (Baker et al., 2016). Returning to "normal life" was a core idea in this study, and RTB represented a way of marking the transition.

The paucity of research concerning this tradition of "ringing the bell" means that although RTB was a positive experience for participants in this study, others may experience a neutral or negative effect, as we saw in shadowed data (Morse, 2001) from our participants. As Gale (2019) reported, many patients with advanced or terminal cancer never get to ring the bell and may well experience negative psychological effects during an already difficult time. Clinicians need to be sensitive to patients' emotions about their journey, and engage in discussions to support their choice—to ring or not to ring is entirely dependent on how the ritual is understood by that person. Likewise, it is possible that family or caregivers may be more enthusiastic about the ritual than the patients themselves. Both caregivers were adamant that RTB should be solely for patients, but perhaps a caregiver bell would recognize that their own journey, while inextricably linked to their loved one's cancer journey, may not always be the same.

Furthermore, while participants reported enjoying the act in the short term, it is unknown how this tradition is later

understood, as exiting treatment and returning to "normal life" is often more complex than expected. Questions regarding whether or not patients would continue to perceive RTB as a constructive or meaningful milestone when the transition does not go as planned needs further inquiry. Similarly, the longer term effects on survivors is unknown. Feelings of uncertainty and abandonment are frequently reported in the months and years following completion of cancer treatment (Hall, Mishel, & Germino, 2014). Our findings suggest a definitive role of rituals in transitioning phases in certain populations, and the need for continued research across the disease continuum.

A noteworthy finding was the role of healthcare providers (HCPs) in the ritual of RTB and the greater transition journey. Specifically, participants in this study spoke to how little the HCPs were involved in the tradition of ringing the bell. Two of them went as far as to say that this was preferable, as it further supported the sense of self-determination associated with being able to have control over at least one aspect of their cancer journey. All spoke positively about interactions with HCPs during treatment. However, both cancer patients reported that HCPs had not been a part of RTB. Additionally, neither the patients nor caregivers were told about the tradition of RTB by an HCP. Rather, the knowledge was spread through word of mouth by other cancer patients or through reading the poems that were placed beside the bells on both the chemotherapy and radiotherapy suites. This indicates that RTB is patient driven, a key characteristic of person-centred care. Future research and clinical work could examine other patient-led supportive traditions and how to best integrate them during the cancer journey.

This study was an initial exploration to identify key concepts central to the RTB experience. As such, there was no intent to transfer our results to other contexts; instead, these concepts can be used as a point of departure. Further work needs to include a wider range of patient and caregivers and include oncology staff perceptions as well.

CONCLUSION

The patient and caregiver participants of this study provided an immersive look into their experiences while leaving cancer treatment, and the role of RTB in their journeys. Specifically, a strong connection of RTB within the larger transition out of cancer treatment was established and represented a meaningful tradition for both patients and their caregivers. The ritual played roles in both the active treatment phase, as well as the transition phase of the cancer journey. During active treatment, RTB served as a symbol of hope, and fostered a sense of community for the patient and caregiver as they received treatment. Upon completion of active treatment, RTB was an enabling and self-determination experience, a tangible milestone in the transition to normal life. Future work should examine the effects of rituals among diverse patient populations and across the cancer transition continuum.

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