CommEmorating the Last Event: calling time on the end of treatment Bell following RAdioThErapy? The CELEBRATE study

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CommEmorating the Last Event: calling time on the end of treatment Bell following RAdioThErapy? The CELEBRATE study

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ABSTRACT

Introduction: In the UK it is commonplace for patients completing radiotherapy to be invited to ring a bell as a form of celebration. The project aimed to explore the experiences of the end of treatment bell from the perspective of patients who had received treatment for cancer, and therapeutic radiographers who treat patients. The study also aimed to consider possible alternative methods of commemorating the EoT, considering the needs of patients, family members and healthcare professionals.
Methods: Online focus groups were held with patients (n = 5) and therapeutic radiographers (n = 4) in December 2020; a joint online event (n = 6) was held in March 2022. They were all facilitated by two members of the research team. Thematic analysis was used for data analysis.
Results: Participants' views and experiences were mixed; however, there was a consensus that alternative forms of commemoration should be available to meet patients' diverse needs. Features of a specification were considered and suggestions made for alternative practices, with a focus upon patients' transition needs after radiotherapy has ended.
Conclusion: The results indicate that departments should consider the harms as well as the benefits conferred by the EoT bell and explore alternative ways to mark an episode of treatment.
Implications for practice: A one-size-fits-all approach is not appropriate in relation to marking the end of an episode of treatment.

Introduction

Ringing an end of treatment (EoT) bell is a practice that has been widely adopted in radiotherapy departments in the UK. The bell is often installed in the reception where the sound travels into the surrounding area. There has been little examination of the impact of this practice upon patients, although positive reactions can be seen in newspaper articles[1] and in social media postings. A small qualitative study (n = 4) has found that there may be some benefits to this ritual[2]; however, there is some evidence that the practice can cause distress to some patients. The results of a cohort, single-centre, prospective study (n = 163)[3] that investigated the impact of the EoT bell in the USA - the country of the EoT bell's origin - indicate the potential harmful effect of this practice. The authors observe that although patients appeared to enjoy ringing the bell, its psychological impact has been unexamined. Their findings show that ringing the bell on the final day of radiotherapy worsened patients' evaluation of overall distress from cancer treatment (mean (standard deviation) 5.6 (2.8) vs 4.7 (2.7) for non-bellringers, $p = 0.045$). Moreover, this distress persisted and even worsened in the months after treatment (6.4 (2.9) vs 5.1 (3.0), $p = 0.009$: mean 103 vs 130 days, $p = 0.056$). The authors speculate that ringing the bell stimulates an emotional response which could heighten the distress incurred by cancer treatment and thus patients' perceived levels of distress.

The potential harm caused by the EoT bell to patients who are not being treated with radical intent, or those living with recurrent cancer, has also been reported in opinion pieces in academic literature and in the media[4,5].[6] Taylor[5] describes hearing the bell ringing as like a 'kick in the teeth,' adding that those ringing the bell are likely to be unaware of the potential negative impact on other patients who are within earshot. In addition, there is anecdotal evidence that some patients feel compelled by family, friends, or health care professionals (HCPs) to ring the bell against their wishes. On the other hand, it has been argued that those who find meaning in ringing the bell should not be denied the opportunity, even though others might find it difficult to witness.[7] Nevertheless, reports that the bell has been removed from one UK hospital[1,8] demonstrates the conflicting attitudes towards the practice and

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an acknowledgement of its potential for harm. The purpose of this study was to evaluate the experience of using the EoT bell from the perspective of both patients and therapeutic radiographers and to identify potential alternative methods of commemorating the EoT which are inclusive of all patients.[9]

Methods

Ethical approval for this qualitative inquiry was gained from the authors' institution (Review ID: ER23634228). A convenience sample of patient and therapeutic radiographer participants was recruited through national charitable organisations and professional interest groups; the study was advertised using a flyer posted on social media, online forums and e-mails. Therapeutic radiographers were included in the study to explore the impact of the bell-ringing practice upon them, as well as the extent to which their beliefs about the practice were aligned with patients' experiences. All eligible interested individuals were recruited; no selection occurred. Written informed consent was obtained from all participants. Focus groups were chosen for data collection due to their capacity to promote interaction between participants using topic prompts provided by the facilitators.[10] Initial focus groups were organised separately for patient and therapeutic radiographer participants to encourage open expression of views and experiences. The use of thematic analysis[11] allowed for open coding of the data, reducing the opportunities for researcher bias in the interpretation of the data.

Data collection

Patient participant (n = 5) and therapeutic radiographer (n = 4) online focus groups were undertaken separately in December 2020, each lasting 2 h and audio-recorded; they were facilitated by two members of the research team. Prior to attending, patient participants were invited to consider three words or images that described how they felt at the end of their treatment. They were encouraged to share these at the start of the focus group and were prompted to reflect upon their feelings about the EoT bell and explore possible alternative methods of commemorating the EoT. Recognising that the activities could evoke some difficult memories for participants, they were checked upon during the focus groups and debriefed and signposted to a range of support services at the end (see supplementary text). Therapeutic radiographer participants were provided with an article[3] to read prior to attending their focus group as a stimulus for thought and discussion.

A further audio-recorded, online focus group lasting 2 h was held in March 2022. It was attended jointly by the patient participants and therapeutic radiographers who were available to attend (n = 6) and facilitated by two members of the research team. This combined group was an exercise in co-design, to formulate a suitable method of marking the EoT which meets the needs of patients, their families and those of the HCPs and the treatment team.

The themes developed from the previous focus groups were shared as a reminder, and to familiarise patient participants and therapeutic radiographers with each other's group themes. They served as a springboard for the group discussion in which all participants were asked to consider the following questions:

> What do you think are the aims of the EoT bell? (What does it intend to offer patients?)
>
> How might these aims be met in alternative ways?

See supplementary text for further details of the focus group plans, including guiding questions.

Data analysis

The focus group audio recordings were transcribed using a professional service which uses encryption to ensure the confidentiality of the files. Subsequently the transcripts were anonymised by two members of the research team. Thematic analysis[11] was used to develop themes and sub-themes inductively from the transcripts. Initially the researchers independently reviewed and analysed the data; they then shared and discussed their respective proposed themes. If any conflicts arose, a third member of the research team would have been invited to make a final decision. All participants were invited via email to comment on the proposed themes from the joint focus group (see supplementary text for prompt questions).

Results

Participant information

Five patient participants and four therapeutic radiographers were recruited to the study (Table 1). Patient participants had previously received treatment for cancer of the breast (n = 3), blood (n = 1) and base of tongue and neck (n = 1). One male and four female participants, with ages ranging from 45 to 69 years, were recruited. Two participants reported having been given the option to ring the EoT bell, which they had accepted.

Some attrition occurred between the individual and joint focus groups due to the difficulties in arranging a date and time suitable for all (patient participant n = 1, therapeutic radiographer n = 1), and the death of one of the patient participants.

Table 1
Demographic details of participants.

Patient participants	Age	Gender	Type of cancer	Option to ring the bell?	Rang the bell?
P1	49	Female	Breast	No	–
P2	69	Male	Base of tongue & neck	Yes	Yes
P3	55	Female	Blood	No	–
P4	52	Female	Breast	No	–
P5	45	Female	Breast	Yes	Yes
Therapeutic radiographer participants	**Age**	**Gender**	**Years since qualification**	**Grade**	**Bell currently used?**
TR1	23	Female	7 months	Band 5	Yes
TR2	46	Female	10	Band 7	Yes
TR3	29	Male	6	Band 6	No
TR4	24	Male	2	Band 5	No

Table
2Key themes and their description.

Key theme	Description
Representation of the EoT bell	Not a moment to celebrate, but a marker of the end of (a period of) treatment, a time for reflection. The bell as intrusive for other patients and exclusionary. There are patients who remain unheard, for whom the EoT bell is never appropriate due to continuing treatment.
Meeting patient need	Emphasis upon listening to patients and respecting their preferences. Appreciating the impact of small actions upon wellbeing. Considering when to discuss with patients their options for marking the end of (a period of) treatment. EoT as a potential time of anxiety for patients due to perceived lack of support when treatment ends: the need to fill the gap and support patients' transition after treatment ends. Patient readiness to engage with information: concerns about providing patients with too much information at the EoT review. The benefits to patients of providing as well as receiving peer support.
Subtheme:	
One size does not fit all	Recognising that everybody's journey is different; and that patient needs change across the treatment pathway. Patients need to be provided with choice and for their preferences to be personalised.
Features of an alternative specification	The options for patients should not be fixed to a particular point in the treatment pathway; promoting reflection; promoting a personalised experience; promoting a sense of support and connection with the patient community; inclusive of the needs of all patients, families, and staff; equitable – offered to all patients; not a replacement for a face-to-face conversation with the patient's HCP; not intrusive to others; evidence-based: drawing on patient experience; mindful of the impact of the language used to describe it.
Subtheme:	
Transition needs	Engendering a sense of connection to other patients; identifying individual patient goals; provision of a list of resources at the EoT review; the role of the department and other provision in meeting transition needs; harnessing patient peer support mechanisms.
Proposed alternatives to the EoT bell	Promoting a reflective experience through touching a stone. Using a digital app for information, symptom monitoring and support.
Subthemes:	
Facilitators to implementation of alternatives	Building upon existing features of the treatment pathway (e.g. embedding encouragement of patient engagement with the initiatives into HCP's job description); empowering HCPs to share up-to-date knowledge; building upon existing expertise and examples from practice; affordability; potential for nationwide implementation; availability of resources for upkeep (e.g. enlisting patient support to update information on app); ability to cater for individual need.
Barriers to implementation of alternatives	Budgetary constraints; conflicting Trust policy requirements; lack of capacity within departments to support the initiatives (e.g. impact on staff workloads; limited HCP awareness and promotion of patient peer support resources; keeping the resources updated); desirability of local specificity of resources for a digital app; the challenge of meeting patients' diverse needs.

The four therapeutic radiographers (Table 1; two male and two female) had levels of clinical experience ranging from seven months to ten years and were aged between 23 and 46 years. Two worked in departments where the EoT bell was being used.

All participants received or delivered treatment from regions across England, including the North East, West and South Yorkshire, Nottinghamshire, Derby, Peterborough, London and the South West of England.

Key themes

The final four key themes (Table 2) were developed from the joint focus group discussion. They consolidated and developed the themes emerging from the first focus groups (see supplementary text). The first focus group round highlighted patients' varied responses to the bell, ranging from excitement to feeling excluded from the activity. Therapeutic radiographer participants also had different views about the practice of ringing the bell, sharing both concern at the potential for harm as well as evidence from practice that the bell was well-received by patients. Both groups explored patients' transition needs after the EoT. While each group's themes did not contradict the other's, there was a different focus. For example, the patient participant group underlined the need for an individual approach to meet need. The practicalities of the EoT bell, including its location and perceived patient suitability to be offered the bell, were discussed amongst therapeutic radiographer participants.

There were no changes suggested to the initial themes circulated to participants (n = 4 responded with feedback). The final key themes were representation of the EoT bell; meeting patient need; features of an alternative specification; and proposed alternatives to the EoT bell (Table 2).

Representation of the EoT bell

Therapeutic radiographer participant 2 noted that the bell was well received by patients in the department where they worked, perhaps due to patients being offered an explanation of the bell's purpose and the choice whether to ring the bell. However there was a range of responses to the EoT bell not only between participants but for the same participants over time. For example, patient participant 5 shared a short video of her ringing the EoT bell at the end of her radiotherapy for primary breast cancer approximately two years earlier, commenting “*you can kind of see the excitement … it felt like a huge celebration … felt like it was all done …*” Her perception was that her cancer could be treated successfully: “*I've finished everything that I'm supposed to do, rung the bell, go back to work.*” After further treatment for secondary cancer, however, she admitted that “*I just didn't feel like ringing it.*” Indeed, some participants commented that they did not feel celebratory. Patient participant 3 drew upon an image of the sword of Damocles hanging over her head to express living with uncertainty about the future:

> “*many people suffering from different forms of life-limiting illnesses, that's what it's like, we never know when that sword of Damocles will (drop). So, even if you ring the bell it might not be the end of treatment …*”

The exclusionary nature of the EoT bell was revealed in patient participant 3's comment that she felt “*left out, because I've never come to the end of my treatment …*” It is reflected in the verse accompanying the bell which includes the phrase “*my treatment's done*” (see supplementary text).

Some criticism of the bell from both patient participants and therapeutic radiographers related to its location within departments. This was due to its potential to cause distress to patients within earshot or sight of the bell rather than the practice of ringing the bell per se. Patient participant 1 identified the long lasting negative impact that ringing the EoT bell had on her:

> *"I ended up with PTSD after I had treatment and the bell was a major, major trigger."*

Therapeutic radiographer participant 2 noted that patients may recognise the potential harm to fellow patients:

> "*I know we had a patient who came back to ring the bell a few days after finishing as she wanted to come at a time where not many patients would be near reception.*"

In the therapeutic radiographer focus group it was highlighted that some patients who are hesitant may feel obliged to ring the EoT bell:

> *"… a number of patients … they said 'I've got to ring this bell' … they feel as if you know, they have to, it's a symbolic thing but just for their family, it didn't mean much to them."* (Therapeutic radiographer participant 2)

The focus during participant discussions shifted from the notion of celebrating the EoT to considering ways to *mark* or *signify* having reached a particular point in the treatment pathway, such as after an agreed number of treatments rather than at treatment end. EoT was also considered a time for reflection.

Meeting patient need

There was a consistent message from participants that 'one size does not fit all' and care should be personalised – *"I think an individualised approach is definitely the answer"* (patient participant 4) - hence this point became a subtheme in its own right. For example, support and counselling provided by their HCP prior to the EoT was perceived as more meaningful for patient participant 2 than the experience of ringing the bell. Listening to patients' preferences and ensuring that there was a point at which patients were told about the options for marking the EoT was deemed important. The significance of small actions upon wellbeing was also highlighted: "… *actually it's all the little things that are most important because they're the everyday things that keep us going* …" (patient participant 3).

There was consideration of when goal-setting could be introduced to patients within the treatment pathway, recognising that post-treatment initiatives such as the *Moving Forward* courses provided by *Breast Cancer Now* incorporate elements of this. Participant discussions were used to reflect upon not only how the EoT is managed but the wider issues of patients' needs as EoT was recognised as a time of transition.

Features of an alternative specification

Consideration of the EoT bell raised questions about how else the EoT, or a phase of treatment, could be marked as participants were receptive to other options:

> "*It wasn't specifically ringing a bell; it was the bell signified a point in time for me. I'd be perfectly happy to do something else or quietly on my own that acknowledges that moment in time as well.*" (patient participant 2)

Several features of an alternative specification highlighted it should:

- be mindful of the impact of the language employed to describe it (for instance, moving away from the notion of *celebrating* towards *marking* an event)
- promote a sense of support and connection within the patient community
- provide an opportunity to promote reflection
- not replace face-to-face interaction with HCPs
- promote a personalised experience
- not be fixed to a particular point in the treatment pathway, given that the significance of each episode will differ between individuals
- be inclusive of the needs of all patients, family members, and HCPs
- be equitable: offered to all patients
- not infringe upon the needs of others – should be a "low-key" event
- be evidence-based, drawing upon the experiences and views of patients and HCPs

A sub-theme relating to the features of an alternative specification was the needs of patients during the transition between ending treatment (or a phase of treatment) and the next stage. However, concern was raised about who might take responsibility for developing care plans and goal-setting; and whether *"we run the risk of overwhelming people with the amount of information we're giving them on the final day if we were to give them extra …"* (therapeutic radiographer participant 4). In addition, there was concern from therapeutic radiographers about a lack of time to update patient information and the impact of outdated details, alongside the potential for some therapeutic radiographers who may lack confidence in correctly signposting patients.

The value of peer support was highlighted, such as online or in-person patient support groups. Engendering a sense of connectedness to other patients through patient peer support was seen as significant. Patients were perceived as "*brilliant at* supporting *each other*" (patient participant 3); additionally, providing support to others brought personal benefits. Proposals for ways to harness this support included adding details of groups to the bottom of hospital letters; posting information leaflets to patients; or creating a digital app.

Proposed alternatives to the EoT bell

Early suggestions for signifying the completion of a stage of treatment included offering patients a certificate or inviting them to have their photograph taken in the department next to the bell or some other feature of their treatment. However, during the joint focus group discussion, two clear options emerged. These were:

- a wall-mounted stone situated in the department, providing something to touch and a space for reflection;
- a digital app providing information, symptom monitoring and support.

A stone for reflection and to touch

Two examples of the therapeutic value of stones were raised by group members. Therapeutic radiographer participant 1 described the introduction of a stone on the wall within the chemotherapy treatment unit of their UK hospital, designed to encourage patients to place a hand on the stone and reflect upon their experiences. The advantages of this approach were felt to include its capacity to provide a personalised experience for patients, and that it could be used by patients at any point during their treatment pathway. The suitability of stones as a source of reflection was highlighted by patient participant 3 who had witnessed the therapeutic worth of stones in her professional work. It was felt that the use of a stone could offer a feeling of connection to others who had touched the stone before them.

A digital app

The proposal of a digital app was also popular among participants. It was seen as having the potential to incorporate the ability to review goals, monitor post-treatment symptoms, and signpost information and support. Innovations in digital resources were known to be in development for some patient groups; patient participant 2 described an app for patients who had head or neck cancer and were deemed low risk for recurrence. Features included the provision of information and signposting support, alongside contact details to enable quick access to HCPs if there were health concerns. Nevertheless, it was suggested that a digital app should not replace the valuable EoT review with a HCP.

A digital app was noted by the participants to have benefits over information in paper format which can be easily mislaid and may not be specific to individual need. Participants suggested that patients may be too anxious or distracted in departmental waiting rooms to take notice of the available leaflets or posters. Conversely, it was agreed by participants that the wealth of information potentially available in a digital app could be tailored to the individual and accessed at a time and pace to suit the person.

Consideration was also given to elements of the proposed alternatives to the EoT bell which are *facilitators* or *barriers to implementation* and are presented as subthemes. It was felt that the option of a stone could be an acceptable proposition to NHS Trusts as a low-cost proposal requiring minimal maintenance and easily replicable across the country. It was recognised that existing infection control measures would need to be implemented if patients were invited to touch a stone installed in the department. The fact that it would encourage silent reflection was an advantage in avoiding potential distress to other patients caused by the noise generated by ringing the EoT bell. Meanwhile, there was support for the idea that a digital app could enhance information-sharing among HCPs and raise awareness for patients, who may also assist in updating patient support group information. Both initiatives were noted to be inclusive of those having ongoing treatment as well as those who have finished, and of family members who could also use them. It was suggested that the task of ensuring that patients were made aware of options for the EoT could be included within a HCP's job specification.

Some barriers to introducing such initiatives were recognised. Staff were perceived to have limited time to spend with patients on their last day of treatment. It was questioned whether the infrastructure was in place to enable therapeutic radiographers to offer emotional as well as practical support. Similarly, in spite of patients' perceived mutually supportive nature, concern was raised about the costs and challenges involved in keeping a digital app updated and locally-specific, as well as identifying who would be responsible for this.

Discussion

This exploratory research was driven by evidence indicating the potential harms associated with the widespread practice of patients being offered the opportunity to ring a bell at the EoT. The aim of the study was to elicit the views and experiences of this practice of a group of patients and therapeutic radiographers and to present the findings for wider debate and discussion. The findings revealed contrasting experiences and opinions about the EoT bell amongst participants; however, a desire amongst the therapeutic radiographers to meet patients' needs was invariably present. In addition, there was an acceptance of limiting factors such as time, money, and expertise in their ability to ensure that supportive care was provided at the EoT. The results identified that each patient's experience along the treatment pathway is different and their needs may change as treatment progresses.

Information obtained at the point of recruitment also highlighted that not all patients had been given the option to ring the bell. This suggests that there was an informal screening process taking place in selecting patients for whom the bell may be deemed unsuitable such as patients receiving continuous or palliative treatment. We can infer from this that practice around the use of the EoT bell can be exclusionary.

There is an emphasis in current healthcare practice on the importance of delivering person centred care. This was echoed in the focus groups within the *meeting patient need* theme. The relationship between patients and those caring for them is central to this.[12] However, research suggests that there are challenges to receiving person-centred care throughout the radiotherapy pathway, as practices may engender feelings of disempowerment, a loss of dignity, and a sense of being hurried through treatment as if on a ‘conveyor belt.’[13,14,15] Perhaps attending to ways in which patients choose to mark the EoT is an opportunity to show respect for the uniqueness of each individual, a key feature of person-centred care.[12,16] Currently, the widespread use of the EoT bell across UK radiotherapy departments does not allow for variation in individual need and so cannot be a person-centred practice. Indeed, the findings of this study support the need to examine current departmental practices and consider alternatives to the EoT bell.

The way the bell is presented to patients and its associated language appears significant, such as exchanging the term *celebration* to *a marker* or *point of reflection*, irrespective of whether it denotes the treatment's end. This perspective is recognised elsewhere and is reflected in the introduction of a ‘milestone bell’ by the charity which provides bells to UK hospitals[17]; as well as the introduction of an alternative poem to accompany the bell written by a patient receiving palliative care.[18] It has also been noted that patients who finish treatment begin another phase as individuals who have experienced cancer.[19] Moreover, being ‘cancer free’ does not necessarily mean free of symptoms related to the cancer, or its treatment. An on-line survey by Macmillan highlights that two in five individuals who had finished treatment in the previous two years were living with moderate-severe pain or discomfort.[20] The same survey identified that the lack of support after treatment finished was likened to the experience of having ‘fallen off a cliff.’ It is well documented that a cancer diagnosis and the toll of the treatment pathway can have a traumatic impact which continues for months and even years.[21] In 1994 the publication of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) acknowledged that life threatening illnesses such as cancer are possible traumatic stressors which may induce post-traumatic stress disorder (PTSD).[22] This is evident in our findings, emphasising the importance of suitable EoT support for patients to ensure a transition that enhances survivors' mental health-related quality of life.

In addition, there is a lack of evidence about the impact bell-ringing may have on those who have a neurological condition such as dementia, a pre-existing mental health condition, or those with diagnosed or undiagnosed neurodivergence such as autism spectrum disorder. Patients and staff may be hypersensitive to loud and sudden sounds, which could negatively impact upon their treatment experience or their working environment.[23] However, moving the bell to a more private location out of earshot may not always be possible due to lack of space. As the practice of bellringing may increase distress,[3] providing a gentler, more gradual and extended ending may be more desirable to maintain emotional equilibrium. The participants in this study provided some possible alternatives to the EoT bell for consideration. Alternative EoT markers can provide quieter, more reflective options which are also inclusive of all patients regardless of the intent of their treatment: “allowing appropriate celebration while being mindful of those less fortunate”.[9] Learning from existing examples of ‘information prescriptions’ in the form of digital apps which have been developed through participatory research, not only with people who have cancer but others such as people with dementia,[24] could enable quicker implementation.

There has been a small but significant growth in public and academic interest in the practice of ringing the EoT bell since 2019. While offering an insight into the opinions of a small number of patient participants and therapeutic radiographers, it is proposed that the findings of the present study could be used as a platform to facilitate further discussion within radiotherapy (and chemotherapy) departments, considering current practice and the wider needs of all patients, both adults and children. The rich discussion generated from this small sample of participants supports the contention that in relation to EoT practices, one size does not fit all.

Limitations

This was an exploratory study which determined the views and experiences of a small group of participants who had experience of the EoT bell, predominantly in radiotherapy departments. It is recognised that the sample size for each focus group was small, and further insights could be expected from larger and more diverse samples; for instance, there was a lack of ethnic diversity in the patient sample. EoT bell practice in chemotherapy departments and the experiences of children with the EoT bell were not addressed.

Conclusion

Although the introduction of the EoT bell in UK radiotherapy departments was well-intentioned, there is evidence to indicate that the practice is not person-centred; it may cause harm and be exclusionary to some patients. Those who have undergone treatment for cancer have diverse needs for managing and commemorating episodes along their treatment pathway and beyond. This calls for thoughtful alternatives to the EoT bell which offer patients some choice as well as being realistic and practical in light of the challenges of living well with and beyond cancer treatment.

Open access

Conflict of interest statement

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.radi.2024.03.006.

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