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CoRIPS Research Grant 184

£5,030 awarded

Title: CommEmorating the Last Event, calling time on the end of treatment Bell following RAdioThErapy: CELEBRATE

Principle Aim

There is growing concern from some patients and clinical staff about the continued use of the end of treatment (EoT) bell in radiotherapy departments. This is partly due to the impact this practice has on palliative patients and those on continuous treatment, who may feel they have little to celebrate, and subsequently may inadvertently suffer distress. There is also research suggesting that the use of the EoT bell heightens the levels of anxiety patients experience post-treatment. The impact the use of the EOT bell has on therapeutic radiographers has not ever been investigated. The project aim is to evaluate the experience of using the EoT bell from radiotherapy patients and therapeutic radiographers' perspectives. The aim is to generate discussion and identify the wants and needs of those directly affected, identifying potential alternative, more considerate methods of celebration to replace them.

Primary research question

To evaluate the experience of using the end of treatment bell from patients and therapeutic radiographers' perspectives.

Secondary research questions

To explore potential alternatives to using the end of treatment bell.

Outcomes

A specification for an end of treatment celebration that meets the needs of patients with cancer, and satisfies the mental well-being needs of oncology staff.

A co-designed end of treatment celebration based on stakeholder needs and preferences.

Review of literature and identification of current gap in knowledge

There is evidence to indicate that the use of the EoT bell is causing significant distress to those patients who ring it at the end of their treatment. The only prospective research that has investigated the impact of the EoT bell was a cohort, single centre study in the USA, ironically the country of the EoT bells' origin (Taylor, 2019, Gale 2019). Williams et al (2019) noted that although patients appear to enjoy ringing the bell, its psychological impact was unexamined. They followed 2 groups who had well-balanced demographics and patient characteristics: one group rang the EoT bell (n=86) the other control group did not (n=77). Levels of distress were measured using an 11-point numeric rating scale in combination with a verbal rating scale: a survey to evaluate their overall stress. Baseline anxiety levels were also measured using the generalised anxiety disorder-7 item scale.

Patients in the bell ringing group reported worse over-all distress scores than non-bell ringers (mean (standard deviation) 5.6 (2.8) vs 4.7 (2.7), P=0.045). This difference worsened further at follow up (6.4 (2.9) vs 5.1 (3.0), P=0.009: mean 103 vs 130 days, P=0.056). Their results suggest that bell ringing at the end of treatment worsens the perception of stress.

There were some limitations within this study: the follow up period for the control (non-bell ringing group) was shorter than for bell ringers (mean 131 vs 103 days, P=0.056). It could be that the difference between the 2 groups may in fact converge if participants were followed over a longer period of time. There was also a lack of randomisation into cohort groups due to the nature of the study design. The study only assessed distress in patients who had undertaken radiotherapy and did not include chemotherapy patients who are also often invited to ring an EoT bell. The study only included adults, not paediatric patients and only those receiving treatment with radical intent. The distress caused by the EOT bell in palliative patients was not investigated. The authors also failed to report if any participant assigned to the bell ringing group declined the opportunity to ring it. Despite these recognised limitations the data does indicate that ringing the bell on the final day of radiotherapy worsens patients' evaluation of overall distress from cancer treatment and this distress persists and even worsens in the months after treatment. Williams et al (2019) hypothesise that although at the time it may be a positive experience; ringing the bell creates emotional arousal that magnifies the distress from cancer therapy and subsequently worsens evaluation of treatment. Because of its ability to arouse emotions at precisely the wrong time, memories of a stress-associated cancer treatment become increasingly influenced by the negative emotion present at the time of the treatment (McCord 1978). Therefore, the best way to keep memory of distress low may be to keep emotions calm during periods of acute distress. Hence a gentler, more gradual and extended ending (quiet ceremony or small gift) may be more desirable. This requires further investigation.

The significant distress the EoT bell has on patients who are not being treated with radical intent or those living with recurrent cancer, has been reported in some articles and opinion pieces in the media very recently. Taylor (2019) describes hearing the bell being rung as like a ‘kick in the teeth,’ and that those ringing the bell are likely to be unaware that celebrating in this brash way can have a negative impact on other patients. Therefore, perhaps there is a need to encourage a culture of understanding and awareness within our chemotherapy and radiotherapy departments, where the feelings of all are considered first and foremost: allowing appropriate celebration while being mindful of those in a less fortunate situation (Horan, 2019). The fact that the bell is often installed in the reception or hallway where the department is accessed, means its ringing is not contained, with the sound travelling into the surrounding corridors, treatment rooms and clinics. This is concerning and has briefly been identified in the literature as causing distress to patients within earshot (Gale, 2019). Further investigation into the wider impact this may have on others is required.

As Watts (2019) identifies; it is not that the end of treatment should not receive recognition or for some celebration, but it should also attend to the needs of those who are troubled by it. However, the removal of EoT bells without a suitable replacement may be contentious; some patients and staff are keen to keep the EoT bell. Hence it is important to develop an alternative celebration method that would meet a range of patient needs. Bell (2019) also explains that the end of the treatment journey for cancer represents the beginning of another, that of living with a personal history of cancer. Being ‘cancer free’ does not mean that person is necessarily free of symptoms related to the cancer or its treatment. An on-line survey by Macmillan highlighted that 2 in 5 of those who had finished treatment in the previous 2 years were living with moderate-severe pain or discomfort. The same survey identified that the lack of support after treatment finished was likened to the experience of having ‘fallen off a cliff’ (Macmillan, 2019). As there is still so much we do not know about long-term cancer survivorship Rowland et al (2013) call for the use of patient-centred approaches to study the experience of cancer survivors. The impact of the EoT bell and any alternative to replace it should be investigated as a priority, with the people it has affected.

It is well documented that for many individuals a cancer diagnosis and the toll of the treatment pathway can have a traumatic impact, continuing for months and even years (O’Connor et al, 2011). 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) (American Psychiatric Association, 2000). PTSD can be defined as a psychiatric disorder that causes an inability to recover from a traumatic event (Leano et al, 2019). The symptoms may last for several months and in some cases, they may not appear until many years later

(Grosklags, 2019). Symptoms of PTSD can include: increased levels of global psychological distress, negative changes in cognition or mood, difficulties in returning to vocational functioning, psychosexual concerns, and for some an increased rate of psychiatric morbidity (Alter et al 1996: Lancaster et al 2016). There are many contributing intrinsic and extrinsic factors that can cause a cancer patient to develop PTSD after their diagnosis. Therefore, it is important that a suitable celebration at the end of treatment is offered to patients, as this time period is a window of opportunity, to ensure a transition advantageous for survivors' mental health-related quality of life. This simple act of bell ringing could be inadvertently inflicting long term damage on our patients (Williams et al 2019).

There is also concern yet to be referred to or commented on in the literature about the impact bell ringing has or may have, on those suffering from a disorder of the brain such as dementia, a pre-existing mental health condition such as bi-polar disorder, or those with diagnosed or undiagnosed neurological differences such as autism spectrum disorder. Some patients or staff may be hypersensitive to loud and sudden sounds, which could negatively impact upon their treatment experience or their working environment (Hendrickx, 2010).

There is a clear need to review the current method of celebration (EoT bell) because of the potential negative impact on patients and staff in radiotherapy. There is also a need to identify what the potential less intrusive and more respectful alternative methods of EoT celebration could be. This evidence would provide adequate rationale and justification for the piloting of new alternative celebration methods.

Methodology

On-line focus group (FG) method will be used to collect qualitative data in order to answer the research questions. This is most suitable for studies where multiple perspectives need to be obtained regarding the same problem. FGs have a strong and well documented history in health and social care research and the design lends itself to be compatible with the interpretative participatory format of this research (Kitzinger & Barbour 1999, Liamputtong 2011). They allow opportunity for an in-depth level of interaction between group members, facilitating a higher level of disclosure compared with other methods of research (Litosseliti 2003). Much of the power of the focus group grows out of the spontaneity and synergy of the group dynamic (Stewart & Shamdasani 1990).

Design of the proposed FGs (including methods to initiate discussion) will be discussed for relevance and persuasion by an independent Public and Patient Involvement (PPI) group from a local radiotherapy department. The design is based on a participatory model founded on constructivism, it is seen that knowledge making occurs through interaction among people, practices and artifacts. Conclusions are drawn in conjunction with users and eliciting the patient voice is central to the study design (Spinuzzi 2005). The chair of the project steering group is a patient advocate, a breast cancer survivor and founder of ‘ABC Diagnosis’. This will ensure the patient perspective and experience is considered at every stage of the project.

A convenience sample of therapeutic radiographers and radiotherapy patient representatives will be invited to participate in a series of co-design focus groups. Recruitment will be undertaken using a network of known charity groups, professional interest groups, using social media and forums. The study will be advertised using flyers and on-line adverts and emails. Interested participants will be asked to make contact with the PI who will provide them with an information pack about the study. The recruitment approach is designed to help to reduce the need for face to face contact and reduce bias, providing a more generalisable data set and a more appropriate outcome, than using purposive sampling methods.

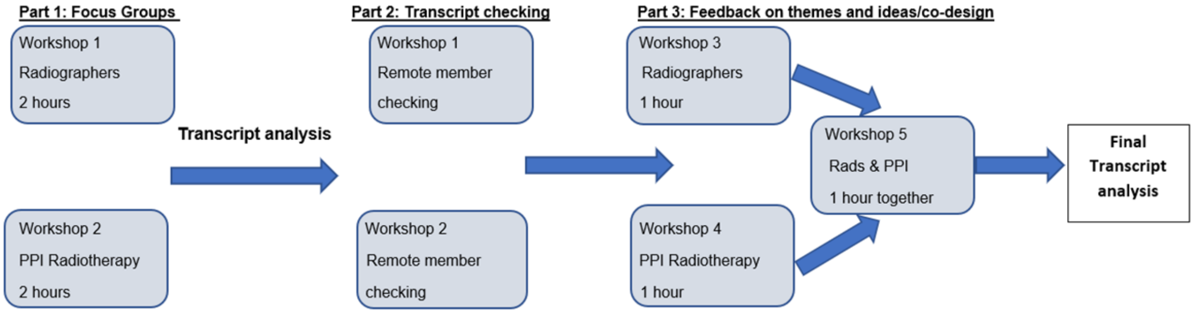

Figure 1 Indicates the format for the co-design process.

Two, 2-hour facilitated on-line FGs will be undertaken initially, where 2 separate groups; the therapeutic radiographers and radiotherapy patient representatives (n=10-12 people) will participate to identify individual experiences of EoT celebrations as well as preferences and needs for this part of the cancer journey (part 1). Transcript analysis (part 2) from the recorded audio will take place afterwards, and thematic analysis using Quirkos software will be undertaken by the PI and a second member of the project team. Initial codes from the two independent analyses will be reviewed to formulate a joint agreed coding thematic structure that will be reviewed by a third member of the project team through a peer-debriefing process, to reduce bias. Once the key themes and sub-themes are identified from each FG they will be sent to all participants within the group for member checking and agreement, again to reduce the opportunity for bias and to ensure a true and accurate account was captured.

There will then be 2 separate 1 hour on-line workshops where group members will be invited back so the project team can feedback on how the themes derived from their first FG might be developed to form a framework or specification for an alternative celebration process. In the second hour they will be invited to merge into one on-line group where the therapeutic radiographers and radiotherapy patient representatives will collaborate remotely for 1 hour to go over the key findings and summarise the outcomes identified within the previous FG. The two groups will work together to develop the themes and any frameworks or celebration specifications (part 3). Transcription analysis from these final FGs will be used along with any written work, drawings, or photographs to document the final products from the research and to allow later reflection by the project team.

Ideal numbers for focus groups are 7-12 participants, it is hoped 12 per group will be recruited. A total therefore of 24 participants: 12 radiotherapy staff and 12 radiotherapy patient representatives.

Ethical approval will be obtained from the University ethics committee. The HRA decision tool was used to identify that NHS ethical approval is not required. Measures will be taken to support participants should their involvement in the focus groups evoke negative memory or emotion. They will be fully prepared and briefed before their participation and debriefed following each workshop. Should they need to be signposted to other support groups this will be facilitated where required. Participant information sheets will be designed with input from the PPI group at a local radiotherapy department and with input from our project chair, patient expert. Consent forms will be utilised to ensure participants are fully aware of the intention of the project and what their participation will involve. They have the right to withdraw at any time, and will remain anonymous in all data collection, analysis and write up. All relevant project information will be provided before consenting, and participants will be given at least 7 days to consider participation before being asked to sign and return the consent form.

The use of Zoom or Webex video communication to undertake the FGs remotely is because of the COVID-19 pandemic. Appropriate system security checks will be undertaken to ensure the online meeting room remains secure and participants confidentiality is maintained.

Potential impact

The aims of this project align to the overarching SCoR vision for research, to improve patient care and outcomes by continuing to develop, grow and implement a high-quality evidence-base that addresses key patient-focussed research priorities. The patient experience will be at the heart of this project with patient involvement throughout the planning and co-design preparation of the FGs. Most importantly this project has the potential to change the end of treatment ‘celebration’ for the better, for it to be more considerate and sensitive to the feelings of others. The next stage of the project could be a pilot test of the suggested alternative celebration approach, assessing feasibility, patient satisfaction and experience.

Dissemination Strategy

Findings will be presented at key conferences including ARC, 2022, and ESTRO, 2022. The study will also be submitted for publication in two peer-reviewed journals including Radiography, to ensure maximum dissemination and impact within the fields of radiotherapy. The PPI group will be utilised to guide dissemination to relevant patient groups and charities. The project findings will be presented at a seminar at the host institution that will be recorded for UG and PG students and disseminated widely to clinical staff and managers for free, to facilitate wide uptake of the study findings.

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