Original Article

Using information and communication technologies to improve the management of pain from advanced cancer in the community: Qualitative study of the experience of implementation for patients and health professionals in a trial

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Abstract

In cancer care, there are emerging information and communication technology systems being developed, enabling real-time information sharing between patients and health professionals. This study explored health professionals' and patients' perceptions of their engagement with an information and communication technology system for pain management to understand the mechanisms that could support implementation into routine palliative care practice. This was a qualitative study, embedded within a randomised control

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trial, using semi-structured face-to-face interviews. Data were analysed using thematic analysis. The role of health professionals was a key component to patient engagement with the information and communication technology system. Where patients engaged with the information and communication technology system, both patients and health professionals reported benefits to system use in addition to usual care. Implementation issues were identified that can be used to guide future system development to support pain management in the context of routine clinical care in palliative care services. Where interventions are dependent on multiple providers, collaborative working and consideration of the context within which they are set are needed.

Background

For patients with cancer, research shows that pain is frequent, burdensome, and undertreated.[1–4] Over two-thirds of patients will experience pain during advanced stages of their cancer.[4] Pain is a major source of suffering and has adverse effects on their quality of life, leading to unplanned hospital admissions with uncontrolled symptoms.[5] Barriers to pain management include knowledge deficits, misconceptions,[6] poor pain assessment,[7–10] and lack of a common language when classifying and assessing pain.[11] Evidence suggests that assessing pain and presenting data to physicians prior to consultation, who then use it within discussions, can significantly improve pain outcomes and quality of life.[12] Assessment alone, without ensuring that this is seen by prescribing clinicians, does not lead to improvements in pain.[13]

In cancer care, there are emerging information and communication technology (ICT) systems being developed in order to share information, such as symptoms (such as pain), function, and quality of life, with health professionals.[14] ICT-based approaches enable real-time information sharing between patients and health professionals and are being developed for use at different stages of the cancer trajectory: from active cancer treatment and survivorship periods[14] through to palliative care.[15] ICT systems for cancer pain management are evolving to include the provision of nuanced and personalised information for patients.[16–19] Used in this way, these systems offer opportunities to enhance existing approaches to cancer pain management.[20,21] Supporting pain management in this way can potentially minimise treatment burden, disruption to patients' lives, and facilitate an experience of personalised care and reassurance.[22] There is scope to explore whether future ICT systems can effectively incorporate existing evidence-based approaches to improving symptom management.[23]

While different approaches to facilitate self-management are emerging, knowledge of their implementation to support pain and symptom management as part of routine cancer care is in its infancy.[15,24] This is an essential component of intervention development, with little known about factors that influence their uptake and engagement for cancer pain management. For ICT systems, engagement could be measured through proxies such as their uptake by users and levels of interaction. Limited examples of such metrics report uptake by patients at 62 per cent[17] and 77 per cent.[16] For ICT systems, which often comprise multiple components, contextual factors are crucial to understanding their success and failure during implementation; these are not always captured when adopting an experimental design.[25] For ICT systems used by patients with cancer, existing trials are largely heterogeneous in the type and duration of interventions as well as outcome assessments, and they are not always well reported.[26]

Currently few ICT systems to support symptom reporting in patients with advanced cancer have been developed;[27,28] however, none supporting pain have been implemented into routine care and

there is no guidance on how to approach this stage of system development. To address this gap in knowledge, we report the findings from a qualitative study embedded within a randomised control trial. We sought to gather perspectives on the implementation of ICT systems to support pain management for patients with advanced cancer in the context of routine palliative care. We report health professionals and patients' perceptions of their engagement with an ICT system for pain management to understand the mechanisms that could support implementation of ICT-based interventions into routine palliative care practice.

Methods

Study setting

Improving the Management of Pain from Advanced Cancer in the Community (IMPACCT) was a 5-year programme grant consisting of interlinked studies aiming to improve the management of pain from advanced cancer in the community. A multicentre randomised controlled trial was the final component, in which the qualitative work outlined in this article was undertaken. This was a pragmatic multicentre randomised controlled trial to assess the acceptability and feasibility of implementation of a complex intervention, its potential cost effectiveness, and impact on pain management. A total of 161 participants were randomised to receive either standard care or standard care plus supported self-management. The supported self-management arm consisted of usual care, access to an ICT system for routine pain assessment and monitoring (PainCheck),[24,29–32] and a self-management educational booklet and DVD (*Tackling Cancer Pain*). These two interventions were introduced to patients by their locally assigned clinical nurse specialist (CNS) within 1 week of randomisation. The trial was conducted between October 2015 and January 2018. For further details regarding study setting, see Allsop et al.(2018)[33].

Study design

Purposeful sample of trial participants (patients and CNSs) were invited to take part in cross-sectional, face-to-face, individual interviews.

Participants

Participants were patients and CNSs purposively selected from trial participants assigned to the intervention condition.

Sampling aimed to maximise diversity of trial sites (four sites) and timing of interviews (6 or 12 weeks after randomisation). Patients consented to be approached for interview at the time of consenting to the trial. Following expressions of interest, participation was discussed by telephone, and interviews were arranged. CNSs were approached initially by email and followed up by telephone.

Data collection

Semi-structured interviews were conducted with patients in their homes, CNSs at their place of work. Interviews were guided conversations to elicit accounts of participants' perceptions of their engagement with PainCheck to understand the mechanisms that could support implementation into routine palliative care practice using a topic guide.

Data analysis

Interviews were audio-recorded and transcribed verbatim. Transcripts were anonymised and checked for accuracy. Data were collected from September to December 2016. We adopted a thematic approach to analysis. Data were initially coded deductively to areas pre-specified in the topic guide; further codes emerged from the data inductively. Codes were grouped to form overarching themes which were iteratively refined over the course of analysis. Recruitment and interviews continued until data saturation. NVivo 10 was used to manage the analysis.

Ethics

A favourable ethical opinion was obtained from the NHS National Research Ethics Service Committee Yorkshire & The Humber – Leeds East (reference no. 15/YH/0235).

Results

In total, 16 patients and 15 CNSs were recruited. Of these, four patients declined to take part (three were too unwell, one did not think they had anything to contribute), one CNS declined, and two were on long-term leave. In total, 24 interviews were conducted (12 patients and 12 CNSs; mean interview length: 23 min; range: 8–30 min).

The current study explored health professionals' and patients' perceptions of their engagement with PainCheck to understand the mechanisms that could support implementation into routine palliative care practice. Two themes emerged from the data: (1) engagement of health professionals with the system is key to patient engagement and (2) implementation and maintenance in usual care.

Engagement of health professionals with the system is key to patient engagement

Health professionals' knowledge, understanding, and familiarity of the system influenced their own engagement, which influenced the extent to which they encouraged and facilitated patient engagement. Consequently, health professionals were key to patient engagement.

Health professionals felt that more proactive support from the research team would have increased their engagement with PainCheck. Although they emphasised feeling well supported by the research team, more information and education at the beginning to clarify expectations and to gain confidence in their ability to do what was expected would have been preferred. Health professionals suggested that updates/refresher training, throughout the trial, might have strengthened relationships and built confidence:

> More information before it started in terms of what we were expected to do and more education at the beginning. I was able to ring up the team, who were very informative and told me exactly what to do. But it might have been useful for you to come back to one of our team days and then you would have been able to answer those questions for us. (Health professional, 12)

Most health professionals had a good level of understanding of the aim of the trial. Some were not clear on their role in supporting delivery of PainCheck. Due to relatively slow recruitment, many only had one or two trial patients on their caseload and therefore felt they never became experienced in what they were supposed to be doing; this was exasperated by lengthy time periods between being allocated new trial patients. When combined, this lack of knowledge, understanding, familiarity, and perceived expertise contributed to some health professionals not being fully engaged:

I haven't looked at any of the electronic stuff. I could have made better use of the materials, and then if I had, I would have been more likely to encourage my patients to make better use of them. (Health professional, 28)

Health professionals' levels of engagement affected the degree to which they facilitated patient engagement with PainCheck. It was clear that when they lacked knowledge, understanding, and familiarity of PainCheck, this influenced the level of investment patients had, subsequently they were less likely to use it:

She was giving me some wrong information about the website, I thought it was a waste of time 'coz she didn't know what we were talking about. If she'd been up to spec on what she was supposed to be saying about it, I might have done it. (Patient, 38)

Although patients had consented to take part in the study, health professionals made judgements on their suitability and sometimes did not introduce them to the PainCheck. Judgements as to whether or not patients would/could engage with PainCheck were made based on factors such as personality type and usual coping strategies. Health professionals were also concerned that if used inappropriately, PainCheck may be an additional burden to patients:

Some like to have something to do as a way of coping with their symptoms. I think for some patients it might be a good thing for them to focus on that, others it might just underline the fact that they've got pain and they're unwell and it's just something else that's making them feel more poorly. (Health professional, 38)

However, patients evidenced instances where PainCheck may not have been perceived as appropriate for them, yet they had found it simple to complete and beneficial to their care:

It was fairly straightforward, it was easy for a dinosaur like me to follow. I really don't like technology, I avoid it as much as possible, but it was easy to do. I would just press the thing and it would come up and then I would answer all the questions and then that was it, so easy. (Patient, 2)

Proactive support and collaborative working between the research team and health professionals delivering ICT systems are necessary in order to support implementation and improve both professional and patient engagement. This is particularly key as health professionals' own engagement influenced the degree to which they encouraged patient engagement with PainCheck. Where health professionals went through the PainCheck system with patients at the initial appointment, patients were more likely to continue to use the intervention. In addition, some had limited opportunity to engage because of low number of patients assigned.

Implementation and maintenance in usual care

Half of health professionals interviewed did not think that being involved with the trial had added to their workload and discussed how they had implemented PainCheck into their usual practice and used it to proactively manage their workload. However, they had reservations about the scalability of their involvement with PainCheck; all felt that responding to PainCheck could become burdensome if they had a higher number of patients on their caseload:

If I had a few patients, chances are I might every day have a quick look to pre-empt my workload. If you can see a bit of a pattern with somebody you might contact them, whereas you might not have been

planning to, or you've been waiting to hear from them, then that obviously makes a huge difference in preventing an urgent call out. (Health professional, 8)

Some health professionals described how, since being involved in the trial, their care had become more symptom focused. PainCheck had prompted them to contact patients when they recorded a high pain score, which they may not have otherwise done. However, although the system allowed them to contact patients online, many were resistant to modifying their existing communication practices, continuing to contact patients by phone or face-to-face. Health professionals seemed sceptical over the extent to which PainCheck could deliver the same tailored care as their usual methods and repeatedly emphasised the value of face-to-face and telephone consultations:

> It's difficult because if you ask people things about their pain over the phone you often get a very different sense to if you ask them the same things face-to-face. You're reading body language and all those extra things that convince you that something's right or not. Anything on a screen has slightly less a flavour to it than you get when somebody's face-to-face. (Health professional, 38)

PainCheck was implemented and usage maintained by the majority of health professionals during their consultations. They described it as providing a real-time structure to work through face-to-face with patients. They were able to begin with a clear baseline which they could then use visually with patients to look at changes in pain over time. This was then used alongside recorded changes in medication to allow a more real-time account of whether medications were working:

> It gives us a clearer guide as to what they're experiencing because it's usually a retrospect look on what's been going on. This is so much easier for them just to show you and you think, 'right ok Tuesday afternoon was obviously really bad for you, can you tell me was there anything else going?' It was useful to do a comparison between the baseline to see very clearly that things had escalated and to see that in visual format. (Health professional, 36)

Patients described how PainCheck enabled them to look back over their pain scores and reminded them to engage in self-management strategies. For some, as PainCheck provided opportunity to reflect on previous pain scores, this reflection provided context for their present pain and enabled them to re-evaluate past pain as less intense than they had remembered:

> It makes you think about what it's been like, sometimes your day hasn't been as bad as you think it has. You can have a pain for a short time and not the rest of the day but it can colour your feeling for that day. It made me realise that pain is not constant for me. I had this really bad thing happen and the next day it was a bit easier and the day after that, so it makes you realise, for me I found that really helpful. (Patient, 2)

Using PainCheck allowed space for patients to reflect on how they perceive pain and to consider whether to use medications or alternative ways to managing it, resulting in improved overall pain management:

> I'm very stoic, grin and bear it as long as you can and then take pain killers when you can't bear it any longer, and basically they were saying 'no don't do that, take the painkillers and then manage the pain with the painkillers rather than waiting 'til it gets worse', they were very good at advising me what to do . . . It [PainCheck] did remind me to take something as well, rather than be stoic. (Patient, 2)

Patients felt that taking part in the trial had increased their levels of care and provided them with a support system. Patients no longer felt isolated, instead felt connected to and embedded within

services. CNSs were fulfilling a role, where previously there had been no one. Subsequently, patients felt reassured that help was there when needed and were more likely to maintain usage of PainCheck:

> It's being connected up and not feeling as isolated. Because it's all one big team and everybody's joined up, there seems to be a complete sort of a treatment whether it be medical or just somebody to talk to, so that's been a big help. (Patient, 47)

Those patients where using PainCheck had resulted in them feeling more connected to a support system, enabling them to reflect on their pain and its management, were more engaged with PainCheck and therefore more likely to have improved their self-management of pain.

Discussion

This study provides insight into the perceptions of patients and health professionals during the implementation of an ICT system for pain management in advanced cancer. The referral process and subsequent context of palliative care are unique and influential precursors to any subsequent ICT system use by patients. The role of health professionals was a key component of engagement with ICT systems; their own knowledge, understanding, and familiarity influenced how they encouraged and supported system use by patients. Where patients did engage with the system, both patients and health professionals reported benefits to its use, including improvement in self-management of pain by patients. Engaging with patients and health professionals also identified issues around implementation that can be used to guide future development of ICT system to support pain management in the context of routine clinical care in palliative care services.

ICT can be perceived positively by health professionals;[34] identifying and addressing concerns around systems is clearly important to ensure effective use in patients' pain management.[35] The experiences in this study highlighted that it is necessary to support increased and sustained knowledge, understanding, and familiarity with ICT interventions for health professionals to be confident in facilitating their introduction and supporting use by patients. Where understanding and familiarity was lacking, patient interaction and engagement was diminished or prevented. A barrier to understanding and familiarity was caseload, with trial patients spread thinly across individual CNSs. Consequently, these health professionals had few opportunities to use and familiarise themselves with the system.

Future implementation of ICT for pain management may require exploration of how PainCheck can be aligned with local models of care delivery, for example, having fewer nurses receiving an increased number of trial patients. Previously, developing new models of clinical care and providing evidence of the benefits of technologies improved achieving clinician acceptance.[36] We demonstrate the need to take time to educate health professionals in the processes they should be engaging in for intervention delivery and the expectations of the research team. These experiences align broadly with barriers identified when evidence-based tools have been implemented into nursing practice.[37] Additional approaches might include building on education that is effective for health professionals' development in palliative care.[38] Such initiatives would be an opportunity to address an underlying misconception identified by health professionals that they would eventually be replaced by technology. Innovation should be used to enhance already existing models of care and aid proactive management of workload. The ubiquity of ICT systems across healthcare, including palliative care, may require a specific focus on how ICT can be integrated and sustainably used as part of patient care.

The use of ICT with patients is increasing in cancer care delivery. While there is an increasing number of ICT systems designed to capture patient-reported outcomes,[14] little is known about the

factors that drive engagement of palliative care patients. Patients in this study reported numerous benefits of being involved, including increased access to care and improved self-management of pain. However, it is apparent that levels of engagement were not solely influenced by perceptions of the usefulness of the interventions. Rather, the relationship between the trial context, the service delivery context, individual perceptions and assumptions, and the interventions influenced participant engagement. Health professionals and patients were aware of their engagement (or not) with PainCheck and were able to reflect usefully on the facilitators and challenges to this. Both had an awareness of the emotional barriers patients' face when accessing interventions delivered by palliative care and of the impact engagement with the interventions had on delivery/receipt of usual care.

Our findings demonstrate the importance of being aware of the potential barriers to acceptability and how these can impact engagement and to be particularly mindful of how health professionals' views impact engagement of patients.

Strengths and limitations

Delivery of interventions in the context of palliative care is important to consider and needs to be managed sensitively as it is a time of high emotional burden. However, as we demonstrate, if patients are approached in a mindful way, the implementation of ICT systems to support pain management can provide patients with a support system and improve both their self-management of pain and access to medications, which was not evident beforehand.

This study is limited by a focus on the implementation of systems in a defined period of time in the context of a clinical trial. Prior research has shown that implementation of ICT in palliative care settings, such as electronic medical record systems, can reveal low initial usability and engagement scores which then increase over time.[39] In order to understand the issues that arise over time, and the sustainability of ICT systems for pain management in palliative care, studies involving long-term implementation into routine care are required.

Conclusion

This study explored implementation processes and identified mechanisms that influenced ICT uptake and use in palliative settings. We demonstrate how proactive support and collaborative working between the research team and health professionals delivering the trial intervention are necessary to support implementation and improve engagement. This is particularly key as engagement of health professionals is key to patient engagement. PainCheck was perceived to improve self-management of pain. Introducing and implementing interventions which are dependent on multiple providers indicates that time needs to be invested in working collaboratively throughout. When integrating interventions into routine clinical practice, consideration of the context within which they are set is needed, and case studies should be utilised to demonstrate positive outcomes and increase engagement.

Author contributions

M.I.B. and B.M.B. proposed the idea for the study and contributed to the design of the study. S.T. carried out the data collection. J.H. analysed the data. J.H. and M.J.A. wrote the first draft of the manuscript and have contributed equally to this work. All authors contributed to the writing of the final version.

Declaration of conflicting interests

Ethical approval and consent to participate

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