

Original Article

Service user involvement in cancer professionals' education: perspectives of service users

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Abstracts

Background: Service user involvement has been demonstrated as an important aspect of cancer professionals' education. There is some understanding of service users' incentive to be involved, but little insight into what motivates them. This study explores this concept more fully.

Purpose: To explore the motivations and experience of service users' involvement in radiotherapy and oncology education.

Materials and methods: One-to-one interviews were conducted with service users who have been involved in education at the university. Thematic analysis was conducted. Five participants were asked about their motivations and experience of taking part in a variety of educational activities.

Results: The experience of being involved gave the participants a sense of wellbeing and purpose. Three sub-themes were identified that related to service users' motivation for being involved in educational activities with undergraduate students. These were to promote awareness by sharing their experiences of cancer; improve patient care through learning from negative experience; and personal reward skills for survivorship.

Conclusions: This study has highlighted the importance of hearing the voice of the service users; a two-way engagement for which there are benefits for both the students and service users. The involvement of service users in education becomes part of their personal journey.

Keywords: cancer professionals; education; impact on service users; involvement; phenomenology; service user

BACKGROUND

Service user involvement is a concept embedded in current healthcare practice and has been conducted in various formats over the years.^{1,2} This has prompted a varied understanding of its practice and importance across healthcare services,

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training providers and educational institutions and is here to stay. Driver policies in education have made this clear and are seen as a core aspect of the various quality frameworks across the board.³

There is some understanding of the impact that involvement has had on the service users partaking in cancer research. The work carried out by Cotterell et al.⁴ has gone some way to undercover this. Although professional education policy drives the magnitude of service user involvement there has been little research primarily focusing on the 'impact of involvement in radiotherapy education on the service users themselves'.

The National Cancer Survivor Initiative: Vision in 2010 states that there were 1.6 million people living with and beyond a diagnosis of cancer with an estimated projection of 3 million people by 2030.⁵ Cancer survivorship membership is increasing along with the number of service user involvement projects.^{6,7} The number of involvement activities is apparent across many aspects of National Health Service (NHS) cancer care and services. Since its mainstream launch in 2007 by the Cancer Reform Strategy Service User Involvement (SUI) has often been perceived as being tokenistic.⁸⁻¹¹ However, this has given way to a wealth of findings which demonstrate the importance and success of involvement, and therefore seems inconceivable to consider that Service Users (SUs) would not be part of service provision, development and review on all levels including that of health professionals' education.¹⁴⁻¹⁷ SUI is here to stay.

Government and professional policy indicates the potential benefits of service user involvement in radiotherapy educational programmes.^{8,12,13,18-22} The wealth of data confirms that this is the way forward for educational providers in order to improve health and social care services at grass roots.^{23,24}

PURPOSE

To explore the motivations and experience of service users' involvement in radiotherapy and oncology education.

MATERIALS AND METHODS

A variety of service user involvement activities were utilised at the educational institution where the research was undertaken. They included the use of video recordings, role play, and various opportunities for face-to-face small group student seminars. Thus participants came onto this study with a variety of participation experience upon which to reflect. However, it was not the intention of this study to explore how the involvement differed, but rather asked generic questions on the impact of involvement across all the settings.

The service user involvement format employed is purposive in order to give the students a powerful and abundant account of their experiences. Creating opportunities for students to engage with service users in a non-clinical setting was an important factor in the organisation of the seminars. These sessions focused away from clinical concerns to enable students to gain understanding and explore the complexities and broad consequences of having lived with cancer. This platform for learning success is well recognised across many healthcare professions' training.^{12,15,23} The main barriers to this method of delivery are the educators themselves and the culture of the educational institution³ in which they reside, however the institution had a strong ethos of service user involvement.^{3,24} Students report enjoyment, motivation and realisation of the significance of their role and their profession.^{24,25} Specific learning occurs through knowledge construction, evaluating emotional intelligence, developing communication skills and facilitation of reflective practice.^{3,26}

During the involvement sessions service users recount their cancer journey. In light of the participants' diagnosis it is clear that they each have their own story and agenda and the unique 'no holds barred' interaction with students may result in a different psychological impact from that of service users involved in research or service improvement.

In order to explore the lived experience of participants' involvement in health professionals' education a phenomenological research approach

was deemed appropriate.²⁷ The harvesting of qualitative data through interviews allowed the participants to reflect upon their own experiences of involvement and explore their motivations, feelings and thoughts. Phenomenological studies are chosen as a method to understand culture and gain a deeper understanding of social phenomena and for the purposes of this study, the 'lived experiences' of participants.²⁸

Data were collected by conducting recorded, unstructured, individual one-to-one interviews. This conversational approach to data collection allowed in-depth exploration of complex thoughts and demonstrates the value placed upon the participants' opinions, without the inhibitions which could stem from group interviews.²⁹

Individuals were eligible if they had been involved in radiotherapy and oncology education. All who had participated were contacted regarding the study in order to reflect the range of experiences and perceptions of the service users. Participants reported a variety of different cancers including testicular cancer, prostate cancer, breast cancer, tonsillar cancer and bone cancer. One of the participants was a carer for their child who had survived cancer.

Ethical approval was secured from the host higher education institution and focused on identifying clear strategies for supporting participants.

Immersion in the data is a fundamental aspect of qualitative data analysis.^{29,30} This involved listening to the audio recordings, transcribing and re-reading as well as noting any changes to vocal tone, volume and linking these with memos recorded during and after interview. The transcripts were coded using a framework suggested by Strauss and Corbin and Charmaz.^{30,31}

A cross-sectional thematic approach to analysis was employed in order to interpret what was being said across the whole set of interviews rather than presenting each participant's data in its entirety. It is acknowledged that the researcher is integral to the collection of the data and must try to present the 'least false' interpretation and sought to recognise this.³² The nature of this

research being exploratory means that the findings cannot be generalised to a wider population and is based on the experiences at one university only. Consent to the study was obtained before participation with explanation and reassurance about strict confidentiality.

RESULTS

Analysis of the data on five (out of the five) service users involved in education delivery is presented. Participants described why they became involved in radiotherapy and oncology education and what they expected to achieve. The findings identified that service users gained a 'sense of personal well-being' from being involved. There were three co-existing themes that emerged from the data that reflected participants' motivation for being involved. Initially this focused on promoting awareness of cancer through sharing their experiences with the expressed aim of improving patient care and subsequently how this activity provides the service user with personal reward.

PROMOTE AWARENESS

Although service users had few expectations of what the educational activities could offer students, their key motivation to be involved in education of professionals was to promote awareness of cancer, its treatment and the issues that patients and carers face. They all agreed that sharing their personal stories was a way of helping students to understand this.

'I wanted to tell what I'd gone through, my story'. (participant 5)

'To share what it's like from a parent's point of view in realistic terms'. (participant 4)

IMPROVE PATIENT CARE

Participants believed that through the act of raising awareness of their experience then this in turn would give students insight so they could improve the care of future patients. However more fundamentally, they saw it as an opportunity to motivate students and to some extent cause students to reflect on their career choice

and appreciate the impact their practice could have on patients and carers.

'What they do is so important and I want them to know that before they even start their careers what they do matters. This will motivate them'. (participant 2)

One patient wanted to give students validation of this career choice:

'I said "...your job is vital, your job is appreciated and it does work and I'm living proof and so are all the other people in the room, just remember that..." you know almost to lift them before they even start'. (participant 3)

Students and radiographers see patients for a short period of time when they are undergoing radiotherapy. Thus, their involvement with the patient can be limited to the radiotherapy treatment and related effects. It is common to never see or hear about how patients have fared after treatment. Therefore, participants see the workshops as an opportunity for students to see what they do as a profession is worthwhile.

'I want them to see me... that I have been there and this is what I'm like at the end just remember this is how we end up and we have got our lives back'. (participant 4)

Participants regarded an important aspect of the students' learning experience was to see how good can come from a negative experience. Interestingly, all of the participants recalled a negative experience (in varying degrees). They particularly wanted to be able to impress upon students how patients would prefer to be interacted with. They believed that through sharing their experiences they could also tell the students what specifically helped them through difficult times. They hoped that through their involvement that students would help improve the experience of other patients.

'I turn the negative into positive, because I would never want to see anyone see their father suffer the way I saw my father suffer'. (participant 1)

Participants wanted a positive outcome from their cancer experience. They see involvement

as a way of ensuring that the difficult journey was not in vain.

'When I go home I think "I'm tired and that was hard work, but I don't think "oh I've had cancer"... I think "I've had cancer and wow look what I'm doing, I'm helping these people!"'. (participant 3)

'I happen to be one of the ones who's dealt with it and used what has happened to me in a positive light ...so I want the students to know that'. (participant 2)

The direct involvement with the university had a clear motivation for those who volunteer for participation. All the participants wanted to share their knowledge for the good of students' education; to help them understand how to work with patients.

'These are the new professionals coming up so it's best to work at that level because then they're starting off right'. (participant 1)

They wanted to help students to learn about how to communicate with patients effectively; to understand what patients want.

'It's got to be a discussion more than information giving, to really facilitate a discussion that will ensure that the patient feels at ease; to make us feel comfortable around all this technical jargon in an unfamiliar place.... I think students need to be really aware of the impact that they have on how you say something'. (participant 2)

'You're tapping into them at grass roots while it's all fresh and preventing bad habits'. (participant 3)

They also wanted to help students to comprehend the importance of treating each patient as an individual. In addition to this the service users feel that it is acceptable for the sessions to be emotive; in fact they see this as being a positive experience in order to develop students' emotional intelligence.

[joking] 'I suppose when someone cries you've done a good job!'. (participant 5)

Two participants highlighted that it is important not to worry about getting emotional or for the students themselves to display sentiment. In fact, some participants said that by seeing a

health professional's emotional response demonstrated that they really do care and the act of sharing emotional feelings helps build the bond between the professional and the patient. They stated that an important aspect of this is to raise students' awareness of those views.

'It can be emotionally draining, but it's worth it'. (participant 3).

PERSONAL REWARD

All of the participants described the cathartic nature of talking about their experiences. Reflecting on their journey 5, 10 and even 20 years after diagnosis they are still learning about their feelings and the effect that cancer had on their life.

'I think it's helpful to everybody and I think it's quite therapeutic to be able to open up to other people at different times'. (participant 4).

For the service users, it was also an opportunity to broaden their own knowledge. They report that they had learned more about radiotherapy generally, their cancer, and the way that the health professionals are trained. Perhaps what was more revealing was the realisation of how things have changed.

'It was definitely a way to express what I felt, some of the high and low points. All the negative things came pouring out and it was nice once I did get there to realise that things had moved on, the care was different, the treatments were different so I was learning which surprised me'. (participant 5)

Many of the service users said that involvement was a way of giving back to the profession. They had experienced the radiotherapy service and as a result were able to feed that experience into student training. They viewed training the student radiographers as a key component in ensuring high-quality standards of service for the future.

The participants describe that giving thanks to the profession for caring for them was an important motivation, however this had also promoted a sense of their own wellbeing and improved self-esteem.

'That is one of my main drives, to say thank you, and if I can help anybody in the medical profession.... gosh yes, in the end they saved my life'. (participant 2)

Individuals expressed this sense of purpose in different ways and for one participant this had an overtly spiritual dimension concerned with a promise to help others:

'Like I say, I promised God, I said if I live through this I will make people aware and I've not gone back on my word'. (participant 1)

They felt that if they were able to survive their cancer then in turn they would be able to help others. Another participant also recalled that they had struck a bargain. In surviving their ordeal they wanted to give back and keep their side of the bargain. At the time they did not know how they would do this, but an opportunity to work with the university came along and it seemed like a good way of giving something back.

Some participants used the term love in the interviews; this was related to the love they felt for others and the feeling of love and caring that they had experienced. They stated that the act of sharing their stories was their demonstration that they care about training professions. They wanted to extend their love to those professionals who demonstrated a caring approach to them. They reported that they had actually felt a sense of love from students; at the time of participation they witnessed students responding in a compassionate manner to them and their stories.

'It makes both the students and the service user feel loved... there might be a little sparkle in their eyes. That's quite powerful, that means I know they're listening to me, they're really listening to me, they can feel what I'm feeling, that's something you can't see in a text book, it's that interaction that's very crucial'. (participant 1)

Participants also recounted how reliving the feelings of their experiences and illness reaffirms the importance of the people currently in their lives. Some recalled that cancer had a devastating effect on all aspects of their lives, but in particular the impact that it had on close relationships. Remembering their mortality and their brush

with death helps them to remember those they care for and to be grateful for the fact that they are alive. Participants stated how after a session with the students they often went home and gave their children an extra hug or told them they loved them again.

'With my child I've told her I loved her more, yes I have'. (participant 3)

Participants regarded themselves as cancer survivors and connected very readily with each other on the days of the activities, reporting a sense of peer support. Reflecting on their involvement there is a collective agreement that working with other service users and the supportive nature of the group was a factor in the enjoyment and success of the sessions. There was a sense of solidarity, camaraderie and acceptance. They all had individual stories to tell and they emphasised that they are keen to build these friendships further and enjoyed the social connection. This social interaction helped to diminish the potentially negative impact that their involvement could have on them.

'...it helped just being relaxed; you're going to be talking to a group of strangers ultimately, but knowing that there are people like you doing the same thing helps you to feel comfortable'. (participant 3)

Survivorship was recognised in a physical way too; participants said the sessions were a timely reminder to check on their own health. Some participants described how after the sessions they would check the date of the next hospital appointment or make sure they performed the physical exercises prescribed to them.

'...it brings it back and you think "I must do it" so yes I have been stretching my mouth more and I've been more conscious that my mouth is stiffer when I have to do that'. (participant 3)

Also, participants saw their appearance as an important way to demonstrate that they have won their battle with cancer.

'So on that day you think "oh I want to look good now, I want to show them how good I am"'. (participant 2)

Participants said that involvement has provided them with tools to dealing with surviving cancer. For some they found that talking about their emotions was useful.

'I really enjoyed being able to talk about it because it really does get it out of your system'. (participant 3)

Some others identified that it was helpful having someone 'different' to talk to as it avoids the need to burden friends and family.

'After a while you do feel like you're boring your family if you do go harping back about it. But sometimes there are times when you do need to go over it again, I actually find it really comfortable talking about it. I don't with my family because they've heard it all, they lived it and they lived it from a very different perspective'. (participant 4)

Some claim it stopped them wallowing in their own self pity and could have prevented depression almost using it as a therapeutic activity.

'Things do get you down, but it's helped me to 'get out there' do you know what I mean?...it's helped me to cope better'. (participant 3)

'It's easy to become depressed if you think about what you've gone through, but it's good to have people to talk to'. (participant 2)

Involvement in this way provides the platform for service users to evaluate and rebuild their lives, improve confidence, be proud of their achievements and reach a deeper understanding of who they are as a person.

'...so its only since I've had cancer, sounds really weird, that I'm actually finding out about who I am and what I want'. (participant 2)

CONCLUSIONS

The overarching theme of a 'sense of wellbeing' for service users reflects their accounts of being involved where they describe both their motivation and experience of the activities in which they took part.

The view that they are able to promote awareness of cancer and the associated psychological

consequences is supported by the concept of 'expert patient' with the premise that they can enhance healthcare education by sharing insight into the cancer experience.^{11,33} This in turn gives the patient a platform so their voice can be heard.^{34,35} This study has highlighted that some service users have come with a motivation to improve services from a negative experience. However, rather than having an 'axe to grind' they are channelling that energy to make a difference to the profession at a 'grass roots' level where they can make an impact.³¹

The notion that the activities could impact on the students' professional development and the quality of cancer services is a strongly held view of the service users and they focus specifically on effective communication skills, a core value of the current NHS.^{24,36} Their input into communication skills workshops with students has demonstrated this as an effective strategy.

This study has highlighted the positive impact that activities can have on the service users themselves. Their accounts did not reveal any negative effects and where emotions were discussed this was viewed as a constructive experience both for students and service users.⁴ The cathartic nature of activities alerts the workshop facilitators that appropriate support and de-brief with service users should be mandatory.¹⁷

There were some interesting insights into the personal rewards that service users report. It suggests an altruistic element of 'paying back' the professionals involved in their care by contributing to education. Peer support was also regarded as a positive experience with the service users involved developing an active support network; building this into future activities is recommended.

Undoubtedly, service user involvement activity prompts reflection and an opportunity for evaluation; as such this should be viewed as a learning experience for both students and service users with appropriate support built into the programme.¹⁷ This sense of 'personal evaluation' by participants was a strong theme within the accounts and contributes to the concept that activities have enhanced their self-esteem, confidence and overall sense of wellbeing.⁵

An unexpected construct that was presented by participants was the idea of love; love they felt for professionals and in turn felt displayed towards them. Perhaps this is a term under utilised by health professionals, or indeed one which they feel uncomfortable with, nonetheless an integral aspect of 'caring' in service users' eyes. The participants clearly evaluated students' emotional responses to their stories and regarded this as positive behaviour. Perhaps the concept of 'love' is worth further investigation in a healthcare context.

The service users report that their cancer had given them a 'sense of purpose'. As a consequence they are able to share the impact it has had on their lives and use this in an educational setting. The involvement activities can also bring with it a sense of 'wellbeing' and contribute to skills for survivorship.

Participants' cancer experience is a unique and permanent part of their lives. In fact, service user involvement has become part of their personal journey and contributed to their view on life, mortality and family. For healthcare students this provides an esteemed insight into the ways in which they can influence that experience.

This study has highlighted the importance of hearing the service user's voice in education and supports the need for two-way engagement providing therapeutic benefits for both. As educators we should acknowledge the value of service user involvement and the impact it can have on professional development as well as the lives of the SU. Education can provide a platform for SU to continue their cancer journey well beyond their medical experiences that can be synergistic for the profession.

Further study is recommended in order to explore the psychological reasoning behind why reliving the cancer journey helps the SUs at various intervals after diagnosis and beyond.

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Conflicts of Interest

None.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the Helsinki Declaration of 1975, as revised in 2008, and has been approved by Sheffield Hallam University.

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