Innovative Approaches to Involving Service Users in Palliative Care Social Work Education


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Innovative Approaches to Involving Service Users in Palliative Care Social Work Education

Audrey Agnew & Joe Duffy

Service user involvement in social work education is now a firmly established concept in the United Kingdom. As a result, it is common practice for service users to occupy central roles in the education and training of social work students and staff in both qualifying and post-qualifying programmes. This paper describes an initiative, undertaken in Northern Ireland, which compares two methods of user involvement employed with undergraduate and post-qualifying social work students. In both situations the students firstly observed and discussed DVD excerpts of narratives from people affected by cancer and secondly observed a live facilitated interview with a 25-year-old male service user who shared his experiences of being diagnosed with cancer at a young age. Understanding the social work role in palliative care is crucial as all social workers, regardless of practice context, will have some degree of involvement in helping individuals and families to address end-of-life care issues. This paper compares the findings of evaluations from two student groups which may help to inform social work educators about the effectiveness of different teaching methods used to achieve meaningful and effective user involvement with seldom heard groups.

Keywords: Palliative Care; End-of-Life Care; Seldom Heard; User Involvement; Education; Social Work; Undergraduate; Post-Qualifying; Postgraduate; Training

Introduction

Social Work in Palliative and End-of-Life Care

Despite the negative perception of social workers portrayed by the media, Beresford et al. (2007) reported a number of positive themes resulting from research interviews with service users about their experiences of specialist palliative care social work. These included the social worker’s ability to enhance the service users’ capacity to cope by
helping to reduce social isolation, by increasing support for loved ones, by minimising their anxieties about practical problems and by supporting people to contend with medical problems (Beresford et al., 2007, p. 120). According to Reith and Payne (2009, p. 6), ‘Social work in palliative and end-of-life care focuses on losses of identity and expectation’. It avoids seeing loss as an individual problem by recognising that loss is both personal and social, requiring involvement from familial and social networks. All social workers, regardless of programme of care, help people with end-of-life issues (Reith and Payne, 2009, p. 1), and recent evidence (Evaluation of the Social Work Degree Qualification in England Team, 2008, p. 13) confirms how students value service user and carer input in terms of meeting the learning requirements of their social work education. People with life limiting illnesses are actively contributing to social work education by sharing their own unique perspectives.

Undergraduate Social Work Training

As part of their professional training, social work students in Northern Ireland are required to undertake two formal practice learning opportunities and 30 additional flexible learning days. The objective of these additional days is that the students can avail themselves of learning opportunities and experiences, not normally accessible through their taught curriculum, which may address gaps in their learning opportunities, such as palliative and end-of-life care. The World Health Organisation (2008) has defined palliative care as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness’. It is primarily the student’s responsibility to organise their flexible learning, however at one university in Northern Ireland, some voluntary events are centrally organised. An invitation to students to attend ‘Diagnosed Young’, using a new Marie Curie Cancer Care training DVD and a facilitated interview with a 25-year-old male service user, was one such event. This was advertised as a flexible learning event, where final year students were offered the choice to attend. Consent was implicit in their decision to participate and to return a completed questionnaire. The students were informed that the results of their questionnaire would be used to evaluate the event. A sample of students (n = 12) attended and appreciated the importance of user perspectives through the two mediums: observation and discussion of DVD excerpts and observation of a live facilitated interview. This learning event was a significant departure from their traditional experiences of user involvement where students would experience service users sharing their testimony in person. In this instance, students had the opportunity to experience user involvement through the medium of DVD followed by opportunities for further clarification with the service user participating.

Postgraduate Social Work Training

As part of their continuous professional development (CPD), newly qualified social workers are required to undertake the Northern Ireland Post Qualifying Education and Training Partnership (NIPQETP) Specific Award in Social Work, contributing
towards an MSc in Professional Development. Post-qualifying awards in social work are a well established part of CPD (Brown et al., 2006) and are considered to be evidence of continued and enhanced competence to practise through a process of reflecting on practice in protected time (Brown et al., 2008). One module, ‘Professional Practice in Health, Physical Disability and Services’, focusing on loss and transitions, offered the opportunity to present ‘Diagnosed Young’ using Marie Curie’s DVD and a facilitated interview with a 25-year-old male service user, to recently qualified social workers ($n = 12$) who were employed by one Health and Social Care Trust in Northern Ireland. This evaluation may also support universities, providing post-qualifying programmes, needing to demonstrate that learning makes a difference to a social worker’s professional development and has the potential to impact on day-to-day practice and service delivery (Brown et al., 2008).

**DVD Teaching Method**

The *Marie Curie Stories* DVD, funded by Lloyds TSB Foundations for Northern Ireland and directed by Crucible Pictures Limited, was specially created to capture the views and experiences of patients and carers about specialist palliative care. It consists of an introduction to palliative care and six themed sections: diagnosed with a terminal illness, being bereaved, protecting loved ones, faith, comradeship and communication. For the purposes of this teaching session, student groups watched three sections: ‘Introduction to palliative care’ which consists of Dr Kelly, a retired Medical Director and Consultant in Palliative Medicine, defining palliative care and presenting key messages and challenges to consider when interviewing patients; ‘Diagnosed with a terminal illness’ where a male service user shares his personal experiences of how his illness and treatment had affected him in all areas of life; and ‘Communication’ which highlights how communicating bad news and information in a timely and sensitive way has been shown to minimise feelings of anxiety and worthlessness in patients and carers.

**Facilitated Interviewing Method**

Having received positive feedback from students and service users about the benefits of facilitated interviews, which the present authors had used in previous flexible learning opportunities in 2007, the authors negotiated an agreed interview schedule with a 25-year-old male service user, who had direct experience of Marie Curie Cancer Care inpatient and outpatient services over an 18-month period. Despite the high prevalence of cancer in older people (Cancer Research UK, 2007), the authors invited this young service user to engage in teaching, due to his motivation and ability to share his unique and challenging cancer journey in a constructive and meaningful way, and his involvement in the *Patient Stories* DVD. The interview questions and parameters for response, identified to meet the aims and objectives of the teaching session and to ensure the safety and well-being of the service user, were mutually agreed between the authors and the service user. Creating a non-threatening teaching environment, with
safe boundaries of confidentiality and content, are integral to the successful outcome of any user involvement event (Oliviere, 2009, p. 55).

Background

User Involvement

In recent years, in Britain, service user and carer participation, explicit within social service planning, delivery, education and research, has developed at a rapid pace, and we have ‘entered a new era of the empowered service user’ (Carey, 2009). Bradburn (2003, p. 24) states that: ‘user involvement in the context of palliative care includes all levels of care from the one-to-one relationship between patient or carer and health professional to service and policy developments’. The author goes on to say that ‘user involvement is an important part of ensuring quality in supportive care services’ (Bradburn, 2003, p. 29). User involvement is an engrained aspect of the health and social care agenda in Northern Ireland with ‘government, employers and professionals ... promoting service user involvement in all aspects of the planning, delivery and monitoring of health and social services, including the education and training of staff’ (Duffy, 2008, p. 10). Whilst the need for involvement is therefore clearly an established facet of the UK government’s personalisation agenda, the realities of the challenges in effecting this should not be underestimated. Some authors, for example, would suggest that only small numbers of people wish to be associated with such involvement (Levin, 2004; Oliviere, 2009). Other problems such as consultation fatigue (Olsen et al., 1997), reimbursement/payment (Hasler, 2003; National Council for Palliative Care, 2008), and tokenism (Chambers et al., 2003) can all collectively act as inhibitors to the achievement of meaningful citizen involvement, some of which we will examine more closely in subsequent sections. Work recently completed in Northern Ireland (Duffy, 2008; Agnew and Duffy, 2009) highlighted the importance of preparatory work when planning user involvement activities, as well as providing feedback to users about the outcomes, to help prevent users experiencing consultation fatigue. However, the need to address problems associated with current heavy reliance on a relatively small sample of highly motivated individuals jeopardises the sustainability of user involvement (National Council for Palliative Care, 2008). This is a view previously shared by Davie and Noble (2003, p. 72), who suggested that ‘sources of users willing to participate need to be cultivated, nurtured and not exploited beyond their capacity’.

Service User Involvement in Palliative Care

Service user involvement in palliative care was introduced through a number of national policy initiatives: the Calmin–Hine Report (Department of Health, 1995) recommended that cancer services should be patient-centred, providing seamless quality services; The National Cancer Plan (Department of Health, 2000) encouraged user involvement by recognising the quality of cancer services as a national priority; Building on the Best: Choice, Responsiveness and Equity in the NHS (Department of
Health, 2003) placed specific emphasis on patient and user involvement in addressing palliative care issues; The End of Life Care Strategy (Department of Health, 2008) called for action to promote public awareness and to change attitudes about death and dying, and called for workforce development initiatives which include training in communication skills so that staff are equipped and confident in initiating conversations and supporting people approaching end-of-life.

This profile was further enhanced through public discussion, organised events, commissioned research and publications (Beresford et al., 2001; National Hospice Council, 2001; Oliviere, 2001; Kraus et al., 2003; Monroe and Oliviere, 2003; National Council for Palliative Care, 2008). Whilst some would claim that user involvement is already engrained in palliative and hospice care through the ‘holistic’ approach which is central to service user care, it could be argued that ‘offering a voice is not the same as accessing people’s own voices’ (Beresford et al., 2007, p. 32). According to Dame Cicely Saunders, one of the key and explicit aims of user involvement in health and social care is to be a voice for the voiceless (Oliviere, 2000). One perceived obstacle to promoting user involvement in palliative care education and training has been that service users originate from two vulnerable groups: those people who are either living with a life-limiting illness and may be facing death, or those people who are living with the impending threat of bereavement or have been bereaved. Additionally facilitators need to understand the practical, emotional and psychological issues faced by service users (Beresford et al., 2001). Users’ experiences and knowledge of services are an important component of developing more integrated and patient-centred care, therefore, assuming users are too unwell to participate may result in stereotyping (Bradburn, 2003, p. 36). Subsequently we need additional creative strategies, which promote service user involvement and overcome barriers, particularly for those who are too ill, too tired or unable to physically attend meetings or with poor levels of concentration (National Council for Palliative Care, 2008). Potential options have been evidenced through the increasing acceptability for professionals to introduce user or carer experiences in public forums or teaching sessions (Oliviere, 2009), and a plethora of digital technological or Internet training resources, using actors for simulated role-plays or real service users telling their own stories, many of which are accessible as digital resources.¹

User Involvement in Social Work Education

The involvement of service users and carers is now a mandatory requirement in social work education in the UK for both qualifying (Quality Assurance Agency, 2000; Department of Health, 2002; Levin, 2004; Duffy, 2006) and post-qualifying programmes (General Social Care Council, 2005; NIPQETP, 2007). Quintessentially, however, user involvement is not a new phenomenon in social work training, as its first inception, as client studies, dates back to the seminal work of Meyer and Timms (1970).

Typically such involvement has entailed service users and carers contributing to aspects of teaching and programme delivery (Bolan et al., 2000; Citizens As Trainers Group et al., 2004; Molyneux and Irvine, 2004), assessing practice learning (Shardlow...
and Doel, 1993; Shennan, 1998), providing feedback in live observations (Crisp et al., 2006), co-facilitating workshops (Manthorpe, 2000), sharing personal testimonies (Elliot et al., 2005), and being involved in programme management and assessment boards (Molyneux and Irvine, 2004).

The benefits associated with such involvement have also been suggested. Duffy (2006), for example, refers to ways in which the user perspective assists social work students to improve their understanding of empathy. In a study conducted in Northern Ireland, social work students and other key stakeholders were surveyed and the results indicated that empathy was a skill area that the user perspective could influence. Brown and Young (2008) similarly found that social work students are facilitated, through user involvement, to make better links between theory and practice as well as practising a range of social work skills.

Nevertheless, the challenges involved in effecting meaningful user engagement in social work education should not be underestimated. Problems in relation to paying service users and carers for their contributions are restricted by a government state benefits system which is prohibitive about permitting additional income without subsequent financial penalty particularly affecting those service users and carers who are in receipt of means tested benefits. Seldom heard and hard to reach user perspectives, despite the challenges for particularly vulnerable groups, need to be made more accessible to ensure that students benefit from a diversity of user perspectives. The importance of training as a way of supporting service users and carers in their role, as social work educators, is also widely acknowledged (Beresford et al., 1994; Levin, 2004; Speed, 2006; Duffy, 2006, 2008).

Scepticism around ‘ordinary people taking on powerful roles’, however, also needs to be considered (Rimmer, 1997, p. 33 cited in Agnew and Duffy, 2009, p. 112). The relationship between service users, students and their educators is potentially one of equal partnership because students and teachers need service users, as much as service users need health and social care professionals (Davie and Noble, 2003, p. 72). There is also some evidence to suggest that service users may experience discrimination by students being disrespectful and patronising in their behaviour and attitudes (General Social Care Council, 2004; Branfield et al., 2007), or being stigmatising towards some service users because of their background (Duffy, 2006). Additionally, as illustrated by Oliviere (2009, p. 60), boundary issues can interfere in user involvement, such as unveiled criticism of health or social care professionals, users expressing discriminatory remarks or issues of confidentiality, particularly in small communities. Once more, some of these issues can be avoided, in educational settings, through appropriate teaching preparation and use of digital technological or Internet resources.

Methods

Sampling and Recruitment

This evaluation involved working with two cohorts of social work students at undergraduate and postgraduate levels. Given that this was an evaluation of teaching
methods, ethical approval was not required. Nevertheless, participants were fully informed that all data would contribute towards a subsequent evaluation of the teaching sessions. Consent was implicit through the return of completed questionnaires. The first group consisted of a convenience sample of 12 final year students studying on the Batchelor of Social Work (BSW) Degree at a university in Northern Ireland. Firstly, the students were invited to voluntarily register for a flexible learning opportunity entitled ‘Diagnosed Young: A Service User’s Cancer Journey’. Given the sensitivities around this subject and the methods of teaching involved, the event was restricted to 20 students and was attended by 12 students. The 90 minute teaching session consisted of observing and discussing excerpts from a patient stories DVD produced by Marie Curie Cancer Care and a facilitated interview with a 25-year-old male service user, diagnosed with a malignant brain tumour, who had direct experience of Marie Curie Cancer Care inpatient and outpatient rehabilitation services during an 18-month period.

The second group consisted of 12 qualified social workers undertaking the Specific Award in Social Work as part of the NIPQETP framework. The event was offered to those enrolled in the module, ‘Professional Practice in Health, Physical Disability and Services’, and focused on loss and transitions. All students had been informed of the sensitive content of the 90 minute teaching session, mirroring the session offered to undergraduate students, and could therefore make an informed choice about their attendance.

Measure

The instrument used to evaluate the teaching session was a voluntary, anonymous questionnaire which collected qualitative and quantitative data. At the start of the teaching session, students in both groups were invited to provide relevant demographic data such as age, ethnicity, gender and experience of social work. In addition, students were asked to rate their perceived understanding of specialist palliative care at three intervals, at the start of teaching (phase I), following the observation and discussion of training DVD excerpts (phase II) and following observation of a facilitated service user interview (phase III). Furthermore, the students were asked to rate the usefulness of the DVD and the interview in terms of integrating social work knowledge and skills into practice. Finally, participants were asked to rate their perceived confidence to work with service users in specialist palliative care, to rate their overall learning and to make recommendations or improvements to the session as a result of having participated in this training.

In order to evaluate the effectiveness of the two training methods, the questionnaire consisted of 14 questions, capturing quantitative and qualitative data. All questions included four-point Likert scales measuring from no understanding to full understanding. This ensured that participants ranked responses ‘in order’ so that the data in each phase could be compared as being higher or lower than, more or less than, data in other phases (Denscombe, 2003, p. 237). Additionally, participants provided qualitative comments in relation to their Likert scale response ratings. This
method was chosen as previous evaluations of teaching, which had relied on quantitative data collection, were criticised (Felton, 2005; Brown et al., 2008). The questionnaire was developed based on Bandura’s concept of self-efficacy as a theoretical driver for evaluation (Bandura, 1997). Self-efficacy theory illustrates the process of learning through which acquired knowledge and skills develop into the targeted cognitive and behavioural objectives of clinical practice. Bandura’s theory postulates that appropriate training (knowledge acquired through the DVD excerpts and behaviour modelled by the facilitated service user interview) fosters confidence in one’s ability to meet objectives (self-efficacy in relation to palliative care social work) and illustrates the value of one’s actions (outcome expectancies in relation to engaging with service users known to palliative care services).

**Data Analysis**

Due to the sample size, all questionnaires were examined manually for changes in perceived understanding in specialist palliative care social work and for themes in qualitative statements following the employment of the two training methods. Demographic data were also descriptively summarised and presented in a table.

**Results**

All participants returned fully completed questionnaires, which was a 100% response rate. As illustrated in Table 1, in terms of gender, group one consisted of five male (42%) and seven female (58%) participants, whereas group two consisted of 12 females (100%). Participants in both groups were all identified as white (100%).

Results will now be presented comparing each student group. In group one, participants were predominantly aged between 20 and 29 years of age ($n = 7$), with the remainder aged between 30 and 39 ($n = 4$) and one aged 40 + , whereas in group two, participants were predominantly aged between 20 and 29 years of age ($n = 9$), with the remainder aged between 30 and 39 ($n = 2$) and one 40 +.

**Employment Background**

In relation to group one, the majority of undergraduate students ($n = 8$) had relevant work experience, prior to commencing social work training, with the remainder ($n = 4$) having limited experience. In relation to group two, the majority of post-qualifying students ($n = 8$) were employed in community social work teams (older people or adults with disability), and the remainder were from hospital social work backgrounds ($n = 4$) and had all graduated in social work between 2006 and 2007.

**Perceived Understanding of Palliative Care**

Based on the degree of perceived understanding of palliative care, measured at three different intervals during the training session, the majority of undergraduate students,
as illustrated in Table 2, had no understanding \( (n = 5) \) or very little understanding \( (n = 5) \) of palliative care at the start of the teaching session (phase 1) and the remainder had some understanding \( (n = 2) \). Students, in group one, who had a degree of understanding about palliative care, indicated that this knowledge had been acquired through life experience \( (n = 5) \), work experience \( (n = 1) \) or attendance at a course or lecture \( (n = 1) \), with the remainder having no knowledge \( (n = 5) \). After observing and discussing the DVD (phase 2), most students indicated that they had some understanding \( (n = 11) \) with the remaining student having full understanding \( (n = 1) \) of palliative care. After observing the facilitated service user interview, most students indicated that they had full understanding \( (n = 10) \) of palliative care with only two students indicating they had some understanding.

As illustrated in Table 2, these results provide evidence that all undergraduate social work students perceived growth in their understanding of specialist palliative care from phase 1 (start of session) to phase 2 (post-DVD), with the majority \( (n = 10) \) perceiving further improvement after phase 3 (post-interview). Due to the sample size it was not feasible to observe trends in relation to the age or gender of students and their perceived understanding of palliative care.

In comparison, the degree of perceived understanding, measured at three different intervals by post-qualifying students, in group two, illustrates that, at the start of the teaching session, all students had very little \( (n = 5) \) or some understanding \( (n = 7) \) of palliative care. This knowledge had been acquired through life experience \( (n = 6) \), attendance at a course or lecture \( (n = 5) \) or through work experience \( (n = 4) \). In some

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Demographic Data of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Group one Undergraduates ( (n = 12) )</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>20–29</td>
<td>7</td>
</tr>
<tr>
<td>30–39</td>
<td>4</td>
</tr>
<tr>
<td>40 +</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
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<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Ethnic background</td>
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<table>
<thead>
<tr>
<th>Table 2</th>
<th>Undergraduate Social Work Students’ Level of Understanding of Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No understanding</td>
</tr>
<tr>
<td>Start of session</td>
<td>5</td>
</tr>
<tr>
<td>After DVD</td>
<td>0</td>
</tr>
<tr>
<td>After Interview</td>
<td>0</td>
</tr>
</tbody>
</table>
cases multiple sources of knowledge had been experienced. Results indicate that after observing and discussing the DVD (phase 2) most students had **some understanding** of palliative care \( (n = 11) \), with the remaining student perceiving herself to have a **full understanding**. After observing the facilitated service user interview, the majority of students had **some knowledge** \( (n = 8) \) of palliative care, and the remainder had **full knowledge** \( (n = 4) \).

As illustrated in Table 3, results indicate that the majority of post-qualifying students had **very little or some understanding** or experience of palliative care prior to attending the training, and that the majority perceived themselves to have **some or full understanding** at the conclusion of the training session. This may be one reason for less evidence of growth in knowledge and understanding of palliative care in post-qualifying students.

Qualitative comments provide further evidence of the benefits of the teaching session. All students, both undergraduate and post-qualifying, indicated that the DVD excerpts and the facilitated service user interview were **very useful**.

The DVD provided a very useful insight into how social work skills can be utilised in order to explore sensitive issues and to begin at the position of the client. (BSW student, ID7)

However, the facilitated service user interview had a more powerful and memorable effect:

Excellent learning experience—much better to hear experiences from an actual person … (BSW student, ID12)

**Impact of DVD Teaching Method**

Analysis of the results regarding how undergraduate students perceived that the DVD had informed their skills and knowledge in relation to palliative care, led to the following learning points being identified: the power of hearing real stories from service users \( (n = 6) \), the demonstration of integrating theory to practice \( (n = 5) \), the importance of seeing the person, not their illness \( (n = 2) \), and the importance of communication skills \( (n = 3) \). A number of undergraduate students identified that they experience ‘information overload’ during their degree training, and that teaching which incorporates service users is extremely valuable, as it helps to integrate theory to practice, by ‘bringing theory to life’, and the facilitated service user interview demonstrates skills and values through modelling. Analysis of results from post-

<table>
<thead>
<tr>
<th></th>
<th>No understanding</th>
<th>Little understanding</th>
<th>Good understanding</th>
<th>Full understanding</th>
<th>Total ( n = 12 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start of session</td>
<td>0</td>
<td>5</td>
<td>7</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>After DVD</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>After Interview</td>
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<td>0</td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
</tbody>
</table>

**Table 3** Post-Qualifying Social Work Students’ Level of Understanding of Palliative Care
qualifying students highlighted the importance of hearing real stories from service users with real experiences of engaging with health and social care professionals \((n = 5)\) and the importance of communication skills \((n = 8)\).

**Impact of Facilitated Interview Method**

Analysis of the results in relation to how the facilitated service user interview had informed their skills and knowledge, showed that undergraduate students identified the following learning points: the importance of hearing the service user’s perspective \((n = 8)\), particularly in relation to how the illness had impacted on all domains of the service user’s life, the importance of communication skills \((n = 5)\) and the importance of demonstrating respect, particularly for an individual’s faith \((n = 4)\).

This is the only talk we’ve experienced that has discussed faith and hope, and the importance of respecting people’s views and including it within the social work process. (BSW student, ID8)

Post-qualifying students identified the following learning points: the value of hearing the service user’s perspective \((n = 11)\), the importance of respecting an individual’s faith \((n = 2)\) and the importance of skills \((n = 1)\). The following quote supports the value attributed to these teaching strategies:

The service user experience proves that no professional knows all the answers . . . all the information helped me to become “in tune” with my feelings in relation to palliative care and the impact that professionals can have on service users. (Post-qualifying student, ID3)

**Perceived Learning Outcomes**

All undergraduate and post-qualifying students valued the teaching session and indicated that attending had improved their confidence in working within palliative care settings. Additional qualitative comments indicated that some students believed the session had increased their confidence \((n = 5)\), others stated it had demystified their assumptions regarding palliative care \((n = 3)\), some were more confident about application of theory and skills \((n = 3)\) and the remainder had increased self-awareness \((n = 2)\). The following quote illustrates some of these key points:

Having an understanding of the complex nature of palliative care provision is crucial to effectively and positively engage with the individual and family . . . this interview gave the literature material life in terms of identifying the key aspects of interacting with service users that create positive experiences. (BSW student, ID2)

All undergraduate students stated that they had learned a lot from attending the session \((n = 12)\) and all post-qualifying students stated that they had a fuller knowledge of palliative care \((n = 12)\). Qualitative comments indicated that some students found the session invaluable or informative \((n = 9)\) or emotive \((n = 3)\), as illustrated by one student in the following quote:
After this session I feel more comfortable in approaching the issues of cancer and palliative care. This was a brilliant and highly informative experience. (BSW student, ID7)

**Student Evaluation of Training Session**

Whilst the majority of undergraduate students \((n = 8)\) were satisfied with the content of the training session overall, the remainder \((n = 4)\) suggested that having more than one service user, highlighting pointers at the start of each DVD excerpt to help students tune in to issues, and offering these sessions to a wider health and social care student audience would be helpful. In relation to post-qualifying students, the majority were satisfied with the teaching session \((n = 9)\), and the remainder \((n = 3)\) suggested improvements. The need to raise the profile of palliative care by offering this training to different professional groups was recognised as well as the need to provide more information generally about the social work role in palliative care and community palliative care services.

**Service User’s Reflections on his Experience of the Training Session**

I was always eager to assist in social work education, particularly after being ill in 2007 and having received support from social workers who were caring and altruistic. Speaking to social work students seemed a small way to repay my debt to the profession. As a history graduate, I frequently draw analogies with historical events. In the 1960s, Communist Czechoslovakia implemented a policy known as ‘socialism with a human face’. Although in my mid-twenties, having just graduated and planning to go travelling and step onto the career ladder, this was suddenly taken away from me through ill health. An obvious question for the students would be ‘if this could happen to him, how many other young people has it happened to?’ By participating in the teaching, I was in effect ‘cancer with a human face’. By being in the classroom I helped to remove any sense of detachment, where I could emphasise that social workers need to remember they are dealing with a person and not a situation and that they should judge each individual and situation with the distinct merit that it deserves.

**Discussion**

With recent changes to social work education in the United Kingdom, service user involvement in the undergraduate and postgraduate curriculum now has an increased and elevated presence, as evidenced by the following:

The degree appears to have been the impetus for developing new methods of delivery of the curriculum, especially in skills lab work, in e-learning and in involving service users and carers. (Evaluation of the Social Work Degree Qualification in England Team, 2008, p. 10)

Whilst this has been positively welcomed, seldom heard and hard to reach service users are still under-represented in undergraduate and post-qualifying teaching
programmes. However, the initiative described in this paper illustrates how meaningful service user involvement, which can be challenging and fraught with barriers (Monroe and Oliviere, 2003; Duffy, 2008; Oliviere, 2009), helped to improve students’ understanding of the social work role in specialist palliative care. Findings illustrate a clear message to raise the profile of palliative care social work by offering this teaching to a wider group of students, as all social workers, regardless of specialist area, help people with end-of-life issues (Reith and Payne, 2009).

Our evaluation, which was an academic student learning experience, indicates that the DVD was an effective vehicle to advance the students’ understanding of the social work role in palliative care, which is a creative means of promoting meaningful user involvement. Whilst our results indicate that observing and discussing the DVD was helpful to both groups involved, the use of the facilitated interviewing method, which modelled interviewing skills in palliative care, yielded more positive learning outcomes for all the students. The challenge however, based on our key finding that observing the facilitated service user interview further enhanced and complemented existing levels of understanding regarding palliative care, identifies potential limitations of using digital technologies in isolation. In terms of quantitative results, this enhancement in learning was particularly apparent for undergraduate students (Table 2) compared to the post-qualifying students (Table 3). This may have resulted from the undergraduate students’ limited exposure to service users, in comparison to qualified students already employed in community or hospital social work settings. However, these results should not be analysed in isolation, as qualitative statements demonstrate that all students, regardless of student status or palliative care experience, felt more confident, in relation to their skills and knowledge, as a result of attending the session, based on observation of DVD excerpts and the facilitated interview. One clear finding was how hearing real stories, direct from service users, facilitated the integration of theory to practice or brought theory to life, which was deemed more powerful than reading books in isolation. These findings indicate the benefits of user involvement within an educational context, which needs to be carefully planned. Furthermore, the use of digital technology should be considered as a method of avoiding some of the potential barriers to user involvement, which have been highlighted in the literature.

Limitations and Future Research

Because this was a pilot study, the results may not be generalisable to the wider student social work population. For example, this study only examined a sample of final year social work students and recently qualified social workers in Northern Ireland, all of whom were white and most of whom were female. The groups of students were not matched in terms of age, experience and gender. Furthermore, the data collection would need to be undertaken over a longer period of time, thereby gathering stronger evidence in relation to the potential impact of the training session on individual practice and service delivery offered to service users and carers within organisations. Additionally, to improve rigour, reliability and validity, any similar replication of this
study may need to consider the use of a control and intervention group, whereby the effect and influence of the learning materials may be measured more accurately. Given the paucity of rigorous evaluative research demonstrating the impact of service user involvement training on service delivery (Ogilvie-Whyte, 2006), and on increasing access to services or improving quality of life for patients and carers (National Council for Palliative Care, 2008), the authors would recommend further longitudinal research with increased numbers of student groups across disciplines. To promote sustainability of service user involvement in different settings and to address issues of payment, tokenism or consultation fatigue, we would recommend continuing innovative partnership arrangements between service users, health and social care professionals and academic institutions, such as those currently employed in the selection of social work students in England (Evaluation of the Social Work Degree Qualification in England Team, 2008, p. 8). Finally, as illustrated in other work (National Council for Palliative Care, 2008), the service user’s voice is predominantly missing in discussion and evaluation about service users’ involvement methods, apart from Beresford et al. (2007), and we recommend addressing this.

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Note


References


