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# LEARNING FROM THE EXPERIENCES OF CANCER PATIENTS AND THEIR CARERS

Claire Job, Sally Anstey and Jane Hopkinson discuss how listening to individuals' stories can improve education

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## Abstract

UK cancer policy aims to improve the quality of cancer services and enhance the experience of people affected by cancer. A recognised barrier to improving services is healthcare professionals' lack of insight into patients' and carers' experiences; this article reports on the process of integrating these into a cancer education programme for nursing students. The cancer academic team identified patients and carers to help co-produce the programme. Students had an opportunity to listen to patients' and carers' stories and to learn from – rather than about – patients.

Small-group work enabled patients, carers and students to explore the cancer experience in a safe and supportive setting. Working collaboratively with people affected by cancer ensured that the focus was on their experience, placing it at the core of the cancer education programme.

## Keywords

cancer, education, nursing students, patient and carer involvement, patient experience

HEALTH PROFESSIONALS can learn directly from patients and carers to gain more meaningful insight into patients' experiences (Tew *et al* 2004, Repper and Breeze 2007, Morgan and Jones 2009, Terry 2012, Turnbull and Weeley 2013). Tew *et al* (2004) pointed out that service users and carers make a unique contribution to the education and training of professionals, particularly in relation to empathetic communication and advocacy. Involving patients and carers in the classroom enables students to hear their needs first-hand, and this approach is valued by students, enabling a patient and carer-centred approach to health care (Tew *et al* 2004, Terry 2012). Terry (2012) highlights that the involvement of service users in pre-registration nursing programmes has been

widely adopted in mental health, and that there are extensive opportunities for user involvement elsewhere in education.

There is an increasing emphasis on improving the experience of people affected by cancer (Department of Health (DH) 2011, Welsh Government 2012, Independent Cancer Taskforce 2015). Macmillan Cancer Support (MCS) (2013) highlights that health professionals lack insight into and knowledge about the experience of those who have cancer, and its treatments, claiming this is the biggest barrier to widespread improvement in services (MCS 2012). The nursing workforce plays a pivotal role in delivering cancer services, and therefore nurse education is crucial to improving the patient and carer experience.

What's your story?



The school of healthcare sciences at Cardiff University and MCS collaborated to target undergraduate nurse education to improve the experience of those affected by cancer. This article discusses one aspect of this work, a collaboration between lecturers and people affected by cancer to improve cancer education for nursing students. It reports on the process of integrating ‘first-hand’ experiences of patients and carers into the education programme. This provided students with a memorable learning opportunity inspired by people whose ‘know what and know how’ make them experts in their own illness management.

### Background

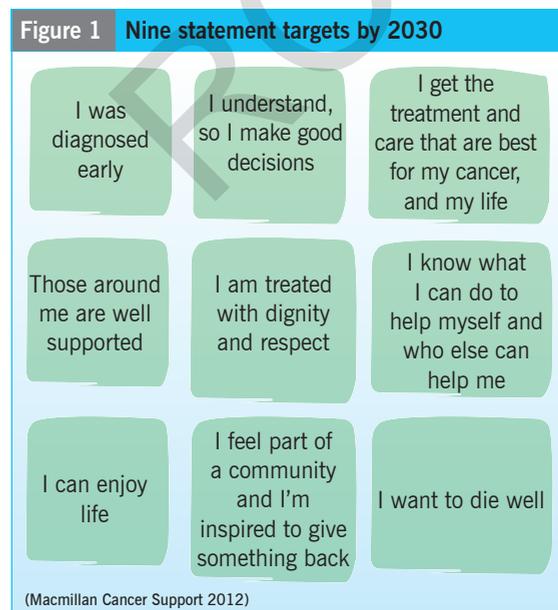
McLaughlin (2009) discusses the contentious issue of what people who have experience of health and social services should be called, pointing out that whichever label is used – for example, ‘service user’, ‘client’, ‘patient’ or ‘expert by experience’ – it is descriptive of a relationship with services and/or professionals, not of a person. Through consultation with the people affected by cancer in this project, it became clear that no consensus could be reached on a collective name. Speed *et al* (2012) point out that even people with the same condition who have gone through similar experiences cannot agree on what they should be called. The meaning attached to words can reflect the person’s attitude to their illness and their personal experience. In healthcare services, people affected by cancer are commonly called ‘patients and carers’. This article acknowledges the expertise of people living with cancer and chooses to name them

‘patients and carers’ in order to be clear and concise, linking this project to contemporary professional practice.

### ‘Learning from patients’ rather than ‘learning about patients’

The planning and delivery of healthcare services is changing from a model of managerial and medical dominance, towards a partnership approach that values the contribution of patients and carers (Health and Care Professions Council 2013). This approach is mirrored in the development of education programmes for healthcare professionals. The Health Foundation (2011) reviewed the evidence for user involvement in education and highlighted that it is important that healthcare professionals learn about, from and with people who are experts about their own lives, suggesting that such an approach can help partnership working (Turnbull and Weeley 2013). This recognition has been championed in the Nursing and Midwifery Council’s (NMC) (2010) standards for pre-registration nursing education, which require those who plan and deliver nurse training to demonstrate user involvement activities.

The purpose of patient and carer involvement in nurse education is to enable students to gain valuable insight into the patient/carer experience and support the development of attitudes that promote patient-centred communication and care (Costello and Horne 2001, Perry and Linsley 2006, Morgan and Jones 2009, Terry 2013). The Health Foundation (2011) points out that direct provision of patient care has featured prominently in nurse training. It is not always possible, however, for nursing students to explore the patient and carer experience from a learning perspective during a placement, because of clinical demands and patient vulnerability at that moment. Therefore, including patients’ and carers’ voices in an academic setting gives nursing students the opportunity to hear their stories and ask questions to support learning in a safe place for all (Terry 2012). Haigh and Hardy (2011) highlight that patient narratives are a valuable resource that can be used to facilitate change and transformation in the provision of healthcare services. In cancer education, therefore, we propose that including people affected by cancer in the classroom fosters a rich dialogue, enabling students to adopt a questioning and inquiring approach that promotes a deeper understanding of patient experience.



## The process of patient and carer involvement

The National Cancer Patient Experience Survey (NCPES) 2010 (DH 2010) highlighted that people living with cancer have a variety of needs that are not always met by services (MCS 2012). The findings of the NCPES inspired MCS (2012) to develop a strategy based on nine statements that it wanted everyone living with cancer to be able to say by 2030 (Figure 1).

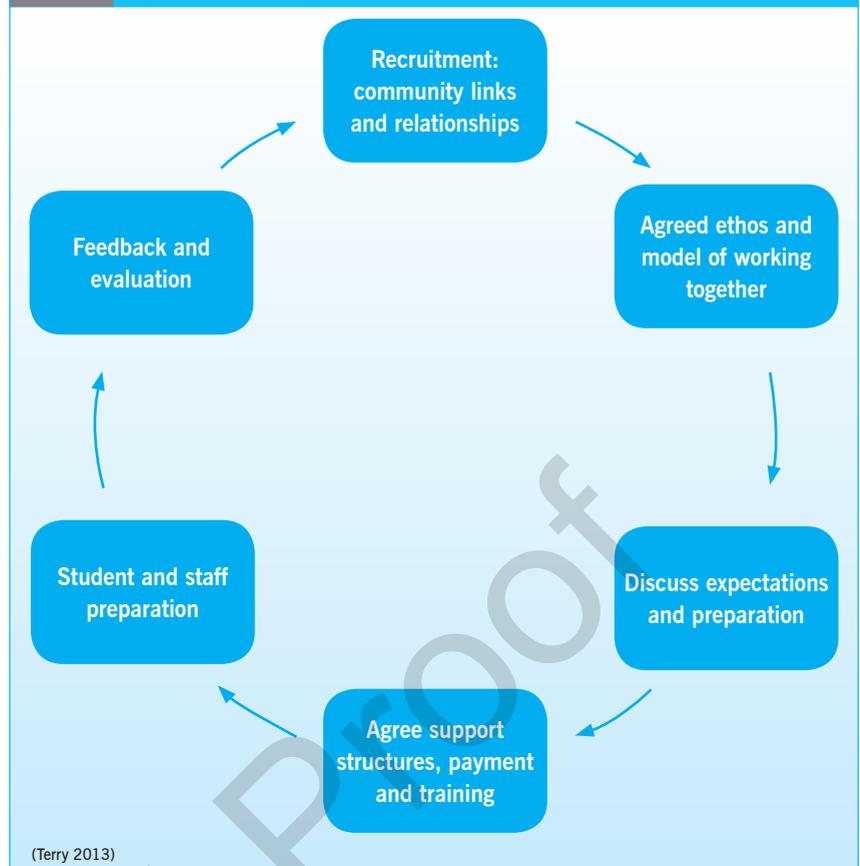
The first eight statements were used as a framework to develop the cancer education programme (note: statement nine 'I want to die well' is explored in a unique element of the curriculum). In the original curriculum, students had only one day of teaching specifically about cancer and its treatments. This was developed into a three-day programme - during the second and third year of training - with a focus on the patient/carer experience, cancer as a long-term condition and survivorship.

**Avoiding the pitfalls** Speed *et al* (2012) highlight that poor or inadequate planning by the academic team can leave patients and carers under-prepared and unsupported in user-involvement teaching activities. Terry (2013) undertook a study tour of higher education institutions in the UK and Ireland as a benchmarking exercise of patient and carer involvement in nurse education. From this work she developed a cycle of essential processes (Figure 2) that aims to support good practice for user involvement in education. This framework was used as a guide to the process of planning and implementing patient and carer involvement in cancer education reported here.

**Recruitment** Patients and carers were approached via established links with the third sector, local NHS cancer services and patient/carer groups. The project was jointly led by the patient/carer group and members of the teaching team. To support other participants, a patient and carer briefing paper was jointly developed to inform patient/carer partners volunteering to take part. This included information about the teaching commitment, our expectations and teaching plans. For the initial sessions, four of the patients and carers were recruited from a local cancer centre patient group. An additional two patients were enlisted via links with third-sector user-involvement projects.

**Agreed ethos and model of working together** The aims and objectives of the teaching programme were established and refined with the patient

Figure 2 Cycle of essential processes in user and carer involvement in education



and carer group. Discussion with patients and carers incorporated a look back at the history of cancer nurse education and exploration of cancer education and policy today. Participants were keen to be involved in teaching students and believed they could make a significant contribution to future nurses' attitudes, values and beliefs about supporting people affected by cancer.

**Discuss expectations and preparation** The aims and objectives of cancer education were discussed and the structure and plan for the day was influenced by patients' and carers' views and expertise (Figure 3). Their storytelling lasted for half a day and the structured group feedback an hour. The patient/carer participants were happy to be allocated a staff member as facilitator to support them in telling their stories and answering students' questions. The patients and carers were clear that they did not want the students to be prepared with questions. They wanted to tell their stories and allow the students to ask questions without censorship. Working together, we agreed the following milestones should be incorporated into their stories:

- The effect of the diagnosis on the person, their family and friends.
- Their communication and information needs.
- Their emotional support needs.
- Their involvement in decision making and care planning.
- Cancer treatment and clinical trials.
- Life now - living with and beyond cancer - lasting effects on all aspects of their lives.

**Agree support structures, payment and training**

Arrangements were made to enable participation by payment of patient/carer expenses as per the university’s patient and public involvement in learning, teaching and research policy.

**Student and staff preparation** A briefing paper outlining the teaching plan for the day was developed for the staff facilitators who volunteered to take part. We discussed the teaching plan with the facilitators on an individual basis and they also had the opportunity to attend the student briefing on the morning of the event. Facilitators primarily supported patients or carers through their storytelling with the student groups. They were also able to help as time keepers. The students were told in advance that a patient and carer day was planned as part of the cancer education programme, and the potential personal sensitivities of this were explored at the outset. They had an opportunity to ask questions about aims, objectives and expectations.

**Feedback and evaluation** Patients, carers and students were able to highlight what was good and challenging about this learning experience, helping us to refine plans for the next cohort. Students then had an opportunity to feed back using the patient story milestones as a guide. During feedback, students were able to identify patient and carer needs based on the voices of those affected by cancer. Patients and carers were invited to a debrief meeting in the week after the event, where they were able to report on what went well and not so well from their perspective.

This teaching initiative was subject to a mixed methods evaluation study that explored its longer-term effect on students’ knowledge, attitudes, values and beliefs about cancer. The results of this have been published by Edwards *et al* (2016), who found students to be more confident in supporting cancer patients and carers compared with those in a preceding cohort who received a single cancer education day and did not have the opportunity to hear patient/carer experiences. Those who completed the patient story days also demonstrated increased knowledge and awareness of cancer as a life-changing condition rather than a ‘death sentence’.

**Outcome**

**Patients, carers and students** Students appeared moved and captivated by the patient and carer stories. The stories imparted simple messages about the importance of information,

Figure 3 Timetable and teaching plan	
<b>Patient and carer stories</b>	
9:00 – 9:30	Introductions and aims for the day
9:30 – 10:00	Student session: explanation of small groups and our expectations of the day Communication skills – getting the most out of the day Professionalism and confidentiality Cancer milestones explained Students to meet in their groups and assign roles
<b>10:00 – 10:30 Coffee</b>	
10:30 – 13:00	Patient and student small group storytelling 10:30 – 11:30 storytelling in small groups (three rounds of 20 minutes) 11:30 – 12:00 student debrief – focus on covering milestones 12:00 – 13:00 storytelling in small groups (three rounds of 20 minutes)
<b>13:00 – 14:00 Lunch</b>	
14:00 – 15:30	Patient and student feedback for 30 minutes Student feedback – creating a picture of the cancer experience – putting puzzle pieces together... what has been learned?
15:30 – 16:00	Student debrief and evaluation of the day

communication and co-ordinated care. The patients and carers were disarming and frank in a way that spoke to students' compassion. Haigh and Hardy (2011) point out that because patient stories touch hearts, they influence minds, providing nurses with an opportunity for reflection. Students and patients reflected together in order to make sense of their shared experience; this reflective dialogue helped all parties to understand the experience. Having the opportunity to listen to more than one story highlighted the parallels as well as the differences in patients' and carers' experiences, enabling students to reflect on needs with an impression of what was most important from the patient and carer perspective.

**Spontaneous written feedback** Several of the students and patients involved in this teaching initiative offered unsolicited feedback on their experience of the day via email. The following are two examples:

*Student perspective* - 'University-based nurse education can feel isolated from clinical practice, it can feel like we are looking in at patients' lives through a window. The patient session allowed us to not only look through their window but sit on their sofa and experience the raw and brutally honest emotion of the worst experience of their lives. Prior to this session, empathy and partnership working were words that had a formal definition, now they are feelings that I aspire to achieve in every patient contact.'

*Patient perspective* - 'So the fact that I had prostate cancer has inadvertently opened up a path that would have been unthinkable before my diagnosis. It was a pleasure to have talked to the students, and on reflection I realised that I had gained so much by it. It's given me more confidence in myself and I hope that I can learn from it.'

**Levels of participation** Patient and carer participation evolved through the initial idea to the planning stages of this project. We encountered no difficulty in enlisting patients and carers. Crucially the structure and design of the day were transformed because of patient and carer involvement in curriculum planning. Tew *et al* (2004) developed a ladder of involvement to illustrate different levels of involving patients and carers in education planning and delivery, highlighting that it is realistic to start with smaller-scale initiatives and work progressively towards greater service user and carer involvement.

**Figure 4 Continuum of participation (service and education)**



Similarly, Lathlean *et al* (2006) outline a model of user involvement called a 'continuum of participation' (Figure 4), which describes the levels of user involvement in projects.

It is suggested that this initiative is an example of Tew *et al's* (2004) level 3 growing involvement and Lathlean *et al's* (2006) users as collaborators, shown by the ongoing involvement and contribution of the patient and carer group in its planning and delivery. This innovative approach to cancer education ensured the voice of those affected by the disease remained at the heart of students' learning experience. Since the project began, four cohorts of students have been exposed to this approach to cancer teaching and learning, with ongoing support from the patients and carers involved. We now have a group of 12 people affected by cancer who are engaged as part of our teaching team.

### Conclusion

The patient and carer perspective is important in the planning and delivery of healthcare services, as well as in the planning and delivery of healthcare professional education (Perry and Linsley 2006, NMC 2010, Terry 2013, Turnbull and Weeley 2013).

Working collaboratively with people affected by cancer enabled us to focus on the patient and carer experience, placing it at the core of the cancer education programme. This provided students with the opportunity to listen to patient and carer stories and learn from - rather than about - patients.

The process of incorporating patient and carer involvement in cancer education required time and planning, but the learning experience was memorable and meaningful for students, patients and carers. The patients and carers are continuing to work with us in the co-production and evaluation of education.

Providing nursing students with the opportunity to better appreciate the experience of people with cancer will arguably improve the care and understanding of the next generation of nurses. The students demonstrated a special interest in oncology and cancer nursing as a result of participating in the programme.

A larger number of students than before chose cancer as the main topic of their dissertation and expressed interest in undertaking a career in cancer nursing.

Research that explored the longer-term effect of patient and carer involvement in cancer education was conducted by a team working

in parallel to the teaching team. This study explored effects on nurses' attitudes, values and beliefs about cancer and the experiences of people affected by cancer (Edwards et al 2016). Our aim now is to explore the perspectives and experiences of the people affected by cancer who are part of our teaching team.

### Online archive

For related information, visit our online archive and search using the keywords

**Conflict of interest**  
None declared

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