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Widening Access; Developing an eLearning Resource for Health and Social Care Professionals Caring for Children and Young People with Cancer

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Abstract Cancer is a key priority worldwide, and caring for children and young people with cancer requires a range of specific knowledge, skills and experience in order to deliver the complex care regimes both within the hospital or community environment. The aim of this paper is to disseminate work undertaken to design and develop pedagogical practice and innovation through an eLearning resource for health care professionals caring for children and young people with cancer across the globe. The work undertaken evaluated an existing cancer course (which has been withdrawn) that was developed and delivered through the Paediatric Oncology Nurses Forum, Royal College Nursing (Nurse Educators) and Warwick University. The evaluation consisted of 26 open and closed questions relating to the previous resource and was circulated to all health and social care professionals involved directly within specialist oncology services through the Children's Cancer and Leukaemia Group. Questionnaires were sent out to a convenience sample of 773 health care professionals and the response rate was 14%. The findings identified that the course was predominantly accessed by nurses, but other health care professionals also found it useful. Participants highlighted several areas where they believed content could be developed or was lacking. This included areas such as palliative and end of life care, nutrition, sepsis and teenagers and young people. This feedback was then used to develop a site dedicated to the care of children and young people with cancer.

Keywords eLearning · Children · Young people · Cancer · Education · Health professionals

Introduction

Cancer accounts for less than 1% of illnesses in children and young people; however, it is the leading cause of death for this age group in the developed world [1]. The main types of cancer in children are leukaemia, brain tumours and lymphomas. Whereas in young people, the main types of cancer are carcinoma, lymphoma, brain and spinal tumours [1, 2]. Children who require inpatient care are normally managed in children's services from the age of 0 to 14 years, whereas young people aged 15 to 24 years are either nursed in teenage units or adult services in the UK. However, it is worth noting that there is no universal definition of a young person, as the age parameters differ within the literature and around the world. Cancer treatment for children and young people can consist of intensive multi-agent chemotherapy, combined with radiotherapy, surgery and immunotherapy as required, and these are provided throughout the UK in regional children's Primary Treatment Centres, Teenage Cancer Units and/or adult specialist centres.

Over the past 40 years, the 5-year survival rates for children and young people with cancer have risen dramatically in the UK. Recent statistics suggest that seven in ten children (70%) will survive cancer compared to three in ten (30%) in the 1960s [3]. Annual figures suggest that in the UK, there are

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an estimated 1600 new cases of cancer diagnosed in children aged 0 to 14 years and, 2200 in young people aged 15 to 24 years [3]. This improvement is largely attributable to the treatment therapies along with the centralisation of care. Furthermore, policy within the UK now enables all children and young people to receive agreed treatment protocols underpinned by controlled clinical trials, national and international studies [4, 2, 5).

The incidence of cancer in children and young people has increased by more than 25% since the late 1970s. This means that there is a greater probability that a health professional from any field of practice will come across children and young people, including those with mental, physical and intellectual disabilities going through a cancer pathway [6]. For those on the cancer pathway, they need to be assured that health and social care professionals involved with their care are knowledgeable and competent, as this will support the delivery of quality care. This reflects the [7]; 2011), which recognises that children and young people require specialist services which are centred to their needs, and this includes developing specific knowledge, skills and experience to support them through their journey and to deliver the complex care regimes both within the hospital or community. Therefore, good quality cancer education is needed in order to strengthen the delivery of cancer care for children and young people [6, 8, 10–11].

However despite this, cancer education for children and young people, within the UK is seen to be varied and inconsistent, and is often embedded and delivered within individual clinical services or Higher Education Institutions (HEIs) [6, 12].

In the UK, care delivery is moving toward being shared by health and social care, however within the literature, there is a distinct lack of empirical research on cancer care involving a more diverse range of health professionals, with most focusing on nurses [6, 9, 13]. This perhaps reflects cancer education in the UK, which is generally delivered to nurses at a post-registration level often because it is seen as a specialist area [13]. Studies undertaken exploring the nurse's experience of dealing with cancer patients have identified a lack of confidence and anxiety about being able to meet the needs of their patients [6, 8, 14]. Reasons put forward for this were found to be the lack of local or specialised courses and resources, which were compounded by the difficulty for staff to get protected time off to access these courses [15, 16].

Positive care experiences and a depth of understanding about the needs of children and young people with cancer are seen to be essential [9, 12, 17, 18]. A UK survey comprising of 350 teenagers and young adults about their cancer experience found that knowledgeable carers were associated with a positive cancer journey experience [19]. Furthermore, the findings highlighted that poor provision of information negatively influence their cancer experience and that participants felt it was important to be identified as a separate specialised group with specific needs.

Delivery of cancer education around the globe tends to be through flexible blended formats, which include didactic, face-to-face, practice and interactive learning using video and other media formats to accommodate working professionals [6, 13, 20]. There has also been a growth in the Virtual Learning Environment (VLE) as this enables teaching, learning and assessing to be delivered online and is desirable for learners who cannot access modules/courses due to geographical reasons [20–23]. It also offers a more flexible and accessible way of engaging with the materials and learning for busy practitioners with varied working patterns [20]. For example, one study that compared the learning outcomes of 148 nursing professionals who participated in classroom learning versus distance learning found that VLE education was an effective alternative for educating and training nurses (das Graças Silva Matsubara et al. [21]. However, future resources should consider developing materials for an international market so that education and good practice can be shared [6, 13].

Background

This paper presents phase one of a study, which evaluated an online cancer course for health professionals caring for children and young people with cancer. The aim of the course was to support health professionals in practice to achieve knowledge and skills in order to deliver efficient and effective cancer care. The course was designed and developed collaboratively by a national group of health care professionals working within a clinical and educational environment to replace an established eLearning course through www.Cancernursing.org. The previous eLearning course was developed by and delivered through the Paediatric Oncology Nurse Educators Group (PONE) which was part of the Royal College Nursing (RCN) Paediatric Oncology Nurses Forum (PONF) in association with Warwick University, within the UK. This course ceased to run in December 2015 with no further access to the materials. Although this was not an accredited course, the participants all received Continual Professional Development (CPD) in hours and a certificate. The initial eLearning education modules developed in 2003 for the website were aimed at adult nurses caring for adult cancer patients. However, further six eLearning modules were developed in 2005 to provide education in caring for children and young people with cancer. The modules were based upon current evidence-based practice and research and concentrated mainly around childhood cancer, for example types of cancer, treatment and organisation care in the UK. Materials were accessed through a protected username and password and would take approximately 35 h to complete online. The purpose of the modules were to deliver a free online course to all health care professionals across the globe involved in the care of children and young people undergoing treatment for cancer. The website also enabled the learners to send in questions on the subject, and receive a response from an expert from the PONE group. The children's cancer education resource quickly attracted learners internationally achieving 10,196 members from 118 countries. The course was mainly accessed by qualified student nurses from Australia, New Zealand, USA, Canada, Saudi Arabia, UK and Ireland.

The lead author is a member of the previously known PONE group, and sought funding through a Teaching Fellow grant from the Higher Education Academy to redesign and develop the materials. This paper presents the evaluation and development of this resource.

Research Aims and Objectives

The aims of this study were to redesign and develop an open access eLearning resource for all health and social care professionals caring for children and young people with cancer and their families across the globe. Social care professionals were included as this was identified as a gap in the resource and a requirement of the new site.

The specific research questions to be addressed were:

- To explore whether the www.CancerNursing.org was useful within their practice and why?
- Gain an understanding of what health professionals currently require for their practice?
- Examine what health professionals require within an eLearning resource?

Method

Data Collection

An online survey questionnaire was chosen because it has been found to be an excellent tool for gathering large amounts of data quickly and objectively [24]. The questionnaire was developed using the Kirkpatrick model [25] which seeks to evaluate the effectiveness of learning through four levels: reaction, learning, behaviour and results. This model supported the design of the questionnaire and then transformed this to ensure the new materials could contribute to influencing care within practice and service delivery [25]. Twenty-six open and closed questions were developed. Three questions related to the participant's role and qualifications, all other questions explored the cancer nursing resource and participant's needs for specific oncology education. Examples of the questions can be seen in Table 1. The use of closed and open questions allowed participants the flexibility to share their understanding and needs in relation to education. For example, participants were sharing examples of supportive care needs as well as discussing the types of cancers seen in both children and young adult.

A pilot study was carried out with six of the nurse practitioners from the CCLG/RCN education group before going live. This ensured that the questions were realistic and the tool was easy to use. The online survey questionnaire was then embedded within the Novi software (a web-based software tool hosted by the University). Novi software facilitates the gathering and analysis of data from different audiences, both on and off campuses. This enhanced the ease of access for all health and social care professionals who volunteered to complete the survey. The online nature of the survey also enabled geographical diversity in responses from health and social care professionals who directly worked within specialist oncology services. Using the software also enabled responses to be collected within a fixed amount of time, which met funding body requirements. The survey opened on the 6th April and closed on the 13th May 2016, and potential participants received two reminders before the closing date. The timeline was tight, as it had to meet the funding obligations.

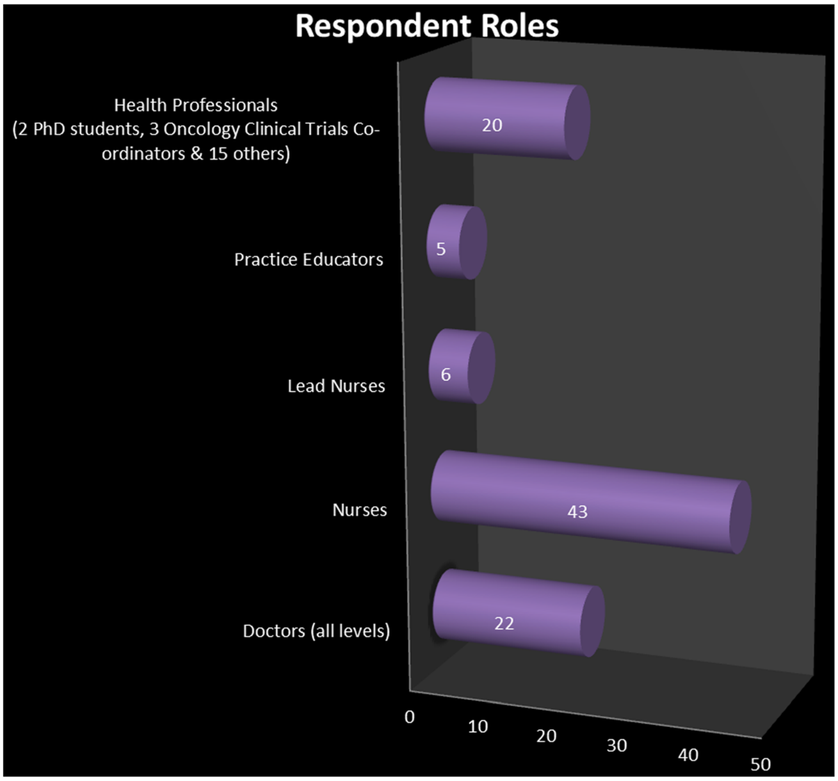
Sample

Convenience samples of 773 health care professionals across the UK were approached through an e-mail sent through the Children's Cancer and Leukaemia Group/Royal College Nursing (CCLG/RCN). This group were members of the PONE, which CCLG/RCN group subsumed. The sample consisted of 197 nurses, 336 consultants, 79 trainee medical students, 76 scientists, 36 non-consultants, and 49 international members who were a mixture of the above professionals. Although the completion of the questionnaire relied on memory about the previous children and young people's courses, the research team were confident that the time lapse from the closure of those courses and the questionnaire being sent would evoke meaningful information.

Table 1 Sample Questions Used in the Study

Examples of the questions
Are you aware of the www.cancernursing.org materials?
There were 7 modules altogether within the course. How many modules did you access?
What areas of care do you think are missing within the course? (Please tick all that apply)
Other? (Please specify)
How would you like these learning modules to be delivered?
How much time did you spend on the resources?
Please indicate the areas of clinical care which you need/desire future educational input?
How frequently did you think it is useful to engage with the resources?

Fig. 1 Roles of Respondents



Data Analysis

Quantitative data was collated and analysed using descriptive statistics through the online Novi survey tool to illustrate the health professionals, who accessed this, what they found useful, how often they used the previous resource. The qualitative findings were transcribed verbatim and analysed using [26] framework. The transcripts were read by two members of the team and coded independently by identifying key themes. Once the initial coding of the data was completed, the codes were then discussed and shared for verification within the rest of the team. Any disagreements were resolved through discussion between the research team.

Ethical

University ethical approval was granted from the School of Health and Social Care ethics committee. All participants received an information leaflet explaining the purpose of the work and that all responses would be confidential. Participation in the study was voluntary, and appropriate consent was obtained from individual participant throughout the Novi tool. All participant involvement was anonymous and able to withdraw up until submission of their responses. Only the researchers had access to the questionnaire data.

Findings

Ninety-six questionnaires were returned giving a response rate of 14%. As can be seen in Fig. 1, the main respondents were nurses which reflected population that the materials were originally developed for. However, doctors, other health care professionals also completed the questionnaire.

Thirty-seven participants responded to questions asking if they knew about the materials, of those responding, 16 (16.7%) knew about it compared to 21.9% who did not. When asked about the number of modules accessed, 35 participants responded with answers ranging from none ($n = 20$) to accessing all six modules ($n = 8$).

Participants were also asked to comment on the content that they thought was missing (see Fig. 2). As can be seen, young people were not prominent within the original course and participants suggested of having a separate section for young people. Participants also recommended that assessment should be embedded within the modules to track their learning. In addition, a certificate for this learning was requested to be built in as proof for CPD.

Findings from the qualitative questions provided two themes. The first theme “New ways of education for speciality areas” highlighted that the online materials were a valuable resource for practitioners. This was especially pertinent to nurses working in shared care hospitals delivering care to children and young people.

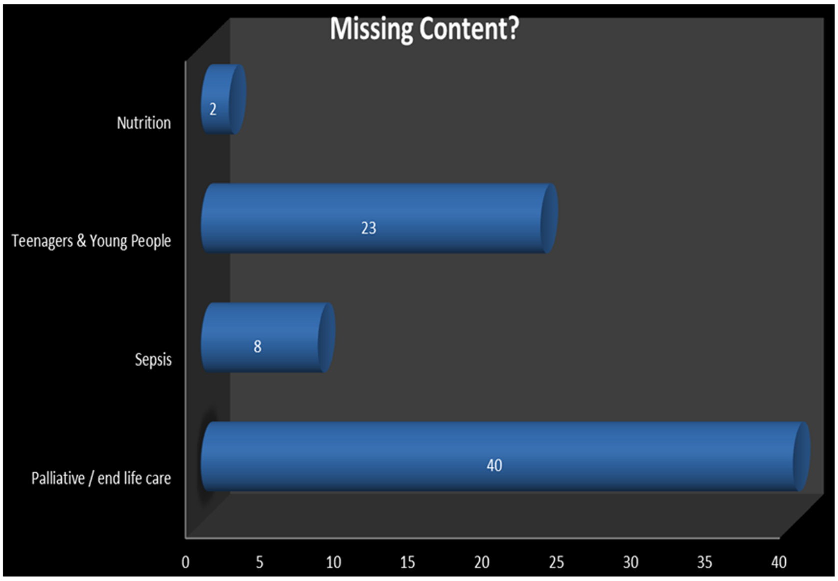


Fig. 2 Contents that the Respondents Thought were Missing

> "The potential for the site to be used to consolidate and standardise foundation learning in the Principle Treatment Centres and Shared Care is massive." (Participant 27)

Both nurses and doctors felt that the resource could be used for centres that are required to have training and education readily available within their unit:

> "It could be used as a template for centres to deliver training and education for their paediatric oncology teams." (Participant 3)

The second theme "The speciality and being new" highlighted that most participants agreed to work within the speciality, knowledge and understanding of the area were vital to ensure the care of this patient group.

> "I have promoted this resource for student nurses on pre-registration programmes and for nurses new to the speciality" (Participant 23).

Discussion and Conclusions

It is clear from this study that health care professionals working within this specialist area welcomed the resources to enable them to provide the best possible care for children and young people with cancer and their families. It was acknowledged that for those working in this area they needed to be prepared both educationally and practically, hence needed the knowledge and skill set to care efficiently and effectively for this patient group. It is important to provide health care professionals with education and training, but in an environment of austerity, free training is welcomed irrespective of it being accredited.

New approaches to learning, teaching and assessing need embracing to ensure life-long learning. Previous research highlights that materials developed through the virtual learning environment can enable participant's to be flexible in their learning, accessing and learning on the course at their own pace [20]. Nevertheless, not all will benefit from this style of learning therefore there remains a role for a blended approach to learning.

Taking these findings on board, eight modules have now been developed in relation to children and young people with cancer and are being accessed across the globe. The materials include didactic as well as interactive work, and are attached to an assessment if the participant wishes to do this for CPD or role development within their practice area. The online nature of the modules and the free access was important, as participants expressed funding of courses and being released to be challenging. Furthermore, many participants indicated courses need not be accredited. Such resources therefore need to be widely publicised, or else, as was found here, practitioners will not know about them and therefore will not benefit from them. To ensure consistent care locally, nationally and internationally a standardised approach to education is needed such as establishing collaborative links with other HEIs nationally and internationally [16]. The need for this can be evidenced by the previous version of these modules being accessed by health professionals across the globe.

Having obtained feedback from 96 participants about the new version, the modules are now complete. Changes have included addressing the deficit in young people's cancer care whilst several other areas have been introduced, such as palliative care and supportive care. A workbook and a certificate are provided on completion of the course. In addition, a community chat room for any participant on the course who requires technical, educational or practice support is made available; with a plan to develop this into a structured eLearning environment in the future. The aim is to provide a forum whereby specific topics are discussed each month, supported and facilitated by expert practitioners and academics.

Phase 1 is now complete and the site was launched in April 2017. Currently, there are 242 enrolled on the course from mainly the UK, North Carolina and Lahti University, Finland. Health and social care professionals have chatted to us online and it is evident from the learning logs that the education is supporting them within their practice areas.

The eLearning course is available through registering for the course. This illustrates the eLearning environment–http://open.napier.ac.uk/course/view.php?id=6.

Education for children and young people often cannot be separated and there is a need to continue to work collaboratively with other cancer experts. The need to support and provide empirical evidence regarding education is therefore crucial as the speciality moves forward. An evaluation of these materials has been carried out and it has been suggested that regularly updates will be required.

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