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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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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 (Cancer Research United Kingdom (UK) 2017). 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 (Scottish Government 2016, Cancer Research UK 2017). Children who require inpatient care are normally managed in children's services from the age of 0 to 14 years, whereas young people 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 7 in 10 children (70%) will survive cancer compared to 3 in 10 (30%) in the 1960's (Children's Cancer Leukaemia Group (CCLG) 2017). Annual figures suggest that in the UK, there are an estimated 1,600 new cases of cancer diagnosed in children aged 0 to 14 years and, 2,200 in young people aged 15 to 24 years (CCLG 2017). 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 (Gibson and Soanes 2008, Scottish Government 2016, Department of Health 2007).

The incidence of cancer in children and young people has increased by more than 25% since the late 1970s (Cancer Research UK, 2016). 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 (Edwards et al. 2016). 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 National Institute for Clinical Excellence (NICE) guidance (2005; 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 in hospital or the community. Therefore, good quality cancer education is needed in order to strengthen the delivery of cancer care for children and young people (Edwards et al. 2016, Komprood, 2013, Sanderson et al., 2004, Watson et al., 2002, Wyatt, 2007).

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 (HEI's) (Edwards et al 2016, McInally et al 2012).

In the UK care delivery is moving towards 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 (Edwards et al., 2016, Jestico and Finlay, 2017, Sanderson et al., 2004). 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 (Jestico and Finlay, 2017). 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 (Tomlinson, 2004; Komprood, 2013; Edwards et al., 2016). 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 (Langton, 2005; Cunningham et al. 2006).

Positive care experiences and a depth of understanding about the needs of children and young people with cancer are seen to be essential (Sanderson et al. 2004, McInally et al. 2012, Gibson et al. 2012; Docherty et al. 2015). 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 (Smith et al 2007). Furthermore the findings highlighted that poor provision of information caused a negative influence on their cancer experience and that participants felt it was important to be seen 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 (Cable and Parr, 2009, Edwards et al., 2016, Jestico and Finlay, 2017). There has also been a growth in the Virtual Learning Environment (VLE) as this enables teaching, learning and assessing to be delivered on line and is desirable for learners who cannot access modules/courses due to geographical reasons (Cable and Pettit, 2012, das Graças Silva Matsubara et al., 2016, Lahti et al., 2014, Voutilainen et al., 2017). It also offers a more flexible way of engaging with the materials and is a more accessible way of learning for busy practitioners with varied working patterns (Cable and Parr 2009). One study that compared the learning outcomes of 148 nursing professionals who participated in classroom learning versus distance learning found that VLE education to be an effective alternative for educating and training nurses (das Graças Silva Matsubara et al. (2016). However, future resources should consider developing materials for an international market so that education and good practice can be shared (Edwards et al., 2016, Jestico and Finlay, 2017).

Background

This paper presents phase one of a study which was an evaluation of an online cancer course for health professionals caring for children and young people with cancer. The aim of the course is 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. This was to replace the well-established eLearning course through www.Cancernursing.org which 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 eLearning education modules initially developed in 2003 for the website and were aimed at adult nurses caring for adult cancer patients. Further eLearning modules were developed in 2005 to provide education in caring for children and young people with cancer. The purpose of the course was 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. All the materials within the course were based upon current evidence based practice and research. The website also enabled the learners to send in questions on the subject, to be answered by the experts from the PONE group providing the expert response. The children's cancer education resource quickly attracted learners internationally achieving 10196 members from 118 countries. The course was mainly accessed by qualified and student nurses from Australia, New Zealand, USA, Canada, Saudi Arabia, UK and Ireland.

As one of the researchers is a member of the previously known PONE group funding was sought through a Teaching Fellow grant to try and redesign and develop the materials. The evaluation of the materials was undertaken from data obtained from the original resource which the Primary Investigator for this study managed to retrieve from the original site before it ceased to run. From the 10196 members on the site 773 of the participants are members of the current Children's Cancer and Leukaemia Group/Royal College Nursing which PONE became part of. Most participants are familiar with the previous site from memory hence the decision to evaluate through this group. The group were also keen that the materials were not 'lost' and that we build another similar course.

The previous course consisted of six modules mainly around childhood cancer, for example type's cancer, treatment and organisation care in the UK. All participants accessed the materials through a protected username and password and would take approximately 35 hours to complete online. This paper presents the evaluation and development of this resource although the new course has been developed using a variety of teaching tools, such as podcasts, Camtasia, infographics, work books and learning logs.

Research Aims and Objectives

The aim of this study was 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. We included social care 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

An online survey questionnaire using open and closed questions was developed using the Kirkpatrick model (1996) 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 transforming this into making sure the new materials were going to make an impact on care within practice and service delivery (Praslova, 2010). A pilot study was carried out with five of the nurse practitioners from the nurse education group to ensure the questions were realistic and the tool valid and reliable to use. On-line surveys have been found to be an excellent tool for gathering large amounts data quickly and objectively (Polit and Beck 2009). The online survey questionnaire was 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 campus. This enhanced ease of access for all health and social care professionals who volunteered to complete the survey. The on-line nature of the survey also enabled geographical diversity in responses from health and social care professionals who directly worked within specialist oncology services. Closed and open questions allowed participants the flexibility to share understanding and their needs in relation to education. For example, sharing examples of supportive care needs as well discussing the types of cancers seen in both children and young adult. Using the software also enabled responses to be collected within a fixed amount of time which met funding body requirements.

Data Collection

The questionnaire consisted of 26 questions. Three questions related to the participant's role and qualifications, all other questions were open questions regarding the cancer nursing resource and their need for specific oncology education. Examples of the questions can be seen in **Table 1**. The questionnaire was piloted with a group of nurses (n=6) from the CCLG/RCN education group before going live. The survey was opened on the 6th April and closed on the 13th May 2016. Two reminders were sent out before the closing date. As this project was funded through the Teaching Fellow Higher Education Academy there was a timeframe set for the work to be completed by.

Sample

A convenience sample of 773 health care professionals across the UK was approached through an e-mail sent through the CCLG/RCN. 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 all professionals mentioned. The completion of the questionnaire may have relied on memory but as the time from the previous course and the questionnaire being sent was within a few months of one another, the research team thought this to be a trustworthy and reliable way to collect the data.

Data Analysis

Quantitative data was collated and analysed using descriptive statistics through the online Novi survey tool and findings exported into an excel sheet for analysis. Pie charts and graphs illustrate the health professionals who accessed this, what they found useful, how often they used the previous resource. This tool allowed for instant and reliable feedback for this research project. The qualitative findings were transcribed verbatim and analysed using Braun and Clarke's (2006) 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 complete, 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. The course was reviewed by three independent specialist nurses who are part of the CCLG/RCN group. Any alterations or additions were then amended prior to the site going live.

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 obtained from individual participant throughout the Novi tool. All participant involvement was anonymous. Only the researchers had access to the questionnaire data which was password protected through the computer.

Findings

Ninety-six questionnaires were returned giving a response rate of 14%. As can be seen from **Table 2**, the main respondents were nurses, as the materials were originally developed for nurses, although doctors, other health care professionals also completed the questionnaire.

.....Table 1 – insert here.....

Thirty-seven participants responded to questions asking participants if they knew about the materials, of those responding 16 (16.7%) did compare 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 content that they thought was missing see **Table 3**. As can be seen young people were not prominent within the course. Participants also suggested having a separate section for young people. Participants also recommended that assessment be embedded to ensure their learning occurred. In addition, a certificate for this learning was built in as proof for CPD.

.....Table 2 insert here.....

Opened questions

One over arching theme, emerged from the open ended questions: *“New ways of education for speciality areas”*

This theme 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.

“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 who 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”* highlights that most participants agreed that to work within the speciality, an acceptable amount of knowledge and understanding of the area was 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 resources to enable them to provide the best possible care for children and young people with cancer and their families. For those working in this area they appreciated that 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 being accredited.

New approaches to learning, teaching and assessing have to be embraced 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, as they can access the course at their own leisure (Cable and Parr 2009). Nevertheless, not all will benefit from this style of learning therefore it is suggested that a blended approach to learning is the way forward.

Taking these findings on board, eight modules have 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, which is 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 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 HEI's nationally and internationally (Langton 2005). The need for this was justified by the previous version being accessed by health professionals across the globe.

Having obtained feedback from 96 participants the design and development of the new version is now complete. Changes include 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. It is hoped that there could be specific topics 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 will be required and an updating the course regularly.

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Table 1

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?