Exploring the Need for, and Feasibility of, a Web-Based Self-management Resource for Teenage and Young Adult Cancer Survivors in the UK

Louise Moody[1], Andy Turner[2], Jane Osmond[1], Joanna Kosmala-Anderson[2], Louise Hooker[3], and Lynn Batehup[4]

[1] Centre of Excellence in Product & Automotive Design, Coventry University, Coventry, UK
{L.Moody,J.Osmond}@coventry.ac.uk
[2] Applied Research Centre in Health & Lifestyle Interventions, Coventry University, UK
{A.Turner,J.Kosmala-Anderson}@coventry.ac.uk
[3] Teenage & Young Adult Cancer Service, University of Southampton Hospital NHSFT, UK
Louise.Hooker@uhs.nhs.uk
[4] Macmillan Cancer Support, UK
LBatehup@macmillan.org.uk

Abstract. The growth in social networking sites and online forums make the internet a potential platform to be considered for the provision of self-management and e-learning support to young people following cancer treatment. However, the feasibility and potential barriers to this as a post treatment option should be considered. A mixed methods approach was adopted that included an online survey, focus groups and interviews with cancer survivors, their parents, and information technology, clinical and social work professionals to consider the potential of aweb-based self-management resource.Barriers were identified to the delivery of care using this method. Developing such a self-management system requires close working between IT and clinical staff, alongside patient representation and usability expertise. As computer access and use amongst this group is commonplace, there is an expectation that self-management needs will be met at least partially in this way in the future.

Keywords: Web-based self-management, young cancer survivors, online support.

1 Introduction

Due to earlier diagnosis and advanced treatments, it is estimated that nearly three-quarters of British teenage and young adults who develop cancer now survive [1]. Since the population of young cancer survivors is constantly growing, there is an urgent need to develop a range of alternative ways of providing post-treatment support as well as addressing on-going self-management issues [2-3].

The growth in social networking sites and online forums make the internet potentially an ideal platform on which to provide self-management and e-learning

support to young men and women following cancer treatment [3-6]. The internet can encourage young people with cancer to socialise with others who are going through the same experience, and provide and receiveinformational and emotional support [7-8]. Despite these benefits, there are few in existence that have been developed with a structured self-management approach specifically for teenage and young adult cancer survivorswith the aim of improving quality of life and psychosocial wellbeing.

The aim of this project therefore was to explore the self-management support needs of teenage and young adult cancer survivors; and to investigate the potential for these needs to be met through a web-based self-management resource. The research was undertaken within the context of the National Health Service (NHS) in the UK.

2   Method

A mixed methods approach was undertaken including:

1. Focus groups and interviews with teenage and young adult cancer survivors
2. Online survey with teenage and young adult cancer survivors
3. Interviews with medical, nursing, social and youth workers
4. Interviews with Information Technology (IT) staff

2.1   Participants

To determine the information and support needs of teenage and young adult cancer survivors in relation to self-management two separate focus groups were conducted with five young adult cancer survivors and their parents. A further two individual telephone interviews (for those young people who were unable to attend the focus group) were conducted. There were four female and three male participants with ages ranging from 16-24.

Eleven semi-structured interviews were conducted with medical, nursing, social and youth workers who were working with teenage and young adult cancer survivors.The occupational backgrounds of the respondents included paediatric and adult oncology nursing and medical staff, social and community workers, and a hospital play specialist.

Eight interviews were conducted to establish the IT requirements for the delivery of a web-based, self-management intervention. The participants included individuals working with NHS IT, nursing and social work specialists, as well individuals with experience of other teenage and young adult cancer survivors online web-based support programmes to establish good practice and potential barriers to success.

The survey was piloted with 5 teenage and young adult cancer survivors who each were given £20.00 in gift vouchers for completion of and providing feedback about the survey. 30 responses were received, of which 24 were fully completed surveys. Respondents' mean age was 21 (range 17-26). Most respondents had Hodgkin's lymphoma (n=7), followed by brain cancer (n=6), leukaemia (n=5), osteosarcoma (n=4) and thyroid cancer (n=2).

2.2   Procedure

The interview schedules were developed through consultation with the project steering group.   The interviews lasted an average of 30 minutes (range 20-40 minutes). Focus groups were conducted face-to-face, lasted for 2 hours and were held simultaneously in adjacent rooms.The focus groups with teenage and young adult cancer survivors and their parents were conducted separately.Teenage and young adult cancer survivors received a £20.00 gift voucher for taking part. The interviews with professionals were conducted over the telephone. The interviews and the focus groups were recorded, transcribed verbatim and analysed independently by two researchers using thematic analysis [9].

The online survey sought to determine the range of different platforms that young people use, their preferences in terms of interaction methods and design styles, and any barriers to acceptance. The questions for the online survey were partly selected from the features identified from the literature review and findings of the focus groups with the teenage and young adult cancer survivors and their parents.   Additional questions were added after consultation with members of the project steering group.

3   Results

The findings indicated that the stakeholders were supportive of the idea of providing a web-based self-management resource to meet the information and support needs of teenage and young adult cancer survivors. This group are "digital natives" and are comfortable with accessing online resources to obtain cancer-related information and support. Therespondents found that information on the internet was not tailored to young people, or contained distressing information such as mortality rates, or contained irrelevant information such as homeopathic cures. They were also unsure as to whether they could find reliable information "I think there's almost too much on the internet isn't there", and "they're all saying slightly different things, so it's like what do I believe in and what's the right thing" (Teenage and young adult cancer survivor).

The potential role of a self-management system, and the required support needs reflected the age and development priorities of this particular age group. There were some strong common information and support needs around body image, fertility, long-term treatment and side effects, fear of recurrence, returning to school/college/work and emotional (e.g. anxiety and depression) and psychological (e.g. confidence and self-esteem) needs. Having a cancer diagnosis impacted negatively on friendships with healthy peers. Teenage and young adult cancer survivors can feel abandoned and "cast adrift" after treatment completion. They also described the importance of having the opportunity of sharing online or face-to-face their feelings and experiences with age-group peers who are going through similar experiences. As one respondent put it: "*You're not glad that they've got cancer, but it's nice to have someone to speak to about it.*"

These teenagers and young adults indicated that they would like a resource to provide clinical, information and social support features including: a summary of

treatment and a follow-up plan, organisation and re-scheduling of appointments, live question and answer sessions or secure messaging with a doctor / nurse, the capacity to look up test results, provision of peer support, and case studies, written resources and links to credible and reliable cancer websites.

All of the other stakeholders (e.g. parents of teenage and young adult cancer survivors, medical, nursing, social and youth workers) interviewed were broadly in favour of these features with the exception of having access to medical test results. The potential for misunderstanding and misinterpretation of medical information was felt to pose a risk of creating anxiety and fear among the young people if not explained and contextualised in person by a health-care professional.

Table 1. Perceived benefits and risks of on-line self-management support

Perceived benefits	Perceived risks
— Less resource hungry than face to face contact	— Financial outlay to set-up
— The on-going costs are less	— The tailoring of the content requires heavy clinical input resource
— Hospitals want to be ahead and innovating and there is a general culture shift to interact more through technology	— Online safety and the how to manage safeguarding risks for young people and their families
— Reduced waiting times because patients are not coming in as often	— Young people might see this as something to do instead of clinics and not be followed up properly
— Reduced follow up length	
— Reduced re-admittances after discharge	— Losing contact with people who might be quite vulnerable but will not ask for help
— Early avoidance of problems as self-management is quicker	— Not all young people have a smart phone or access to a PC
— Enables networking / teenage and young adult cancer survivors peer interaction	— Engaging and retaining young people
— Has the potential to be used in other areas e.g. congenital heart defects, allergies etc (transition from child to adult services), different age groups.	— It may be inappropriate for young people with learning difficulties, brain tumours, memory problems, ADHD or who are vulnerable.
— Reaching a wider geographically dispersed group that may not be able to, or want to attend face to face events.	— Having to close down the system down due to resource issues could adversely affect the relationship with the young person
— Help teenage and young adult cancer survivors feel like they are no longer a patient	— Logistical problems with providing a resource for small patient numbers at different parts of treatment pathway
— One central resource	— The time required to develop and moderate content of any forum / posting elements

It was identified that a self-management intervention (in terms of a standard informational and developmental resource)is straightforward to develop, but that working within the NHS in the UK involves issues in terms of information and data governance structures. It was identified that it is advisable to separate out social networking and patient: patient interaction, for example,from clinical support. This would be more straightforward to manage in terms of implementation and governance, but also ensure credibility of the information sources available.

4   Discussion

The results indicated some key content needs for a potential online self-management system including information and support around body image, fertility, long-term treatment and side effects, fear of recurrence, returning to school/college/work and emotional and psychological needs.   Teenage and young adult cancer survivors described the importance of having the opportunity of sharing online or face-to-face, their feelings and experiences with others who are going through similar experiences.

A self-management intervention offering information is straightforward to develop and can offer a reliable and credible web-based resource in addition to individualisedface to face interventions from staff, and contact with peers.   Other potential functionality needs further consideration. The desire amongst young people for online contact with health professionals needs to be further explored; for example in terms of the types of communication, gaps in the current service and the support that professionals may need to use this mode of communication appropriately.The mixed views regarding the desirability and feasibility of accessing medical test results as part of a web resource warrant further work to explore the discrepancies in desirability, and explore how in the longer term teenage and young adult cancer survivors may be helped to interpret results remotely. Equally the mixture and balance of social networking, patient to patient interaction and clinical support within a single system needs further consideration.

Barriers to implementation need further exploration within the context of use, for example whether the system sits within an NHS Trust, a hospital, university, within a charity or independently. There were concerns about the interfacing of a self-management system and existing NHS systems in terms of the maintenance of security and protection of data protocols. However, such a system could be hosted by an external hosting centre (e.g. a cancer charity), provided it did not hold secure patient / hospital data. This would preclude the desired interactions in terms of appointments and medical records.

Any system developedshould be multi-platform, taking into account widespread use of smartphones amongst young people. There is a need for close working between information technology and clinical staff to ensure clear communication regarding user and governance needs, system functionality and barriers to development and implementation as well as to share learning from other projects. Computer access and use amongst this group is commonplace, and therefore it is an expectation that self-management needs will be met at least partially in this way in the future.

5   Recommendations

The research led to the following recommendations for future work:

- A self-management intervention (in terms of a standard informational and developmental resource) should be developed to meet the information and support needs of young people and those who support them. This should provide a reliable and credible web-based resource in addition to face to face / direct interaction.
- The format should include key behavior and self- management techniques such as goal setting, action planning, problem solving and self- monitoring presented in a developmentally appropriate manner.
- The features should include online appointment arrangements / alerts, Q & As with medical professionals, and patient to patient communication.
- Social networking functions are best provided separately from clinical functionality. Moderation of social networking features is important to ensure appropriate content and safeguarding vulnerable young people.
- Two complimentary systems are recommended one providing social networking and patient: patient interaction and the second offering clinical support in terms of Q & A sessions with health professionals and access to information resources, and access to appointment information. This should be more straightforward to manage in terms of implementation and governance, but also ensure credibility of the information sources available.
- The desire for online contact with health professionals needs to be further explored for example in terms of the types of communication, that are suitable and the support that professionals may need to use this mode of communication appropriately.
- There are mixed views regarding the desirability and feasibility of accessing medical test results as part of the web resource. This warrants further work to explore the discrepancies in desirability, and explore how in the longer term teenage and young adult cancer survivors may be helped to interpret results remotely.
- Any systems developed should be multi-platform, taking into account widespread use of smartphones amongst young people.
- There is a need for close working between IT and clinical staff to ensure clear communication regarding user and governance needs, system functionality and barriers to development and implementation as well as to share learning from other projects.

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