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Citation for published version:

Griffiths, C, Panteli, N, Brunton, D, Marder, B & Williamson, H 2015, 'Designing and evaluating the acceptability of Realshare: an online support community for teenagers and young adults with cancer (TYAC)', *Journal of Health Psychology*, vol. 20, no. 12, pp. 1-13. <https://doi.org/10.1177/1359105313519154>

Digital Object Identifier (DOI):

[10.1177/1359105313519154](https://doi.org/10.1177/1359105313519154)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Journal of Health Psychology

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Designing and evaluating the acceptability of Realshare: an online support community for teenagers and young adults with cancer (TYAC)

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Competing interests: None declared.

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Acknowledgments

We would like to thank to the Teenage Cancer Trust and the Youth Cancer Trust for their financial support and Phones4charity for supplying smart phones, Georgina and Max Hillman from Sambecktts who developed the website, all of the Realshare members who championed the community and Eleanor Troke who facilitated the online forum.

Introduction

Adolescence can be a difficult time for any young person. The stress of having cancer including multiple hospitalisations and the physical and psychological effects of associated treatments such as body image concerns, anxiety and depression, can add further pressure, increasing the likelihood of key developmental processes being disrupted (Abrams, et al., 2007; Larouche & Chin-Peuckert, 2006). Social support is an important factor for helping adolescents cope with cancer (Varni et al., 1994). However healthy friendships and acceptance from peers, which are important in the development of social skills and self-esteem (Bukowski, 2001; Hartup & Stevens, 1997), often suffer due to periods of hospitalisation and feeling unwell which can prevent young people from attending school, work and social activities (Elwell et al., 2011). It is not surprising therefore, that some adolescents with cancer are dissatisfied with the support they are receiving from their healthy friends (Nichols, 1995), are requesting more opportunities to meet other young cancer patients and survivors (Kent et al., 2013) and more social support to cope with their illness (David et al., 2012).

Face-to-face peer support groups can benefit young people with chronic health conditions such as cancer. They allow young people to meet and socialise with others in the same situation to discuss their cancer experiences, exchange medical and treatment information and emotional support (Meltzer & Rourke, 2005). However treatment side effects can prevent young people from attending face-to-face meetings and large geographical distances between the young person and nearest group can make attending difficult (Elwell et al., 2011). Online communities can help address some of the barriers preventing access to face-to-face support groups.

There are an increasing number of online communities, support groups and blogs for adults with cancer. Such communities provide members with social support and medical knowledge, help to release negative emotions, develop inner strength, provide a sense of belonging and empower users to make medical decisions (Campbell et al., 2013; Chiu & Hsieh, 2012; Wen et al., 2011).

However only three studies to date have explored the impact of online communities for teenager and young adults with cancer (TYAC). The first study involved a content analysis of an American online community for young adults with cancer. The results showed that the community helped young adults to display their membership to the community, to describe their cancer experiences and exchange emotional and informational support (Love, et al, 2012).

The second thematically analysed the messages on 'Group loop', an American online community for teenagers and young adults with cancer (Gaulin, 2010). Messages were analysed from both the discussion forum and the weekly forum support group that was facilitated by trained clinicians. Adolescents used the forum to exchange peer support and information about treatment. Members reported that the support received from other TYAC and from the facilitators helped them cope with their cancer experiences. This suggests that facilitators might be a useful addition to online communities for young people with cancer.

In the third, Elwell et al (2011) explored the type of social support that was provided in the American online community 'Teens living with cancer (TLWC)'. Unlike 'Group loop', TLWC was not facilitated by a health professional. Therefore all conversations were instigated and maintained by the young members themselves. The findings revealed that members frequently used the group to exchange informational support about medical and treatment issues and diet and body image concerns. Emotional support was provided when

other members were experiencing difficulties such as treatment side effects or when struggling with school. Some reported that their relationships with healthy friends had deteriorated and others felt closer to their online friends compared to their healthy friends. These findings imply that TYAC can benefit from interacting with others in a similar situation in an online community, even without a trained facilitator instigating conversation.

These studies show promise about the benefits of online communities for TYAC. However they explored the impact of American online communities. The most successful online communities at encouraging social inclusion; are those that link online communication with face-to-face socialising (Warschauer, 2004). Young people in the UK can access these sites, however they are unable to participate in any face-to-face interaction and are therefore prevented from fully benefiting from the online community experience. Currently no online community exists that is exclusively for TYAC in the UK. This suggests that there is a need for a UK based online community for TYAC, which can provide young people with the opportunity to interact with others face-to-face as well as online.

Very little research has explored the role of facilitators in online communities. Many recognise the need for a mental health professional to facilitate face-to-face support groups (Treadgold & Kuperberg, 2010). Facilitators can encourage peer interaction; providing continuity and security to the community (Herron, 2005). However it is important for facilitators to act in a way which is appropriate to the patient population. Particularly for TYAC groups, facilitators should not behave like a teacher and the young person must not feel like they are at school (Barrera et al., 2006).

It remains unclear whether facilitation is necessary in online communities and whether facilitator support offers any additional benefits to the support that young people receive from their online peers. However if members interact online in a similar way to face-to-face

groups, trained facilitators might be beneficial for online communities. Evidently the issue is in need of more in depth exploration.

The current study outlines the development of an online community co-created for and by TYAC in the South West of England. The geographical dispersion of patients in this region often means that not all patients have access to the same support. The development of the online community aimed to provide a facility where young people with cancer could meet and communicate with other TYAC and overcome the geographical distance and physical restrictions that can result from adverse treatment effects, which can hinder young people from attending specialist centres.

Aims:

1. To design the Realshare website based on the young people's design and feature preferences.
2. To explore and compare how young people with cancer use the Realshare community when a facilitator is present compared to when one is not.
3. To determine the acceptability of Realshare among TYAC.

Method

Design

A participatory action research approach was used as this was consistent with the participative-user led nature of the study and because the researchers wanted to empower the young participants to take ownership of Realshare (Kemmis & McTaggart, 2000).

Participatory action research is based on participants and researchers working together as

partners in the change process. The study design was similar to Kemmis and McTaggart's (2000) spiral model of participatory action research. This involved self-reflective cycles of problem identification, planning a change, acting and observing the process of the change, reflecting and evaluating on the process and then re-planning, acting and observing the process of a change and so on. This allowed the researchers to gather and incorporate users' needs and views in the design of Realshare continually throughout the project. The project involved two phases. Phase 1 was the design phase and involved conducting pre-intervention focus groups where participants were asked about their needs for such an online community and their impressions of the prototype website. Phase 2 was the evaluation phase, which involved young people using Realshare over 2 three-month intervention periods; without a facilitator present and with a facilitator present, to identify whether a facilitator would influence how young people used Realshare. During both periods participants recorded their views and suggested design improvements in the forum while they were using it. After the intervention phases were complete, post-intervention focus groups asked participants about their opinions and experiences of using Realshare.

Participants

To be eligible to take part; participants had to be aged 16 – 25, live in the South West of England, were currently receiving or had previously received National Health Service (NHS) cancer treatment and had access to a computer and the internet.

A total of 12 participants (7 females and 5 males), aged between 16 and 30 ($M = 21.08$, $SD = 4.15$), who previously or currently had cancer took part (5 participants were in remission and 7 were in treatment). Participants were English speaking and had a range of cancers: sarcoma ($n = 2$), hodgkins ($n = 2$), tongue cancer ($n = 1$), brain tumour ($n = 3$), leukaemia ($n = 2$),

chondrosarcoma (n = 1) and cervical cancer (n = 1). Two participants, one 26 year old and one 30 year old, were also included in the study. Although the recruitment target was ten participants, the research team wanted to include as many young people as possible to ensure a diverse range of viewpoints were incorporated into the design phase of Realshare. It was felt that the older participants' contributions would still be valuable when creating Realshare, since they had 'been through it' and could provide retrospective opinions, which the younger participants currently in treatment could not.

Materials

A graphic design team created the basic structure of the Realshare website. This included the discussion forum where a number of forum topics were started (including 'Share', for users to share information, 'Regional information', where users could socialise with others who lived in a similar area and find information about regional events and 'Realshare SW Info & Web Support', where users could offer design improvements). Users created a profile, which they could upload one photo and add basic personal information (name, age, gender).

Realshare also included a 'useful links' section with contact details of charities and support groups for TYAC.

Procedure

Following NHS and university ethical approval, young people were recruited via adverts on the Youth Cancer Trust, Teenage Cancer Trust and 'My Name is Not Cancer' websites.

Participants were also recruited via a Teenager and Young Adults Clinical Specialist Nurse

who informed appropriate patients about the study during routine consultations. Participants were provided with the study information sheet and signed a consent form. For adolescents under 16 years old, parental/ guardian consent was also obtained. Participants were informed that the research team was developing an online community for TYAC in the South West of England called Realshare and they wanted a group of young people to help design and test out the community.

There were two pre-intervention focus groups which were led by two members of the research team. The first group consisted of five participants aged 16 - 21, and the second, involved seven participants aged 21 - 30. Two participants that were unable to attend the focus groups were interviewed on the phone. The focus group and telephone interview questions asked participants about their opinions and needs for an online community for TYAC, their impressions of the prototype website and the ways that it could be improved. After the focus groups were completed, amendments were made to the website based on the participants' feedback.

Participants were then provided with the Realshare website address and individual usernames and passwords to access the community at home. In the first 3-month intervention period, participants used the community without a facilitator present. They were told that they could use the community in any way they liked, they could offer design improvements or just meet and socialise with the other members. In the second 3-month intervention period, a facilitator was introduced to the Realshare community. Their role was to instigate and maintain conversations in the forum and to provide informational and emotional support to members. They also developed rapport with members who were reluctant to use Realshare via email and the telephone and organised face-to-face Realshare events. Facilitators checked the

forum once a day for new messages. Amendments to the website were continually made in response to participants' design requests as they posted them in the forum. Since interactions in the forum were low in the period without the facilitator, participants were offered a £50 Play.com voucher when the facilitator was introduced, providing they logged into Realshare three to five times a week.

Post-intervention focus groups were led by two members of the research team and were the same as the pre-intervention focus groups (determined by the age of participants). The focus groups explored participants' experiences of using Realshare in order to identify their preferences for online facilitation and whether Realshare was an acceptable resource that met their needs. Final amendments were made to Realshare based on the focus group feedback.

Data analysis

Inductive thematic analysis (ITA) was used to analyse the focus group data and the messages posted in the Realshare forum using Braun and Clarke's (2006) guidelines. ITA is a flexible method used to identify themes within data, offering a rich account of the subject area. When an area is under-researched such as this study and no specific theory is available, an inductive approach is the most appropriate. The analysis was conducted using the NVivo qualitative analysis computer program (<http://www.qsrinternational.com>).

The focus groups were transcribed verbatim. The focus group data and the forum messages were then analysed using Nvivo. This began with the researcher repeatedly reading the data. Initial codes were allocated to relevant aspects of the data and codes that were similar, common and helped answer the research question were organised into potential themes. Less common codes were also developed into themes, when they provided useful insights into the aims of the study (Braun & Clarke, 2006). The findings were reviewed by a second member

of the research team to increase the validity of the analysis. Any inconsistencies in themes were negotiated between the researchers and amendments were feed back into the analysis.

Findings

Phase 1: design phase

Pre-intervention focus groups

The pre-intervention focus groups aimed to identify participants' expectations and reactions to Realshare after being shown the prototype site and to identify their design and feature needs. Three themes were identified.

Design recommendations

All of the young people liked the idea of Realshare and thought it would be useful for TYAC. *'I am very impressed'* (P1, male, 23). However, they wanted to change the homepage content *'looks crowded on the front page'* (P11, female, 16) and colour scheme *'choose your own colour scheme'* (P10, male, 17), post photos, videos and play online games, *'anything from platform games to chess'* (P2, male, 17). A few of the young people requested a private /instant communication function as *'some people would rather have a personal chat or a private message'* (P6, female, 23), smartphone access and a *'continual newsfeed'* (P9, female, 17), with notifications of when others had posted information. All participants wanted a health professional to facilitate the community, in case members needed a *'bit of extra support and help'* (P2, male, 18).

Benefits of Realshare

A regional online community for TYAC

All of the young people liked the concept of Realshare because it offered the opportunity to meet other TYAC in the local area, *'if you see someone from Gloucester...maybe you can send them a message and say I'm from Gloucester wanna meet up'* (P1, male, 23). A third of participants had been on other cancer websites and found them difficult to relate to because they were either American sites or were more tailored to adults *'(Cancer charity) website...there wasn't that many people my sort of age, not that their advice wasn't good or anything but it didn't feel quite connected in the same way'* (P5, female, 26).

Peer support

All participants reported that Realshare would be an ideal place to access social support when they were unable to communicate with people face-to-face *'..when it gets to 3am sat in that hospital bed and you think I wish I could just log on to something and talk to some people right now'* (P3, male, 21). The majority of young people felt that Realshare could help comfort users by reassuring them that they were not alone which would reduce feelings of isolation. A few young people who have been through treatment reported a desire to support others who were currently receiving treatment, *"..if anyone is having any problems I would quite like to help them"* (P9, female, 17).

Clinical information and links to trusted websites

The majority of young people thought Realshare could provide links to trusted websites and clinical information about cancer and treatments written by experts but in a more accessible

format which is specific to young people. ‘...*from a younger point of view and explain in readable English, rather than some of the more technical things you get given by the hospitals*’ (P5, female, 26)

Concerns about establishing Realshare

The major concern among a third of young people was that the website would not get used because there would be a lack of members to promote adequate levels of interactions to keep the website interesting ‘... *the more people who use it the more it’ll get used. If only a few people use it then it’ll die out..*’ (P9, female, 17). Of those concerned, the majority were worried that established websites such as Facebook, may draw attention away from Realshare. ‘*it might not get used....because Facebook is a form of this site*’ (P2, male, 17). Since Facebook was the primary social network site for all participants ‘*because everyone is on it*’ (P11, female, 17) , young people felt it might monopolise the time they spent social networking, leaving little time for Realshare. Although the strength of existing social network sites was a concern, all participants felt strongly that Realshare presented a unique opportunity ‘*just to talk about having cancer and stuff like that*’ (P12, male, 20).

Subsequently, a third of young people articulated that using both Realshare and Facebook would be beneficial, as it would allow them to keep the cancer component of their lives separate from the rest, ‘*I’d keep them separate, it’s two very different [...] you have your friends who you’ve met through something you’ve been through (cancer) and you don’t necessarily want the whole world to know about*’ (P1, male, 23).

After the pre-intervention focus groups, the website was amended based on the feedback and participants were given access to the community.

Phase 2: Evaluation of Realshare

This phase aimed to identify how participants made use of the online community with and without the presence of a facilitator encouraging discussion and providing support.

Intervention period without a facilitator (3-month duration)

The number of interactions in this period was relatively low. There were 43 messages posted by 8 young people and 4 messages posted by the graphic designer.

Three themes were identified that related to how participants were using Realshare in this period.

Patient voice

A few members began to take ownership of the Real Share community, suggesting design improvements and giving Realshare members a group name. *'Gotta say - I like the SWOT or SWOP'*, (P3, male, 21). Website design improvements included changes to the overall look of the website and adding additional features such as interactive tools. *'I would like a different font... perhaps even in a more bold print for those with less good eye sight'* (P5, female, 26)

Socialising online and face-to-face meetings

There were some brief instances of young people discussing non-cancer related topics such as sharing their interests and day-to-day activities. *'I have since done my oh so stressful A levels and am now at Cardiff doing history- ahh the joys'* (P7, female, 19).

Members who lived locally to each other made arrangements to meet and socialise with other

members face-to-face, '*...we could always organise a meet-up somewhere, or maybe just a couple of us who live around the Bristol/Clevedon area?*' (P3, male, 21).

Informational support

A few young people used the forum to exchange cancer-related informational support. Requests related to clinical information about treatments or side effects, '*....I have to go in to the hospital every few weeks...so that they can take a few pints of blood from me.... I was wondering if anyone's had this?*' (P1, male, 23). In response, other members provided specific information about the treatment or advice based on their own personal experiences in order to reassure others. '*... patients with haemochromatosis give blood regularly and it is a pretty effective control, considering how basic an intervention it is..*' (P3, male, 21)

Intervention period with a facilitator (3-month duration)

The number of messages in this period doubled compared to when no facilitator was present, with 102 messages posted by 8 young people (including 3 new participants that had not posted during the period without the facilitator) and 33 posted by the trained facilitator and 1 by the graphic designer. A number of significant design amendments were made to the website in this period; this included the addition of forum applications such as Chat, and photo/video posting.

The themes identified in the previous forum phase became stronger and more frequent when the facilitator was introduced. Three new themes were also identified.

Emotional impact of cancer

Around a third of members began to discuss in depth, the emotional impact of cancer ‘...people can not underestimate the psychological effect at any age, let alone in your prime, that cancer has’ (P5, female, 26). They described apprehension, anxiety and sometimes depression at various stages of the illness, from the initial diagnosis, to the moment when they received their last round of treatment. ‘I started to get so anxious and worried about every little thing I could hardly make any decisions.... I would just cry my eyes out pretty much all the time for absolutely no reason..... I was terrified all this horrible crap happening was permanent...and I was, essentially, losing my mind’ (P1, male, 23).

Isolation

Of those who described the emotional impact of cancer, all reported that their feelings of isolation contributed to the psychological distress. Some experienced isolation in terms of being physically isolated on a hospital ward, whereas for others treatment side effects stopped them from going out and participating in day-to-day activities. ‘I would agree about the isolation being tough, for me personally it was one of the most difficult things’ (P10, male, 17). A few members discussed how they had become distanced or had lost friends during their treatment. ‘...2 years of treatment have gone on most of them have dropped away or I have chosen to distance myself from them’ (P10, male, 17). This isolation provided members with time to reflect on their experiences and for some this was very hard to cope with. ‘....being stuck at home, prevented from studying...just left me thinking of all the what-ifs, and why-me thoughts, and the you're-a-bloody-medical-student-why-didn't-you-spot-this-earlier thoughts were possibly the worst!’ (P3, male, 21).

Exchanging emotional support

Over half of the young people provided emotional support to others in this period. Rather than in response to direct requests, emotional support was provided in response to posts where members discussed difficult experiences; such as feeling fatigued or waiting for test results. Emotional support was provided in a number of ways, e.g. offering reassurance and empathy, *'I'm really sorry to hear that you're in hospital at the moment. I really hope you start to get better soon! Definitely keep us all updated! Thinking of you'* (P9, female, 17), describing their own experiences, *'Well done mate, almost there. I know what you mean about feeling apprehensive, you go through the day to day motions of treatment and then suddenly it's done and you move in to the realm of check-ups and reviews'* (P1, male, 23), asking how other members were doing, *'How's the last round of chemo going...'* (P4, female, 30) and encouragement when things were going well. *'*high five* definitely worth a celebration!'* (P3, male, 21).

Post-intervention focus groups: evaluation of participants' experiences of Realshare

The aim of the post-intervention focus groups was to explore the participants' experiences of using Realshare, their opinions about online facilitation and the future success of Realshare. Overall users were positive about Realshare and although they offered a number of design improvements, they felt that the community would be a useful resource for TYAC. Four themes were identified.

Design and feature evaluation

Realtime was the most popular feature of Realshare. This allowed users to select a symbol relating to what they were doing (e.g. listening to music) and then write a statement linked to

this symbol. The majority felt that Realtime was *'an easier way to communicate'* (P4, female, 30). Although some wanted the design updated, over half of the young people liked the forum because they could talk to others in the same situation and exchange support. *'...you can share experiences with people and they don't think badly of you'* (P10, male, 17). All users liked the profile, but they wanted it *'expanding a bit more'* (P7, female, 19). They wanted to upload more photos, display more information about themselves; interests, type of cancer and the area they lived in; so they could contact others with the same cancer or who lived in the same area. *'.. you can..see that they've had leukaemia as well and they might be the people who you want to have a quick chat with'* (P1, male, 23). Half of the young people liked 'Chat' (private messenger) because they didn't want to talk about personal matters in a public arena. *'.. get personal help, they might not want to share it with everyone on the site..'* (P11, female, 16)

The importance of the facilitator

All members reported a positive difference in the forum activity when the facilitator was introduced. *'....I got the phonecall (facilitator) and I think lots of people got the phonecall... just in general there was more people to interact with and talk to and more input in the forum and it's got a lot more used recently'* (P7, female, 19).

All participants reported that the facilitator was beneficial in many ways for the effectiveness of the forum. This included *prompting* less active participants into the site by phoning them individually *'more people to interact with, talk to, and more input in the forums'* (P7, female, 19); *starting discussion threads* *'introducing more forums that people wouldn't have thought of'* (P4, female, 30) and *replying to posts*. The latter was viewed as comforting as they knew *'someone would reply'* (P9, female, 17). Furthermore the facilitator helped *connect*

community members to each other, by using their knowledge about commonalities, such as cancer type, treatment stage, or locality 'initiating things and bringing people together' (P4, female, 30). Offering social support, listening to problems and providing advice was also seen as their role. '..it's good to have someone like (facilitator name) on there to help you with your issues' (P2, male, 18).

All users recommended that a facilitator should still be present, even in the future when Realshare membership is greater. However they thought the role would shift from encouraging general interaction, towards making connections between young people to *'..bring people together' (P7, female, 17)* and offering support *'..to have someone there that you could just talk to ..and would be available to listen to' (P11, female, 16).*

Benefits of Realshare

The majority of young people felt that Realshare had fulfilled the benefits that they suggested it offered in the pre-intervention focus groups.

Peer support

Most of the young people reported that Realshare offered users an opportunity to connect with *'people who have experienced it' (P7, female, 19)*, share their experiences and exchange support with *'others who are able to help' (P9, female, 17)*. All of the users felt that Realshare could help young people with cancer feel part of a community, which would reduce feelings of isolation. *'.. having the forums discussing your feelings ..just being a member.. you are instantly involved in a community of people who are going through things you are going through.. will make you feel less isolated' (P9, female, 17)*

Half of the young people suggested that some of the older users who had ‘been through it’, could act as ‘Realshare champions’ when Realshare goes live, to instigate discussion topics in the forum and provide support. *‘..knowing what else might be helpful that other people might not know about’ (P3, male, 21)*

Clinical information and links to trusted sites

Despite being discussed as an advantage in the pre-intervention focus groups, none of the young people reported using Realshare in order to find reliable clinical information. This seemed to be due to the stage of treatment that young people were in, either having finished treatment or being at the very end. This suggests that appropriate medical information has more value at earlier points of treatment. *‘I am out of the tunnel now, but I think that it will be really useful to people that are going through that’ (P7, female, 19)*

Future of Realshare

After experiencing Realshare, all of young people concluded that the community was a useful tool for young people with cancer *‘.. people can share about what they are going through or share emotions about it ..with people that have been through it’ (P5, female, 26)*. A few young people were concerned about Realshare having enough members to keep interactions going, *‘to keep it going, we need more people’ (P4, female, 30)* and suggested that clinicians such as consultants should invite young people to join Realshare, in order to encourage membership. *‘recommendation and consultants refer, can we do that?’ (P5, female, 26)*.

In a world dominated by Facebook, the majority of participants still felt that Realshare would be used because it offered information and experiences that were specific to TYAC.

Although they felt young people would use *'it in a different way'* (P5, female, 26) to Facebook. *'... talking about the cancer aspect of it rather than the social, because facebook kind of does the social but doesn't do the illness side of stuff'* (P9, female, 17)

'..I'm still seeing this more as sharing more personal things, you know not flippant responses on Facebook..' (P3, male, 21)

The importance of having an online community exclusively for young people with cancer was further supported by the concerns of some users who wanted to ensure that membership was only granted to those with cancer or survivors *'how would you stop people who haven't experienced it or whatever using it?'* (P1, male, 23). This desire for separation of their cancer lives and their 'normal' lives was further reflected in some of the young people's wishes to not add friends made on Realshare to their friend list on Facebook *'No I'd keep them separate'* (P3, male, 21). This further emphasises the need that TYAC have for a facility to meet, communicate and exchange support with other TYAC.

Discussion

Engaging young people with cancer in the design and evaluation of Realshare, not only allowed the website to be tailored to their needs; increasing the likelihood of members utilising the community, but the process of making design improvements also allowed young people to exert their 'patient voices'. Overall, the results indicate that Realshare was an acceptable facility for TYAC. Young people approved of the design and felt Realshare offered TYAC a unique place to communicate and exchange support with other TYAC.

Young people used Realshare to exchange informational support about cancer and treatments. This suggests that the informational needs of young people with cancer are not being fully

met by current support provision. It might be that these young people desired more personalised informational support that is specific to their immediate situation. Realshare may therefore offer a facility for young people with cancer to receive this support. This is consistent with research by Willis (2013) which found that online communities provided people with arthritis with informational support that was tailored to their health needs.

The isolation and emotional impact of cancer discussed when a facilitator was present in the forum showed clearly that members wanted to discuss these issues and receive support for them. Furthermore, in the post-intervention focus groups, all of the young people reported that Realshare could help to reduce the feelings of isolation commonly experienced during treatment. This supports previous research that suggests that the emotional needs of these young people are not always being met by current support provision (David et al, 2012). Realshare may therefore offer a way for young people to receive emotional support in the comfort of their own homes which might be beneficial for those that live far away from others or those who are not well enough to attend face-to-face meetings.

In addition to communicating online with other TYAC, young people also used Realshare to arrange to face-to-face meetings with others who lived in their local area. This is consistent with research by Warschauer (2004) which suggests that successful online communities are those that link online communication with face-to-face socialising. It also provides further support for the importance of having a regional online community rather than a national resource. A regional community means that all users are living in the same region of the country; which makes it easier to organise face-to-face meetings.

When a facilitator was present in the forum, young people discussed more sensitive topics such as the emotional impact of cancer compared to when one was not. Consistent with these findings, in the post-intervention focus groups members themselves expressed the positive

difference that they felt the facilitator had made to the community. Young people reported feeling grateful for the emotional support provided by the facilitator and felt their contributions both inside and outside the community were necessary to instigate and maintain interactions. These findings suggest that the presence of a facilitator can be beneficial when developing an online support community; especially when membership is still low. This supports previous research which indicates that effective facilitators can cultivate a sense of security within the group (Herron, 2005). Therefore Realshare users may have felt more confident to discuss sensitive topics because a facilitator was present and responding to members' messages.

However it is important to note that Realshare also received design changes and an incentive to engage in the forum was offered during this period, which is likely to have influenced participants' interactions. Nonetheless the findings still indicate that at the initial stage of developing an online community, incentives and online facilitation may be necessary to develop and encourage user interaction. Another key point is that the facilitator was already known and involved in the users care before they became a Realshare facilitator. This might have influenced their success with the young people. Future studies may want to consider choosing an online facilitator that has already developed trust and rapport with users outside of the online community.

Concerns were raised regarding the ability for Realshare to maintain an active user base, as other established social network websites such as Facebook were already ingrained in the young people's lives. Nevertheless, Realshare was not viewed as a substitute for these websites but more as an accompaniment; since its exclusivity and specificity to TYAC provided different benefits. Using them both allowed the users' different social spheres (cancer versus normal life) to remain separate. This is important as previous research has found that mixing social spheres (e.g. parents versus employers) on Facebook is associated

with an increase in social anxiety (Marder, Joinson & Shankar, 2012). In the future, it is therefore crucial that Realshare maintains its position as a website for connecting young people affected by cancer and does not transform into a more general social networking platform or one connecting cancer sufferers of all different ages.

Limitations

Realshare only had a small number of users and posts compared to other online communities. However previous studies indicate that only posting a few times or just logging in and ‘lurking’ can have psychological benefits including improved self-esteem, acceptance of disease and feeling better informed (van Uden-Kraan, et al., 2008).

Members were offered an incentive (£50 Play.com voucher) to interact in the community during the second period (when the facilitator was introduced) because forum posting was slow in the first intervention period (when no facilitator was present) and the researchers wanted more users to explore and provide design amendments for the website development. This incentive may have influenced the interaction differences when a facilitator was present compared to when one was not. Even so, these findings still suggest that the inclusion of a facilitator and incentives are important in the development stage of an online community and can encourage member participation and more diverse interactions; which may benefit users. Design amendments were made throughout both intervention periods, but particularly when the facilitator was present (such as the introduction of forum applications e.g. Chat, photo/video posting). This may have impacted interactions in addition to the inclusion of a facilitator. This provides further support for the importance of a user-led design when creating online communities, in order to increase the likelihood of user interactions.

The findings indicate that members were using Realshare to provide and receive support; however it is not clear whether individuals actually perceived themselves as benefitting from Realshare. This was a development and acceptability study to create Realshare and identify the acceptability of Realshare and users' preferences for online facilitation. A further randomised controlled trial of Realshare will use outcome measures pre and post-intervention to identify any psychosocial improvements such as increases in social support that Realshare may offer and whether incentives and facilitators are needed when membership is greater.

Recommendations

During forum interactions, TYAC expressed a need to receive more informational and emotional support, in addition to the support that they were receiving from face-to-face oncology teams. These findings have the potential to inform the support that healthcare professionals working with these young people provide.

This research proposes the need for facilitation at an early stage when an online community is being developed; which is imperative for instigating and maintaining peer interaction when membership is low. Facilitators should be a known and trusted health professional. Organising events for members to meet up face-to-face appears also to be an important component for an effective online community. Furthermore, when researching this stage of website development, the need to incentivise user interaction through a reward scheme seems apparent. Undeniably bias will arise, as user interaction will be to some extent artificial, but without such incentives, it is predicted that interactions will be too low for the community to be effective and develop. The website will then have more time to grow to a size where the number of interactions can support themselves.

Realshare (www.realshare.co.uk) is now available for young people with cancer throughout the South West of England.

References

- Abrams A, Hazen E and Penson R (2007) Psychosocial issues in adolescents with cancer. *Cancer Treatment Reviews* 33: 622-630.
- Barrera M, Damore-Petingola S, Fleming C and Myer J (2006) Support and intervention groups for adolescents with cancer in two Ontario communities. *Cancer* 107: 1680-1685.
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77 - 101.
- Bukowski WM (2001) Friendship and the worlds of childhood. *New Directions for Child and Adolescent Development* 91: 93 – 106.
- Campbell, K, Coulson, NS and Buchanan, H (2013). Empowering processes within prostate cancer online support groups, *International Journal of Web-Based Communities*. (In Press.)
- Chiu YC and Hsieh YL. (2012). Communication with fellow cancer patients: writing to be remembered, gain strength, and find survivors. *Journal of Health Psychology*. Online first.
- David CL, Williamson K and Tilsley O (2012). A small scale, qualitative focus group to investigate the psychosocial support needs of teenage young adult cancer patients undergoing radiotherapy in Wales. *European Journal of Oncology Nursing* 16: 375–379.
- Elwell L, Grogan S and Coulson N (2011) Adolescents Living with Cancer: The Role of Computer-mediated Support Groups, *Journal of Health Psychology* 16: 236 -248.
- Gaulin N (2010) *The experience of adolescents using online social networks to cope with their cancer: Exploring Grouploop's discussion board and online support groups.* <http://sunzi.lib.hku.hk/ER/detail/hku/3840056>
- Hartup WW and Stevens N (1997) Friendship and adaptation in the life course. *Psychological Bulletin*, 121: 355-370.

Herron L (2005) Building effective support groups: Report to the Australian Department of Health and Aging. Sydney, Australia, The Cancer Council Australia.

Kent EE, Smith AW, Keegan, THM, Lynch CF, Wu XC, Hamilton AS, Kato I, Schwartz SM, and Linda C. Harlan, LC (2013). Talking about Cancer and Meeting Peer Survivors: Social Information Needs of Adolescents and Young Adults Diagnosed with Cancer. *Journal of Adolescent and Young Adult Oncology*. Online first.

Kemmis S and McTaggart R (2000). Participatory action research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 567–605). Thousand Oaks, CA: Sage.

Larouche SS and Chin-Peuckert L (2006) Changes in body image experienced by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 23: 200–209.

Love, B, Crook, B, Thompson, CM, Zaitchik, S, Knapp, J, LeFebvre, L, Jones, B, Donovan-Kicken, E, Eargle, E and Rechis, R. (2012). Exploring Psychosocial Support Online: A Content Analysis of Messages in an Adolescent and Young Adult Cancer Community, *Cyberpsychology, Behavior and Social networking*, 15, 1 – 5.

Marder, B., Joinson, A., & Shankar, A. (2012, January). Every post you make, every pic you take, I'll be watching you: Behind social spheres on Facebook. In *System Science (HICSS), 2012 45th Hawaii International Conference on* (pp. 859-868).

Meltzer LJ and Rourke MT (2005) Oncology summer camp: Benefits of social comparison. *Children's Health Care* 34: 305-314.

Nichols ML (1995) Social support and coping in young adolescents with cancer. *Pediatric Nursing* 21: 235–240.

Treadgold C and Kuperberg A (2010) Been there, Done That, Wrote the blog, The Choices and Challenges of Supporting Adolescents and Young Adults with Cancer. *Journal of Clinical Oncology*, 28: 4842 – 4849.

van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER and van de Laar MA (2008) Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research*, 10, e18

Varni J, Katz E, Colegrove R and Dolgin M (1994) Perceived social support and adjustment of children with newly diagnosed cancer. *Developmental and Behavioral Pediatrics*, 15: 20-26.

Warschauer M (2004) *Technology and Social Inclusion: Rethinking the Digital Divide*. The MIT Press, Cambridge, Mass. and London.

Wen KY, McTavish F, Kreps G, Wise M and Gustafson D (2011) From diagnosis to death: A case study of coping with breast cancer as seen through online discussion group messages. *Journal of Computer-Mediated Communication* 16: 331–361.

Willis E (2013) The Making of Expert Patients: The Role of Online Health Communities in Arthritis Self-Management, *Journal of Health Psychology*, 0: 1 - 13.