

Towards Social Connection For Young People with Cancer

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ABSTRACT

People with cancer have to contend with a variety of physical, emotional and social difficulties. Young people with cancer are often faced with the additional burden of isolation from their peers and social network. This paper outlines early results from a collaborative project seeking to use emerging technologies to develop and evaluate a peer-based social support system to support social connectivity amongst young people with cancer. We introduce an integrated service named *MyTrac*, which combines online social network applications and mobile broadband telephony. Seven young people (18-25yo) participated in the three month study. The study encompassed in-depth interview data, questionnaire data and an analysis of system audit logs, which documents participants' use and experience of the system. In this paper we highlight specific communications mediated by *MyTrac*, showing how they are a reflection of both the individual personalities of participants and a reflection of their cancer journey. We illustrate how these individual identities construct a collaborative identity for *MyTrac*, one which both encompasses and excludes particular types of interaction. We conclude by articulating some design considerations for social connectivity systems which seek to support young people with cancer.

Categories and Subject Descriptors

H5.m. Information interfaces and presentation (e.g., HCI):
Miscellaneous.

General Terms

Design, Human Factors.

Keywords

Social isolation, Social connectedness through technology, peer support, interaction, handheld devices and mobile computing,

1. YOUNG PEOPLE WITH CANCER

1.1 The problem of social isolation

Young people with cancer (YPWC) are increasingly recognised as amongst the most disadvantaged and isolated patients in the health care system, both nationally and internationally [2, 11].

In the state of Victoria (Australia), there are approximately 400 young people between the ages of 16 and 30 diagnosed with cancer each year. Unlike those 15 years and younger, who are typically treated in paediatric hospitals, these YPWC are treated in one or more of the 67 Victorian adult hospitals. For these patients, the quality of life and the ability to adhere to treatment, is greatly influenced by psychosocial and peer supports [7].

While in hospitals YPWC are either in a private room (due to concerns of cross infection while having chemotherapy) located in a ward with much older people (due to the nature of their disease). Approximately 30% of this cohort has to travel long distances to access hospital services. Currently there are few means of maintaining contact with peers when YPWC are unwell, in hospital for long periods of time, or have fallen outside their usual social, working and educational spheres. Access to appropriate information and education is often limited and some of these young patients go through their entire treatment without ever seeing or meeting a patient of a similar age. Anecdotal evidence indicates that young people find that hospitals provide very poor access to the internet. This can be very isolating, particularly for this age group where peer-interactions and support are so important. There are several key barriers to social inclusion for young people with cancer. These include:

Lack of critical mass. Fortunately cancer in young people is rare. However, as a consequence young people are distributed throughout a cancer system that is dominated by an older population. 85-90% of young people (aged 16-25) are managed in the adult cancer system [6], yet they are only a small proportion of the overall population of people with cancer. In contrast, although cancer in young children (under 15 years) is 3 times less common than in young people (aged 15-25) [11], their concentration in paediatric hospitals decreases their sense of isolation.

Inadequate Resources. The lack of a critical mass of young people with cancer within any single treating institution has seen few resources that have targeted this group, creating a sense of isolation for carers, patients, their peers and families.

Physical Isolation. The 'silo' nature of institutional health care means that young people and their carers are isolated physically from each other for significant periods. Cancer care for many young people entails prolonged chemotherapy over many months, as well as radiotherapy and surgery. In addition, the loss of mobility associated with limb amputation or major reconstructive surgery increases isolation for these young people. The challenges of physical isolation are exacerbated for young people from rural and regional Victoria, who comprise approximately 30% of this population. Regional and rural patients and their families face the additional challenge of

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distance, both from treating services but especially from other young people with cancer.

Psychosocial Stress: Finally, cancer itself, whether curable or palliative, induces anomie and alienation in young people from their communities and peers at a time when these relationships are critical. Indeed, adolescent cancer patients rated isolation from school as one of the two most distressing aspects of living with cancer [5]. High rates of mental disorder are also described in this population [9].

1.2 Social connectivity through technology

Strong social networks are essential to providing psychosocial benefits that contribute to overall well-being. Given the state of emerging telecommunication infrastructure, and the high level uptake of young people utilising ICTs (Information and Communication Technologies), it is increasingly important we investigate the role technology can play in facilitating social networks between young people with cancer and others such as their peers, and their family support networks. Research in the socio-technical fields has clearly demonstrated the pervasiveness and significance of ICTs in mediating social networks among young adults [3]. This paper reports some early results from our work which combines the knowledge and expertise in these two fields by using emerging technologies to allow a small group of YPWC connect with other YPWC via a social networking site, *MyTrac*.

2. ONLINE SUPPORT FOR YPWC

2.1 Social Network Sites

Amongst 18-25 year olds the use of social networking sites such as Facebook and MySpace is growing dramatically [1]. While there are many social networking sites designed for people living with chronic illnesses (e.g. virtual.thewellnesscommunity.org, fightingcancer.ning.com); sites specifically oriented towards young people with cancer are very rare. Sites such as <http://myplanet.planetcancer.org> and <http://www.grouploop.org> are the exception and provide a valuable service to YPWC. However the target audience for these sites is not Australian. These sites provide information, services and treatments that are not always available to Australians.

With this in mind, we devised a social support system that extended young people's experiences of popular social networking sites such as Facebook, while specifically designed to engage YPWC living in Australia.

2.2 MyTrac

MyTrac is a purpose-built social network application intended to support online connection for YPWC. MyTrac is based on the *ning* platform (<http://www.ning.com>). The MyTrac name reflects the notion of cancer being an individual journey, which is taken alongside others through the social support network. This was reflected in the figurative presentation of the sites header which features young people forming the letters which make up the letters of MyTrac.

Given the exploratory nature of the study, the functionality of the site was kept to a minimum, allowing members to provide feedback about functions they might want to see added to the site. Like other social network sites, members are able to create their own personal page which includes a profile, photographic images and background. The main page of the site featured a

forum page, an activity log, photos, links to members' personal pages and hyperlinks to popular youth-oriented cancer websites. The main page also includes an RSS twitter feed.

2.3 Twitter

Mobile phones are very common amongst young people. We acknowledge that mobile phones can play a significant contribution to social connection, especially for YPWC who may spend much of their time at home or in hospital, and may have physical limitations which prevent them from meeting face to face. Twitter provides a social networking facility to the mobile phone. Twitter (<http://twitter.com/>) is a popular micro-blogging service that supports the exchange of messages of up to 140 characters. Whilst Twitter is a web-based application it can be integrated with mobile phone telephony which extends its range to personal and social functionality allowing for immediate forms of communication and response.

Thus MyTrac combines the connective power of social networking applications with the pervasiveness of mobile telephony to create a social networking service that is accessible on the desktop and the mobile phone.

3. THE MYTRAC STUDY

3.1 Selecting participants

This study was subject to review by the ethics committee at Peter MacCallum Cancer Centre. Potential participants were identified by a social worker and a psychologist from the research team. Participants were selected according to recruitment criteria. Participants had to be diagnosed with cancer, aged between 18-25 years, well enough to participate, and have a mobile phone and email account.

We recruited 7 participants to the site, 4 women and 3 men. The 7 participants' were at a range of stages in their cancer journey, 3 were palliative, 2 were post-treatment and one was newly diagnosed and was having active treatment (chemotherapy). Two participants had cancer of the bone, three had blood-borne cancer, and one had cancer of the brain. Two participants were from regional Victoria (living 40 kms outside Melbourne). For the purposes of this paper we will use pseudonyms to differentiate between the participants. Participant 1 (P1), 19 year old (yo), female named Stephanie. P2 is a 22 yo girl named Samantha or 'Sam'. P3, Kara is a 20 yo female. P4, Basil is a 22 yo male, P5, Jamie is a 25 yo male, P6, Liz is a 24 yo female and P7, Michael is a 22yo male. During the course of the project one of the participants (P4) withdrew due to ill health, and P7 withdrew for personal reasons.

3.2 Research Design

The study spanned twelve weeks. Throughout the course of the research there were a range of data-generating practices with the participants. Each participant completed interviews at baseline, and at the middle and end of the data collection process.

Participants were shown the MyTrac site and signed up for the Twitter application on their mobile phones, at the beginning of the study. Twitter enabled them to send messages to MyTrac and 'follow' participants anytime and anyplace. Other than an invitation to post messages a couple of times a week, participants were given little instruction on how and what they should post on MyTrac.

Participants also completed a range of on-line questionnaires, filled out a log once a week of their technology usage and sent messages via twitter and the internet to MyTrac. This paper will primarily draw upon the MyTrac and Twitter data.

3.3 Technological provision

Each of three partnering institutions involved in the research provided different forms of technological support. The cancer hospital provided the study with 7 laptops and webcams, for participants who did not have them. The telecommunications company provided support in the form of broadband coverage via wireless modems for the data collection period and a desktop video-conferencing application.

4. RESULTS

4.1 Introductions

All the participants (except P4 who was too unwell) built their own personal page using the templates provided on MyTrac. These pages tended to be bright and colourful, and provided the participant with an opportunity to introduce themselves. Participants added photographs, typically taken before their diagnosis.

The participants included details of their disease, diagnosis date, and place of treatment as well as personal information such as hobbies and interests. The participants were asked to send a favourite quote or saying – these tended to evoke positive comments from the participants such as “happiness is having something to look forward to” and ‘Life isn’t about waiting for the storm to pass. Life is about learning to dance in the rain’.

4.2 Invitations

As participants became more confident and comfortable with the site they began to invite members of their current social networks to become members of the site. Sam (P2) invited over 25 friends and family to join MyTrac. Most participants limited their friends’ requests to social contacts also living with cancer, although there were no instructions to do so. Three of these contacts became frequent contributors to the site. Liz (P6) said that she had considered inviting friends to the site, but ultimately felt that the site was ‘just for me’ in that it should reflect her experiences, and she did not want to share it with others. P7 (Michael) was particularly disappointed when none of his friends accepted his invitation to join the site.

4.3 Messages

Sam (P2) was the most prolific sender of messages to the site, logging on and sending messages most days. Sam sent ‘welcome’ messages to all new members, and sought to include them in conversations. She posted individual messages to others members’ pages, usually asking them what they were up to and wishing them well. Sam also sent a number of twitter messages (21 messages). The topic of her messages varied from updates on her activities “working up a sweat on my Wii. It’s great to be alive”; to queries about the service “wondering y she still isn’t getting Twitters ... Oz network down still?”; to specific updates about her progress with cancer. Sam’s twitter updates were always optimistic, even if she had experienced a difficult day. This reflects an ethos within the cancer community which argues that positive attitudes lead to positive health outcomes [12].

Michael (P7) also sent a variety of twitter messages; however his messages tended to reflect his current mood. He sent

messages when having a crisis e.g. when his condition suddenly deteriorated, he used his mobile phone to send a twitter message from an ambulance going to hospital. Michael sent messages which were construed as being negative (“I hate the world. I hate my life”) and then follow with more positive messages (“I wish u all a good night and sweet dreams :-))”). It was evident that while the other participants sought to support him in his distress, with offers of help and invitations to phone, they found these messages to be quite confronting (“keep your negative bullshit to yourself i dont wanna hear about it”). Michael’s physical limitations, which had arisen from his cancer treatment, made voice phone calls and use of computer keyboard very difficult. However he was able to use his mobile phone for texting with one-hand and so he continued to communicate through twitter for some time.

Despite being the first participant recruited, Stephanie (P1) did not develop her personal page for six weeks, and thereafter had little interaction beyond posting photographs of her and friends at play. She occasionally logged into the site and eventually began to receive messages and respond to messages on her mobile phone. Stephanie’s inactivity on MyTrac can be partly explained by the fact that she had an extensive social support network. Family or friends were with her almost every hour of the day. This was particularly the case when having treatment.

4.4 Connections

It was apparent from both the interview data and the website logs that particular participants began to make connections with other members. For example, P5 (Jamie) and P6 (Liz) had a shared interest in landscape gardening. This interest extended into posts which discussed a relationship between landscape gardening and cancer. For other members, a shared cancer type became a focal point for discussion. Liz, Kara and Sam all live with a similar type of cancer, however while Kara and Liz had returned to some type of normal life after treatment, Sam had relapsed. This was clearly a source of some difficulty for Sam, and she outlined her experience in great detail on the site and elsewhere. Sam also began a forum called ‘when you’ve relapsed you are not alone’. Once connections were established on MyTrac, some participants ‘channel-hopped’ [4] their interactions to other forums, such as facebook and MSN.

4.5 Forums

MyTrac had 15 forums. The forums, created by the research team, were on topics such as ‘Life Matters’ and ‘Relationship Issues’. These forums were not used by the participants. Liz said that she preferred to post messages to people individually, rather than put it on a wall for everyone to see. Other members made attempts to create their own forums including one which cited ‘quotes to brighten your day’.

5. THEMES

It is evident that interactions on MyTrac reflect the cancer journeys and care trajectories of the participants [10]. There are times when participants reach out to others e.g., when seeking reassurance, when worried about a forthcoming test result or when they want to share a positive event. Equally there are periods when there will be little interaction, in particular, when participants are having chemotherapy or radiotherapy, when they are having surgery, and when they are struggling with pain. It is important that both participants and researchers are sensitive to these lulls in interaction. For instance, P5 desired to take part, but his physical limitations, in particular his inability

to even sit up in bed and stay awake for more than a few minutes, precluded him from doing so.

Members of the site may also call out for support when they are at a stage of personal crisis, as Michael did on a number of occasions. However it is evident that these individual requests are often framed according to the norms of the collective. If framed in a 'negative' way, they can adversely affect the mood of other participants, who are trying to maintain a positive attitude. While members may be willing and able to support individuals in crisis, some may be struggling with their own (on one occasion Stephanie was in hospital with a temperature of 39 degrees), and may resent the additional burden this placed on their emotional resources. This raises the possibility that certain features of emphatic communities [8] on social networking sites may negatively affect participant's health.

6. DESIGN CONSIDERATIONS

This research suggests a number of design considerations for the social networking sites for YPWC.

Shared Histories: Sites for YPWC should allow participants to share their backgrounds, their interests and their journeys with cancer. Individual cancer journeys alone are not sufficient to sustain new connections. Rather we have seen that a shared hobby, passion or interest – as well as shared journeys with cancer – facilitated connections between participants.

Flexibility: Sites should allow some flexibility so that participants may construct and develop aspects of the website which are of interest to them. Pre-determined forums and other discussion hubs are not always used. Designing sites so that active participants may adopt different roles may be helpful. The participation and role of a moderator should be considered carefully in the context of individual sites.

Sensitivity: It is important that participants are able to recognize and facilitate support for different stages of their illness. It was evident from our work that newly diagnosed participants have different needs from palliative and post-treatment participants. Furthermore, we should consider what action will be taken if a participant dies during the life of the site. Do we leave the participants personal page running? Do we create an in-memoriam page? How do we recognize the contribution of the participants to the site? How do we support other participants who have connected with the deceased participant? These issues demand careful consideration from a practical and ethical standpoint.

Multiple Social Networks: Designers need to recognize that when individuals make connections within the website, these connections may extend beyond the boundaries of the website onto other social networking sites (e.g. facebook, myspace) and other applications (MSN). For small groups this may lead to unexpected and unexplained interactions on the site.

7. CONCLUSION

The population of young adults who have cancer is low, but their need for social connection is very high. We have

demonstrated that a social networking service, such as MyTrac which combines an online social network application with a mobile micro-blogging facility (twitter) can act to introduce and enable contact between YPWC, which may assist them to feel less isolated.

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