

COLLABORATIVE CANCER SUPPORT NETWORKS GRANTS PROGRAM

Round 3

Final Report

Using Emerging Technologies to Improve Supportive Care for Young Adults Living with Cancer

Partnership Organisations

- onTrac@PeterMac Victorian Adolescent & Young Adult Cancer Service, Peter MacCallum Cancer Center
- Department of Information Systems, Melbourne University
- Telstra

Project Team

The project is a collaboration between onTrac@PeterMac, The University of Melbourne's Department of Information Systems (DIS) and Telstra. The team consists of the following members:

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Project Time

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1. Background

Adolescents and young adults (AYAs) living with cancer are increasingly recognised as disadvantaged both nationally and internationally [1, 2]. In Victoria, there are approximately 400 young people between the ages of 15 and 30 diagnosed with cancer each year. Unlike those under the age of 15 who are typically treated in paediatric hospitals, AYAs with cancer 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 [3].

While in hospitals, AYAs are either in a private room (due to concerns of cross infection while having chemotherapy) or located in a ward with much older people (due to the nature of their disease). Approximately 30% of this cohort travel long distances to access hospital services. Currently there are few means of maintaining contact with peers when AYAs 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. Furthermore hospitals typically provide very poor or no access to the Internet. This can be very isolating, particularly for AYAs for whom peer-interactions and support is 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 [4], 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) [2], 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 alike.
- *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 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. High rates of mental disorder are described in this population [5].

Strong social networks are essential to providing psychosocial benefits that contribute to overall well-being. Given the state of emerging telecommunication infrastructure (e.g. broadband Internet, WiFi, 3G) and the high level uptake of young people utilising Information and Communication Technologies (ICTs), it is increasingly important we investigate the role technology can play in facilitating social networks between AYA's with cancer and their peers, their family and other support networks. Research in the socio-technical fields has clearly demonstrated the pervasiveness and significance of ICTs in mediating social networks among young adults [6].

AYAs are typically very IT-literate group and have proven to quickly adopt and manage new ICTs [7]. However prior research into the use of technology for psychosocial support has overwhelmingly been in the areas of information provision and in improving contact with health care providers. Even though appropriate information and access is essential, telecommunications

services should also help facilitate social well-being. However little is known about the role of technology in building social connectivity amongst AYA themselves, as well as enabling them to maintain contact with their broader network of existing friends and family members. This is particularly salient where illness and treatment has taken away so much of their independence and control. The process of achieving this is mostly left to chance opportunities. What technological infrastructure and services will promote social cohesion between young people with cancer and remote and rural families? And for young people with cancer and their peers who are living with a similar illness? For young people with cancer the answer to this question should not be left to chance, but should be researched, codified and made available to those who need it.

2. AIMS

This project aimed to:

- identify the psychosocial requirements of young people living with cancer that can be best met by broadband related services;
- establish the nature and type of clinical support that is most suitable for ICT based supportive care for young people living with cancer;
- create new ICT services that integrate the needs and span the communities;
- trial and evaluate these services;
- document best practice that facilitate social cohesion and support using ICT's in a manner that is sensitive to ethical and privacy considerations.

In order to achieve the aims, four objectives were outlined:

(i) Integrate Expertise: establish a shared expert understanding (i.e. between Cancer and Information Systems) of how current and emerging technologies can be used for support by young people living with cancer.

(ii) Requirements Analysis: This objective is to empirically determine the requirements for technologically mediated social support for young adults with cancer.

(iii) Prototype development: This objective is to use participatory design techniques to develop a prototype (based on the requirements) and evaluate its use.

(iv) Sustainability and Outreach: document best practice for facilitating support amongst young people with cancer by using ICTs in a manner that is sustainable and sensitive to ethical and privacy considerations

3. Enabling Technologies

Several technologies, hardware and software, were used in the investigation:

Laptops with Webcam

Participants were provided with laptop computers running Windows XP. Each laptop had a webcam with video and audio capabilities.

Wireless Broadband

Participants were provided with wireless 3G broadband for their laptops, generously provided by Telstra.

Click-to-Meet

Video conferencing software called Click-to-Meet, provided by Telstra, was trialled in the project. The software supported video-conferencing for multiple people on desktops/laptops using Windows.

Mobile Phone

All participants had a mobile phone. The use of their mobile phone was an important technology for communication between participants and to the social network site (see below).

MyTrac

The use of social networking sites such as Facebook and MySpace is becoming increasingly popular, especially with AYAs. While there are many social networking sites designed for people living with chronic illnesses (e.g. <http://thewellnesscommunity.org/>, <http://fightingcancer.ning.com/>); sites specifically oriented towards young people with cancer are less common. With this in mind we created the site *MyTrac*, which extended young people's experiences of popular social networking sites such as Facebook, while specifically designed to engage AYAs living in Australia.

MyTrac is a purpose-build social network application intended to support online connection for AYAs with cancer. *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*.

The functionality of the site was purposefully 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 were 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.

Twitter

The communication medium of choice for many AYAs is the mobile phone. Mobile phones often play an important role for social connection, especially for AYAs 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 is an emerging technology service that can integrate the mobile phone with social networking facilities. 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.

4. Participants

Participants were chosen who were 18-25 years old, living with cancer, and potentially had a need for increased social contact. In addition they were thought to be physically and psychologically well enough to be able to participate in the research.

Seven men were approached. Four men declined to take part (one was travelling overseas, another was returning to working life, one parent declined on his son's behalf, and the fourth did not give a reason). All four women approached agreed to take part.

In total seven participants were recruited to the project; four female and three male. Three participants had curative cancer. Two participants were within 12 months of completing curative therapy. Two participants were palliative patients (i.e., in whom the goal of care is no longer curative).

Three of the participants were from rural or regional locations (greater than 50km from the CBD). Two of the male participants withdrew during the course of the research due to ill-health.

Name*	Age	Cancer	Status	Disability
Stephanie	19	Bone	Newly diagnosed (Active treatment)	Limited movement in arm
Samantha (Sam)	22	Blood	Palliative	-
Kara	20	Blood	Active treatment	-
Basil	22	Bone	Palliative	Unable to walk
Jamie	25	Bone	Post-treatment	Unable to walk, aided by wheel chair
Liz	24	Blood	Post-treatment	-
Michael	22	Brain	Palliative	Unable to walk, tracheotomy, no movement in one arm

* pseudonyms

5. Tasks

This project took place over 12 months from March 2008. The data collection phase occurred during the months of June-August 2008. Participants involvement was phased in over three week intervals, in recognition of their various illnesses and treatment plans. Over the course of approximately 12 weeks, each patient was asked to take part in the following:

- complete two questionnaires, each administered at the beginning, middle and end of the twelve week period. The questionnaires took approximately 5 minutes each to complete, and were administered online;
- participate in three, 1 hour semi-structured individual interviews. These interviews took place at the beginning, and end of the twelve-week period. The second interview was conducted via 'click-to-meet' video conferencing technology or face-to-face if necessary. All the interviews were video-recorded;
- participate in three on-line focus group session using 'click to meet' technology. These focus groups were voluntary, did not last more than one hour in length and took place where-ever participants were located at the time (e.g. home, hospital, etc) via click-to-meet video-conferencing technology;
- make contributions to the social networking site (MyTrac) either online or using mobile phone technology (Twitter);
- regularly (weekly) enter on-line log data about their recent technology usage (e.g. use of mobile phone, email, internet sites visited, social networking sites used, etc).

6. Data

6.1. Scenarios

The project team devised two scenarios, one for a hypothetical young woman living with cancer (Jane) and one for a hypothetical young man living with cancer (James). These scenarios are attached in Appendix A and B. The group referred back to these scenarios throughout the course of the project in order to support the process of developing and refining the MyTrac prototype.

6.2. Questionnaire data

We provided participants with a self-administered copy of a FACT (Functional Assessment of Cancer Therapy) questionnaire at baseline, midway and at the conclusion of the twelve week cycle. The actual questionnaire we applied is called the FACT-G, which is a General version of the scale that can be used with patients of any tumor type (available at <http://www.facit.org/qview/qlist.aspx>). The questionnaire specifically addresses four quality of life domains: physical well-being, social/family well-being, emotional well-being and functional well-being. This questionnaire was completed either online (through the MyTrac website) or by paper at the time of the interview, as the participants desired.

In addition, we adapted the Motivation For Internet Usage questionnaire [8] at the beginning, halfway point and end of the twelve-week cycle. This questionnaire uses a combination of

interpersonal, media and new technology motives to measure motivations for using the internet. To construct the motives scales the authors used interpersonal (affection, inclusion/companionship and control); media (entertainment, habit, information, social interaction, escape, surveillance, passing time and relaxation); and Internet (time, control, convenience, economy, and expressed need) motives. Respondents used a 5-point Likert scale (5=exactly, 1=not at all) to address issues of their internet use.

6.3. Interviews

Semi-structured interviews were conducted with individual participants as a means of understanding their supportive care needs, their experiences of using the technology, and the interplay between these. These interviews took place in the first, middle (via 'click-to meet' technology) and final weeks of their participating in the research. These interviews lasted approximately one hour and were video-recorded to assist in later analysis.

The baseline interview included discussions of the following.

- Background data (family size, composition)
- The participants illness and, the practical and social means by which it is managed
- Existing forms and levels of social contact between the young person living with cancer and their healthy peers
- Existing forms and levels of social contact between the young person with cancer and their peers who are also living with cancer
- Existing forms and levels of social contact between the young person and their family
- Access and experience of supportive care
- Current levels of technology usage (mobile phones, computers, internet)

The second interview (conducted via 'click to meet' technology) responded to issues and themes arising from the initial interview and questionnaire data. They explored the following:

- Any major changes in the participants life which have occurred since the last interview (including changes in their illness, treatment etc)
- The young persons experience of the technology (who uses it, when, why)
- Any changes in social connectivity (between the young person and his well and unwell peers) which have occurred as a result of the technology

Drawing upon findings from previous interviews, observations and data logging, the final interview explored the following:

- Changes in social connectivity due to technology use
- The individuals overall experience of the technology (both positive and negative).
- Comparisons of their experience of using video (web conferencing) audio, document sharing and messenger chat. This is with a view to learning what the participants' value most – and least- about the software.
- Changes in supportive care as a result of technology use

By comparing and contrasting the experiences of individuals over the twelve week period (across the three interviews) the project team aimed to understand the AYAs use of the technology, and to determine whether there has been an increase in contact between distributed young people living with a rare cancer.

6.4. Log data

In order to gain an understanding of the participants' general means of communicating with friends and family, we asked them to document their interactions, on one random day per week, across the 12-week data collection period. That is, we asked participants to document their use of telecommunication devices e.g., landline and mobile, Instant messenger chat (MSN), social networking sites (e.g. MySpace, Facebook, MyTrac) and face to face contact. Specifically the log

data recorded the participant's name, who they spoke to, and the medium via which they communicated with their contact. For example they might enter 'Hilary' contacted 'Shawn', on 9/07/2008, via mobile SMS text, the topic of the conversation was 'coming home from hospital'. This information was entered onto an online form via a link on the MyTrac page. Requests and reminders to enter log data were sent via Twitter to participants' mobile phones and to the MyTrac site.

7. Results

7.1. Questionnaire data

The purpose of the questionnaires was to provide background patient information, to motivate the interviews and to contribute to methodological design for future work. The questionnaires were not intended to produce statistically significant results due to the small number of participants taking part in the study. We present a summary of the questionnaire data.

7.1.1 FACT-G

All patients completed the questionnaires, with the exception of two palliative patients who were excluded at baseline due to difficulties with completing the questionnaires.

Items that participants most frequently rated with the lowest scores were:

- I am able to work (include work at home)
- My work (include work at home) is fulfilling
- I worry that my condition will get worse
- I have a lack of energy
- I am bothered by side effects of treatment
- I am forced to spend time in bed

Items that participants most frequently rated with the highest scores:

- I feel close to my friends
- I get emotional support from my family
- My family has accepted my illness
- I have accepted my illness
- I am satisfied with family communication about my illness
- I feel close to my partner (or the person who is my main support)

The data suggests that most participants were unable to work, and those that did find work, it was fulfilling (at the time of this study only one of the participants was engaged in any work outside the home). The participants in the study did not appear to worry that their condition would get worse, did not have a lack of energy, were not bothered by side effects of treatment and were not forced to spend time in bed. Furthermore they felt close to their friends and family, felt that they and their family had accepted their illness, and were satisfied with family communication about their illness.

7.1.2 Motivation for Internet Usage Questionnaire

In respect to the Motivation for Internet Usage Questionnaire, the following is a summary of the results:

- All participants felt satisfied with the feedback they received from their face-to-face contacts however going online fulfilled a different or supplementary form of interaction (e.g. sharing their experiences, supporting other AYA's with cancer).
- One participant felt that the MyTrac community did not have enough expertise to be helpful; this participant was our oldest member who was living with a very rare form of cancer.
- All participants agreed that they could express themselves freely online.
- All the participants agreed that composing a message online allowed them the opportunity to say "exactly" what they wanted to say.

- There was a perception that online support is both always there and always available.
- Information seeking and entertainment were strong motivators for going online for our participants.
- All participants either agreed or strongly agreed that having access to other AYA's with cancer was important.

7.2. MyTrac

7.2.1 Introductions on MyTrac

All the participants (except P4, 'Basil' who was too unwell) were asked to introduce themselves to the group through the social networking site, MyTrac. All the participants 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. Most of the participants added photographs, typically taken before their diagnosis, and one participant added a link to an online video that he had posted.

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".

Participant recruitment was staggered. The 6 participants who created their own pages, did so across a number of weeks. Consequently, as each new page was added to the site, it prompted a flurry of welcoming messages from existing MyTrac members.

7.2.2 Invitations to join MyTrac

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, some of these contacts built their own personal pages, some simply exchanged commentary with individual MyTrac members, while others simply 'lurked' on MyTrac. Surprisingly some of these external invitees had met each other on camps and other outlets created for AYA, and this initially became a focus for messages.

Most of the original six 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.

7.2.3 MyTrac and Twitter 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 the most 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.

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 that were construed as being negative ("I hate the world. I hate my life") and then

followed them with more positive message ("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 occasionally found these messages to be quite confronting.

The psychologist attached to the project arranged additional consultations with Michael when it was evident that his mood was very low. She also advised him about the tone of messages he should send to the group in order to receive positive responses and feedback.

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. This pattern of interaction reflected her use of a MySpace page that was largely centred on her boyfriend who was supporting her through her battle with cancer. Stephanie 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 was newly diagnosed with cancer, was having extensive treatment (including chemotherapy) and had a very supportive existing social support network. Family or friends were with Stephanie almost every hour of the day. This was particularly the case when she was in hospital (which occurred throughout this data collection period).

7.2.4 Making 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' their interactions to other forums, such as Facebook and MSN.

7.2.5 Forums

MyTrac had 15 forums. The forums were created by the research team and reflected forums which were successfully utilised on Young Adult-based cancer sites overseas. The forums included 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'.

7.2.6 Other themes

It is evident that interactions on MyTrac reflect the cancer journeys and care trajectories of the participants. There were times when participants reached out to each other 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 group. 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 problems (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 on social networking sites may negatively affect participant's health.

7.3. Click to Meet

In this section we report on a trial of the desktop video conferencing technology Click-To-Meet (CMT) by a psychologist. This is an informal evaluation. To fully and formally evaluate videoconferencing as a method of providing counselling would require a reasonable sample size of 10-15 patients, and a number of counsellors providing the service, to overcome the influence of patient or counsellor variables. This was beyond the scope and resources of the project. The objective of this study was to explore the use of videoconferencing to provide psychosocial services within an Adolescent and Young Adult Cancer Service. We report firstly on the use of CTM for individual consultation and secondly its use in a focus group.

7.3.1 Individual Consultation

Individual counselling sessions were provided on three occasions to a patient 'Michael'. At the end of each consultation Michael was asked to share his experience of the video-counselling format.

Patient background

'Michael' is a 22 yr old male, who was diagnosed with a brain tumour several years ago. Numerous operations had been unsuccessful in removing the tumour, and it remains a threat to his life. The tumour growth had been controlled for many years through RT, chemotherapy, and a new trial drug, and he has spent the majority of recent years in and out of hospitals. He used a walking stick due to poor mobility. He had very poor control of his right arm and hand, and no movement in his neck, which was supported by a neck-brace. A few years ago, he required a tracheostomy due to post surgical vocal chord paralysis. He was frequently in hospital due to chest infections, ventilation problems, severe pain symptoms, and poor vision. At the time of the study, he was single and lived at home with his mother and younger brother.

During the course of the psychological intervention, Michael was required to go interstate for further neurosurgery, and would spend several weeks in hospital. Usually the psychological treatment would be postponed until his return, however with CTM software available to us at this time we decided to trial CTM video-counselling while he was away. Two sessions were conducted while he was away and a third when he returned to Melbourne.

Benefits of the sessions

- Continuity of treatment. Michael was able to access support when physically unable to attend appointments
- Support could be provided during a particularly vulnerable period (having major surgery)
- Michael was computer literate and had his own laptop with web cam and microphone and wireless Internet connection.
- Both patient and psychologist felt that the visual connection provided by seeing each other was far more powerful than a telephone conversation. They were able to see each other's facial expressions, and experience the 'presence' of the other person more powerfully than a phone conversation.
- They had the added benefit of the text/chat facility so that when the psychologist was unable to hear Michael clearly due to his impaired speech, he could type the sentences - this was an even

greater advantage than the face-to-face sessions when he just repeated himself until he was understood.

- Quality of image was quite good
- Confidentiality could be assured with the secure privacy setting provided by CTM software. The psychologist assured Michael that she was in a private office and would not be interrupted.

Problems with the session

- Technical issues. It took approx half hour to setup
- There was a slight time delay for the video and voice communication
- Normal phone lines to communicate throughout the session because the audio connection was poor,
- Direct eye contact was not possible due to the hardware configuration of the camera sitting above the screen so the image input and output do not match.
- Subtle facial expressions are missed (in face to face sessions there are cues that someone is 'thinking' about something and a probe can be offered to explore this, which may be missed on the video stream)
- Privacy was compromised by interruptions from nursing staff and at home. It is the responsibility of the patient to ensure his or her own privacy, where as in face-to-face sessions the therapist controls this.
- Less control for therapist to ensure privacy and confidentiality.
- Increased likelihood that clients can disengage, and less control for therapist to help them stay engaged when the 'emotional work' becomes challenging.

Summary

In summary, there were clear advantages and disadvantages to this video-counselling and overall the experience was positive. The videoconferencing format was used for the clear purpose of providing an access to psychology intervention for a patient who was unable to attend appointments due to a hospital admission. The sessions were planned, scheduled in advance and part of a broader therapeutic intervention. The therapeutic alliance between client and therapist was fundamental to psychological interventions was established prior to the videoconferencing session. This alliance involves the development of a good rapport, clear boundaries around confidentiality and privacy, and an environment of unconditional positive regard, which enables clients to trust that their personal experiences will be respected, not judged, and not shared outside of the relationship with the therapist. The evidence base examining the efficacy of the therapeutic alliance is based on face-to-face communications, and further research is required to evaluate the quality of the therapeutic alliance developed through videoconferencing interactions only.

A fundamental aspect of a counsellor's role is to provide a safe and secure place for patients to share their inner most private experiences. The foundation of this space relies upon privacy and confidentiality; an environment without risk of interruptions, nor the risk that others can overhear or have access to the conversation. In traditional face-to-face counselling it is the responsibility of the therapist to create this environment, and we take much care in doing this. In video-counselling, the therapist had much less control over these parameters, and needed to rely on the patient to ensure this. For these reasons and the instability of the software, the efficacy of this medium to provide effective psychotherapy may be compromised. However, when these issues are appropriately addressed there would be increased potential for video-conferencing to be an effective medium for counselling. As a secondary and interim measure it is certainly useful tool and has much benefit for patients in need.

7.3.2 Group work

Providing a group intervention over videoconferencing has all of the advantages and disadvantages of individual consultation with the added challenges of managing group process issues while conducting the intervention. We conducted three group meetings using CTM, the first with 2

participants, the second with 5 participants and the third with 3 participants. The psychologist facilitated each session.

Meeting one: Wednesday (9 July 2008)

Participants: Kara and Sam on teleconference only.

Apologies: Michael and Basil - both unwell/unable to attend

Summary: The meeting was set up 20 mins prior to scheduled meeting time. Patients were called prior to meeting time to ensure they had received email invitation and had started downloading the software for CTM. Basil was in hospital with an infection and was not able to participate. Michael had a domestic issue and also could not participate. Kara initially had some problems logging into the meeting, but she returned back to original instructions from the invitation email and was able to join the meeting. Stephanie has difficulty joining the meeting and required help for 30 mins. A general discussion was held between the participants. The communication was effective and easy to follow. The content was light hearted and non-specific, and flowed easily.

Lessons learned: Set up software for participants and test prior to session.

Meeting two (11 July 2008)

Participants: Kara, Sam, Michael, Liz, Stephanie on teleconference only.

Apologies: Jamie and Basil- both unwell/unable to attend

Summary: A meeting was scheduled for 1.00pm. Fifteen minutes prior to the commencement of meeting, the psychologist attempted to log into the meeting and was unable to obtain access to the meeting site. The psychologist emailed all participants to let them know there was a delay in starting the meeting. Technical problems were eventually sorted out. The psychologist set up the teleconference by calling each participant to link them into the phone call. The communication was clear and effective between all participants. Often a separate dialogue occurred via the 'chat' text function, while others were conversing through video and teleconference. Due to the lack of time remaining after the lengthy set up time, the formal structure of the meeting was aborted. The conversation was therefore sociable and free-flowing in nature. It was easy to follow the communication and all participants were involved. All participants were very patient with the process. They were comfortable using video and confident in exploring the software. The multiple communication aspect, with verbal and 'text chat' going in parallel, created a dynamic and engaging session.

Lessons learned: Importance of stable software. All participants should be set up properly before meeting commences.

Meeting three (16 July 2008)

Participants: Kara, Jamie and Liz.

Apologies: Other participants unavailable.

Summary: Set up time for the session took approximately 30 mins. The official discussion group began and was recorded by other researchers who observed the session but were not visible to participants. Participants understood this. The context for discussion was for AYAs to talk about the disruption to social support during treatment and sense of isolation young people can feel when in hospital. The initial questions for the group were to stimulate discussion about their own experiences of social connectedness and/or isolation and discuss the barriers for staying connected (i.e. long hospital stays, feeling so unwell, etc). The change from light-

hearted social conversation that we had in previous meetings to a more serious focus, changed the mood of the group and not all members found it easy to share their thoughts. The flow of the conversation relied more heavily on the facilitator to lead and direct the discussion, and participants said they were worried about talking over the top of each other so there were longer pauses between speakers than their might have been if we were face to face. The knowledge of having two 'silent' observers as well as the videotaping of the session, may have also contributed to people feeling more reserved in sharing their personal experiences. Another difficulty was the poor eye-contact available, as we could all look at 4 faces almost simultaneously. Therefore it was difficult for people to demonstrate they are 'looking at' the speaker, and people may have felt somewhat self-conscious looking at themselves while talking. The slight delay in video and sound increased the problem of reduced conversation flow.

Lessons learned: It may take time and practice to adjust to the new format and adapt to new ways of communicating. Need to establish a faster way of indicating who is speaking so that participants do not worry about talking over other people.

Overall

From a therapy viewpoint, the CTM sessions were problematic in the group format. It is likely this was due to technical problems, unstable software, and unfamiliarity with the medium for use in groups. The added sense of being watched and videorecorded may have further interrupted the engagement and comfort within the group. The final problems from a clinical perspective was that the facilitator had provided individual counselling to most of the participants and this change in context to a group setting can take sometime to adjust to, as participants need time to trust that the psychologist would not share things they had said in individual sessions with the wider group. Until this trust is demonstrated there can be an underlying anxiety about this.

Nevertheless, group video-conferencing has excellent potential to work when formally set up as a support group or therapy group, particularly in a context in which individuals had already met and mixed with each other. However, the group will need an IT support person and a qualified facilitator. There is also great potential for group videoconferencing to be used in a clinical to clinical basis, where the psychological factors are not relevant.

7.3.3 Summary

There are many benefits to developing videoconferencing for wider use within this service. The service will need to be appropriately set up to adhere to clinical practice, ethical, legal, safety and privacy standards. Funding will be required to resource this development adequately. Interventions need to be evaluated formally and researchers need to ensure that efficacy of the intervention is sufficient to warrant further investment in the development of this service. ICT support will be required to assist with setting up hardware and software for applications, and addressing problems that may arise. Clinicians will require training and skill development in new technologies, and clients will require training and education in using software and in the clinical parameters of this intervention, such as protecting their own confidentiality and privacy. The advantages of a successful video-conferencing service are far reaching and will undoubtedly be part of all health care services in the future.

8. Findings

8.1. AYAs with cancer desire social support and social connection

It is evident from this research that despite the fact that participants felt they had sufficient familial support (as evidenced by the FACT-G questionnaire results), they were hungry for social connection and social support outside this context. That is, they stressed that having access to other AYAs with cancer was important for them, as this afforded them the opportunity to provide supplementary forms of interaction outside the familial context, and with a group of people who are living with similar experiences. This desire for social connection and possibly social support during their cancer journey provided an opportunity for this unique group of individuals to engage in meaningful and supportive interaction.

8.2. AYAs with cancer are a suitable group for connecting via new technologies

Adolescents and Young Adults with cancer are a suitable group for using new technologies to forge new connections, they are usually highly technologically literate, and already use or have used a variety of social networking tools such as Facebook, MySpace, and MSN. Half of our participants owned their own laptops, and all of them had email accounts and mobile phones. However these participants desired social connection beyond their existing familial and social contexts. They desired the opportunity to connect and communicate with other AYAs with cancer, particularly when they were isolated at home, or were hospital-based (where internet connectivity is poor) for long periods of time.

It was evident from our interviews with the participants that most of them had spent some time searching online sites either for information about their illness, or for accounts of other AYA with cancer who had similar experiences. Unfortunately at the time of this study, the majority of the sites relating to AYA with cancer were American. There was some evidence that the participants felt that these sites were not sufficiently relevant to Australian based AYAs with cancer (as treatment regimes, drug use etc are often different to what is available in Australia). Notably, outcomes from the motivation for Internet Usage questionnaire indicated that all participants felt that they could express themselves freely online (while they might not be able to do so in person), and felt that composing a message online enabled them the opportunity to say exactly what they wanted to say.

8.3. AYAs with cancer make connections if they have shared interests outside their cancer experience

This research focused on six AYAs living with cancer. The MyTrac site was designed specifically for these individuals, although they could invite existing family members and friends to take part in the site if they wished to. It was evident from this research that cancer alone is not a sufficient enough motive to forge social connections between individuals who are initially strangers, yet happen to be living with cancer. Rather we found that sharing stories of their cancer journeys in conjunction with shared hobbies or interests, helped to afford connections between AYAs with cancer. For our participants' discussions of landscape gardening, travel opportunities, pets (particularly dogs), outrageous haircuts (often in anticipation or response to hair loss resulting from treatment from cancer) and other topics, more commonly provided a platform upon which friendships were based. It is worth noting that two of these friendships have survived beyond the life of this project.

8.4. AYAs with cancer have different technological and social needs.

We found that AYAs with cancer have different needs depending upon the stage they are at in their cancer journey. For example, newly-diagnosed patients may require more information-based support (e.g. information about what kinds of treatment are available, what will diagnosis mean for their immediate future etc). Our newly-diagnosed participant appeared to have a strong supportive

community, while those participants who had been living with cancer for a period of time felt that many of their friends and some family members had become less supportive over time. In contrast, we found that palliative patients require more social support from existing family members and friends as they were nearing the end of their lives. Our palliative patients also required additional psychological support which was provided outside of the MyTrac context, by the psychologist attached to the project either in person, or on some occasions via the video-conferencing technology.

In the event of the design of a site for AYAs with cancer that is open to a much larger group of participants, we would suggest that designers might consider designating specific areas of the site for individuals who are at different stages of their cancer journeys (e.g., newly-diagnosed, post-treatment, palliative) in recognition of the differing needs of these individuals. However it is also important to recognise that individuals may move between these groups throughout their cancer journey.

8.5. AYAs enjoyed the opportunity to meet visually via Click-To-Meet

The participants were afforded the opportunity to meet visually via the Click-To-Meet technology. This opportunity was unlikely to arise in a non-technological social context as the participants would be unlikely to be co-located at one time due to their physical disabilities, various stages of illness, and disparate locations (e.g. some at home, some in hospital, one has returned to work). While there were some technical difficulties with the audio aspect of the video-conferencing software, there was sustained interest on the part of the participants to talk to the others in the group. All the participants desired to take part – only illness constrained two members from doing so. While our group session was initiated and managed by the psychologist in the group, the participants indicated that they would have liked to have un-moderated contact with the other participants. It was apparent that all the participants enjoyed the opportunity to meet visually (i.e., via video-conferencing) as well as online. Indeed, after the video-conferencing there was heightened activity on the MyTrac site. The participants reported that the visual and verbal connection deepened their experiences with the group.

8.6. Roles on MyTrac

The participants in this study evolved self-determined roles on the MyTrac site. These included educating others about cancer (although this was tempered with caution about being careful about what was said), providing support when individuals were struggling with their illness, etc. Only one participant felt that the MyTrac community did not have enough expertise to be helpful, this participant was our oldest member who was living with a very rare form of cancer.

This research raises the possibility of a need for a moderator for the site, as is common in other sites (see for example, <http://www.realitycheck.org.au/> a site for people with Type 1 diabetics in Australia.). While the research staff ‘followed’ the participants using the Twitter application, and checked the site daily, the instantaneous nature of twitter allowed individual participants to send text messages to the site without serious forethought about what they were saying. In one instance this became problematic when one individual posted a series of text messages which were seen as being ‘negative’ by the group. It was apparent from this interaction that participants may find it difficult to be supportive of others who are experiencing a particularly difficult time, when they too are feeling unwell, having treatment or feeling low. In this instance, the psychologist attached to the project spoke to all the participants in turn to ensure that they were coping with the situation. This indicates that sites such as MyTrac which provide a social outlet for difficult and emotional issues, such as living with cancer, have to carefully consider whether a moderator should monitor and possibly take action on the site. Furthermore, access to a psychologist for distressed participants should be a major consideration. This is despite the fact that participants may prefer autonomy in their transactions online.

9. Design considerations

This research suggests a number of design considerations for the social networking sites for AYAs with cancer.

9.1. Shared Histories

Sites for AYAs should allow participants, where appropriate, 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.

9.2. 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.

9.3. 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 should be taken if a participant dies during the life of the site. How is their digital information managed ethically and sensitively? Is the information left untouched or is there an acknowledgement of the passing on the site? How are other participants, who have connected with the deceased participant, best supported? While this event did not take place during the course of this study, these issues demand careful consideration from a practical and ethical standpoint.

9.4. 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 (e.g. MSN). For small groups this may lead to unexpected and unexplained interactions on the site.

10. Publications and Presentations arising from the project

10.1. Papers

Davis, H., Vetere, F., Ashkanasy, S., Dyson, G. Schofield, P., Thompson, K. Withers, G. and Thomas, D. (2008) Towards Social Connection For Young People with Cancer, *OZCHI 2008 20th Australasian Conference on Computer-Human Interaction, Cairns, Australia (8-12 Dec)*, 319-322

Ashkanasy, S., Vetere, F., Shanks, G. and Davis, H. (submitted) Finding the other 5%: Understanding the role of social networking technology in building personal communities for young adults with cancer *ECSCW 2009 European Conference on Computer Supported Cooperative Work*

Schofield, P. and Vetere, F. (submitted) Overcoming the tyranny of physical and psychological distance: Use of Information Communication Technology to address the needs of adolescents and young adults with cancer. *Nature and Clinical Oncology*

10.2. Presentations

Ashkanasy, S. (11 August 2008) Support at First Byte? Addressing Conflicts in Online Peer Support for Young adults with Cancer, *Affect and the Human/Machine Interface Symposium*, Melbourne, Australia

Davis, H. and Vetere, F. (9 Oct 2008) Towards Social Connection for Young People with Cancer, *University of Melbourne Biomedical Multimedia Unit Seminar*

Davis, H. (31 Oct 2008) Towards Social Connection for Young People with Cancer, *University of Melbourne Interaction Design Group Seminar*

Dyson, G. (6 Nov 2008) "Learning to dance in the rain" using emerging technologies to combat social isolation in young adults living with cancer, *Adolescent Health 2008, 7th Annual Australian and New Zealand Adolescent Health Conference*, Melbourne

Ashkanasy, S. (7 Nov 2008) Support at first byte? Addressing conflict in online peer support for young adults with cancer, *Adolescent Health 2008, 7th Annual Australian and New Zealand Adolescent Health Conference*, Melbourne

Davis, H. (5 Dec 2008) Individual Representations of Self on MyTrac, *HCSNet (ARC Network in Human Communication Science) Summerfest 2008*, Sydney

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APPENDIX ONE

Scenario 1: JANE

Background: 1st year University of Melbourne student, oldest of 3 siblings

Location: Resides in Melbourne

Diagnosis: Acute Myeloid Leukaemia

Actor: Jane (19 years) lives in Coburg with her mother and two younger sisters. Her father, with whom she has a distant relationship, lives in Sydney with his new partner. Jane finished high school last year and had started the first year of a physiotherapy degree at the University of Melbourne. Jane's hobbies include socialising with friends, reading and playing tennis.

In March, Jane began to feel tired and listless and she was experiencing accumulating nausea and vomiting, Jane was taken to her local GP by her mother, where an urgent admission was arranged to the local hospital. Blood tests and scans were undertaken. Jane was diagnosed with AML - Acute Myeloid Leukaemia.

Chemotherapy treatment commenced immediately. Unfortunately because of the aggressive nature of the disease Jane was unable to discuss fertility options or look at long term options to preserve her reproductive organs. She was informed by her Haematologist that treatment would be intensive and that she would be unable to continue her studies for at least six months. Following this, a period of monitoring would occur and if the disease returned, she would have to consider further treatment and a Bone Marrow Transplant.

Jane became increasingly withdrawn as she missed her friends and university colleagues. Jane's mother and sisters and a close friend visit her in hospital twice weekly. Jane also has in-house support from a psychologist, social worker and others. However, Jane does not want her father and other friends to learn that she is unwell, unless she believes it is absolutely necessary. Jane is adamant that she will be well. However she is particularly upset about the side effects of chemotherapy, such as losing her hair and the possibility of infertility. Jane would like to have children in the future.

Jane spends much of her time at Peter Mac in a private room. She reads magazines and watches TV. She has a mobile phone which has a prepaid plan, paid for by her mother, which she used for texting. Jane would like to keep in touch with her ex-school friends, (some of whom are travelling overseas, some of whom are working, and some of whom have travelled interstate) without necessarily disclosing that she is unwell. She would also like to connect with other young people her age who are living with a similar disease, in order to learn more about their experiences living with cancer.

Technology Background: Comfortable with computers, Jane has basic computer skills and, when at home or at University she uses email and Facebook to keep in touch. Jane does not own her own computer, and would usually use her mobile phone to make arrangements to meet up with friends. Jane has been receiving occasional texts from university classmates but cannot bring herself to reply to them at this time.

Problem Scenario (Analysing Requirements): Jane would like some means of keeping in touch with her family and friends while in hospital, and recuperating at home. Jane requires technological support which allow her to disclose her illness to some people (e.g. mother, siblings, close friends) while keeping it private from others. Given that the treatment for Leukaemia usually results in hair loss; it would be helpful if Jane could have options for disguising her appearance (e.g. the use of avatars, the use of non-visual communication etc) and her location (at Peter Mac).

In addition, Jane would benefit from ICT which allows her to connect with other young people living with Leukaemia, particularly when she is based at Peter Mac.

APPENDIX TWO:

Scenario 2: JAMES

Background: Apprentice, middle child of 3 siblings

Diagnosis: Osteosarcoma, cancer of the bone.

Location: Wangaratta

Actor: James (18 years) lives in Wangaratta with his parents and siblings, older brother Luke and younger sister Hannah. He has a good relationship with his family and is particularly close to his brother. James finished Yr 10 at school, but didn't complete Yr 11 & 12 as he was diagnosed with an osteosarcoma, cancer of the bone. He underwent intensive chemotherapy and surgery in Melbourne, including amputation of his right leg to the knee. James prefers not to wear prosthesis. Treatment occurred over a nine month period. During that time he had limited visitors as his friends and family are all located in Wangaratta (270 km north of Melbourne) where his parents manage a farm. Following rehabilitation, he was able to return home.

Since returning home, James found an apprenticeship with a local electrical firm. He was in a relationship with Kelly his girlfriend and was saving to move out of home. One morning after a night out with his mates at the pub, James awoke with pain in his leg. He thought that perhaps he'd had too much to drink the night before and knocked it. Popping some pain killers, the pain disappeared within a couple of hours.

The next week he returned to the oncologist for his routine follow up. He was informed that the recent scans showed his disease had returned, not only to his upper leg, but it had also spread to his chest. After discussions with his doctor and treatment team, James and his parents were informed, that the disease could no longer be cured and that treatment would be limited to work which would prolong his life, and give him quality of life. James is not expected to live more than a year.

Technology Background: James is familiar with computers, although he has not had formal training in using them. James parents have a computer at home and they recently brought him a laptop to keep him occupied when he is unwell. He currently uses his laptop to play computer games, download music and send occasional emails. James uses a mobile phone to keep in touch with his family, friends, and girlfriend. When he is hospital his mobile phone and laptop become costly.

Problem Scenario (Analysing Requirements): James has limited mobility because of his amputation. James would like some means of keeping in touch with his family (in particular his brother), friends and girlfriend while in hospital. When he is at home, James would like some means to keep in touch with his physicians and social worker. Currently he speaks to them on the telephone approximately once a fortnight. He would also like to connect with other young people living with cancer of the bone. James is anxious about the future but determined that his last few months will be spent doing the kinds of things he enjoys most.