

# Finding the other 5%: Understanding the role of social networking technologies in building personal networks for young adults with cancer

Shawn Ashkanasy<sup>1</sup>, Frank Vetere<sup>2</sup>, Hillary Davis<sup>3</sup>, Graeme Shanks<sup>4</sup>

<sup>1,2,3,4</sup>University of Melbourne, Parkville, Australia

<sup>1</sup>shawna@unimelb.edu.au <sup>2</sup>f.vetere@unimelb.edu.au, <sup>3</sup>davish@unimelb.edu.au

<sup>4</sup>gshanks@unimelb.edu.au

**Abstract:** In this paper we explore the ways in which young adults with cancer (aged 17-24) build support networks through computer mediated personal networks. The support networks are influenced by technological affordances and the ongoing experiences of living with the illness and treatment regimes. We report a single, in-depth case study of one young adult with cancer and her use of mobile telephony and web based social networking sites in building support networks. Three important themes emerge from this case. First, in this context computer mediated communications (CMC) are not exclusive to the maintenance of online relationships, but mediate networks of “core”, “significant,” and new ties (primarily online) over time. Second, the social engagement between the subject and members of their social networks is dynamic with different modes of communication predominant at different points in time and different relationships significant at different points in time depending on state of illness, treatment and context. Finally, the interplay between CMC and different ties influence the characteristics of the networks, which is characterized by bridging and segmenting networks.

## Introduction

Current literature suggests that people are utilizing communication tools such as the internet to find specialized information and support with people whom they share similar experiences and stories of illness (Burrows *et al.*, 2000; Hardey,

2002). Against this background, we find that young adults with serious or chronic illnesses are going online to find information as well accessing existing and new social relationships through online tools (chatrooms, blogs, forums, social network sites such as Facebook and Myspace). Evidence shows, these technologies are potentially connecting young adults to both existing networks of relationships as well those based on specialised interests or experiences. In a study of online self-help groups for breast cancer, Høybye *et al* (2005, p.216) found that sharing personal accounts of illness (stories) led to transformation and empowerment by offering a mode of action – “Internet based support offer a space for recognition, a social level for sharing knowledge and experience and an individual level for finding ways to live with breast cancer.” Again, Bowker (2008) highlighted in a study of people with disability that the lack of visual and social cues allowed them to meet strangers and converse based on common interests rather than physical, mental or social signifiers. However, the study of people with either a serious or chronic illness has primarily focused on online groups (e.g. [www.grouploop.org](http://www.grouploop.org) an online support community for young adults and adolescents living with cancer) who share goals and interests, and promote active participation (Preece & Maloney-Krichmar, 2003).

On the other hand, authors such as Boase *et al* (2006) argue that the use of communication technologies by these users varies according to the changing situation of their condition and health needs although, they are interacting with a circle of core and significant ties that predate their diagnosis and subsequent illness. The author’s define core ties as people with whom the individual has frequent contact, emotional intimacy and availability of network capital. Wellman (2001, p.233) refers to network capital as the availability of resources through ones interpersonal ties that are “widely available, usually specialised, and unevenly distributed among people, ties, and networks.” Significant ties on the other hand, refer to people outside the individual’s core ties. They usually have less frequent contact and are not as closely affiliated and, whilst they are not strangers, their interpersonal importance can fluctuate over time as people access these networks to get help or advice. On a day-to-day basis, the individual may have contact with a variety of core and significant ties through different social networks both face-to-face and computer-mediated.

As such, how people in this situation use communication technologies to access support through different networks and social ties is articulated through their personal networks. *Personal networks* can be described as networks of ties derived from a sample of individuals that enumerates the local social networks (Marsden, 1990), kinds of relationships they contain, and the kinds of resources that flow though different kinds of networks (Wellman, 2007) that shape individual and group action. However, through our research, we also observed that the communication medium itself constrained and influenced the action and social relations between the people and their personal networks (Rice, 1994).

The following paper inquires into the relationship between the communication medium and the support needs of the individual and how this influences the individual's personal support network (which is a subset of their overall network). This is explored through empirical evidence from a recently completed study of a group of young adults being treated for a range of cancers and at different stages of treatment. In particular, we focus on the life of one of the participants, Bianca, and her use of computer mediated communication (CMC) in accessing support and information. Firstly, we explore her cancer experience and how it affected her support and informational needs. We elaborate upon the circumstances of her illness and how it shaped to some degree her communication with different members of her network. Secondly, we discuss the interdependency between different social ties and communication through CMC. We develop this further by providing different examples of her support needs and how this influenced the way she communicated and to whom, including her use of technology and how this also influenced her personal network. Finally, in the discussion, we draw out the relationship between the communication medium and the support needs of the individual through Wellman's theory of *networked individualism* (Wellman, 2001). By placing this socio-technical relationship within a social network discourse, we argue that Wellman's theory provides new insight into the factors that shape the use of collaborative technologies and, in particular social support through social networking technologies.

We begin by elaborating upon current theoretical work in CSCW that addresses personal networks and collaboration. This is followed by the research design and the case study. Subsequently the case is analysed using networked individualism, including implications for the study of personal support networks and CSCW.

## CSCW and personal networks

The use of personal networks in CSCW in both workplace studies, as well as those that address social support are scant. Nardi *et al* (2000) provides, perhaps, the best example of a workplace study that uses personal networks. They found that individuals within the workplace managed their own personal networks of work contacts with whom they collaborate with over short or long periods of time. These "intentional networks" as the author suggest, are not well understood through existing explanatory models of workplace collaboration – "our study documents the wider, less predicable, set of social relationships in which workers are implicated" (Nardi *et al.*, 2000). They argue the structure of intentional networks is not likely to be based on common experience, unlike existing notions of community. Rather, they are oriented around the individual and not necessarily based on an ongoing commitment; they are widely distributed rather than based on a fixed location; they are more flexible, yet organized in deliberate

ways by the individual; they are affected by temporal patterning, whereby the network can transform over time.

As such, intentional networks link the individual's immediate work community with a much more distributed and temporal one. The two social worlds exist simultaneously, while affording different social opportunities and access to resources. At any point in time, the individual may be engaged in any number of social networks with specific properties, members, types of support and forms of communication. Furthermore, the networks are not mutually exclusive insofar as they may share members, whereby the communication medium itself may connect more than one network, while other communications mediums may exclude or segment the network.

Conversely, the tendency in CSCW has been to investigate local groups of potentially knowable members from either an organizational setting or local geographically situated communities of citizens. An early example can be seen in the work of Mynatt *et al* (1998) who studied three multi-user domains or MUDS, which connected members of a relatively small network of local ties within an organizational setting. They argued that certain communication media were more apt to provide users with a sense of virtual place than others by virtue of their persistent, flexible and multi-user environments. These "networked communities" (Mynatt *et al.*, 1998, p.123) are limited at least in theory to understanding community as local forms of social groups that are bounded, small and characterized by dense social relationships. Similarly, more recent examples of work in CSCW that address community building, participation, and information sharing can be seen in Kavanaugh *et al* (2007) and Munkvold and Ellingsen (2007) respectively. Whilst both these authors address the interplay between technology and interpersonal relationships, the emphasis on group level interaction neglects the broader social and technological setting in which these relationships are embedded. This is less a criticism and more an acknowledgment of the limitations of this approach to understanding the dynamic structure of personal networks and how people use them to socialise and find support.

## Research Method

The following account uses an interpretivist approach to draw out themes and outcomes from a case study of one participant's interviews and field observations. The unique characteristic of young adults with cancer (YAWC) makes studying this group often difficult in the sense that their lives are to an extent unpredictable and volatile. There is strong evidence that cancer amongst young adults ranging between 18-24 years of age is one of the most complicated conditions. This is due to a combination of rare and invidious cancers that affect young adults as well as many psychosocial aspects associated with this stage of life (Bleyer, 2002). These psychosocial concerns are social and sexual development, identity and self image,

work and education, goal achievement, peer pressure, intimacy, fertility and reproduction, and the need for independence and autonomy (Bleyer & Barr, 2006; Bleyer, 2002; Ettinger & Heiney, 1993; Thomas *et al.*, 2006, Woodgate, 1998). Hence, it is generally acknowledged by oncologists and psychologists working with this group that the psychosocial aspects of cancer are not only unique amongst the age group, but they are also broader in their scope than in the rest of the population (Bleyer, 2002). This would also account for the relatively limited number of studies that address their communication needs and practices. As such, we argue that a single case study of this nature fulfils Yin's (2002, p.40) rationale as "revelatory," whereby the situation under investigation has been previously inaccessible to systematic observation (Yin, 2002) and the description of information alone is revelatory.

The findings examined in this paper are the result of empirical data collected from a recently completed study of YAWC. This paper refers to a single in-depth case of one patient, which is part of a larger body of research. The unit of analysis for the study is one particular journey through diagnosis and relapse over a two-year period. The data presented in this paper was collected over a three-month period and were taken from three sources. Firstly, three semi-structured interviews were conducted starting in early June 2008; sections of these will be presented in the following. Secondly, observations were made from a purpose-built web-based self-help site for YAWC, called *MyTrac*. Observations from the participant's use of the site were taken both during and after the completion of the study, which also provided reference points for the interviews. Thirdly, electronic logs were generated from messages sent through *Twitter*, which is a mobile phone to web-based micro-blogging service. Twitter allows the user to provide status updates from their phone or computer to their own Twitter page as well as other users who are 'following' them. The system distributes these messages to a potentially infinite network of connected followers.<sup>1</sup>

In the context of this paper we distinguish between the roles of *MyTrac* in relation to other more 'familiar' modes of web-based social communication, such as social networking sites like Facebook and Myspace. Given that we distinguish our research aims from studies that focus on POC and online communities, we also apply this distinction to the participant's use of *MyTrac* in relation to, for example, Facebook (i.e. the former being an example of a POC). As is borne out in the data the participant's use of *MyTrac* is clearly different to her use of Facebook and, similarly, her use of Twitter in relation to her other mobile communication practices. As such, much of the data presented focuses on her use of Facebook and other tools such as Instant messenger (IM), which she used actively before and during the study. References to *MyTrac* and Twitter provide supplementary evidence of her personal networking across groups and mediums.

---

<sup>1</sup> Twitter has since ceased providing the update to mobile phone service outside America, India and England.

## Data collection and analysis

A qualitative approach was used in order to understand the particular context and setting in which CMC are used. We selected to focus on Bianca because she was the most “appropriate participant” (i.e. those who can best inform the study). In other words, qualitative inquiry points to depth rather than breadth: “In qualitative research we are not interested in an “on average” view of a patient population. We want to gain an in depth understanding of the experience of particular individuals or groups” (Greenhalgh & Taylor, 1997, p.741). Themes presented in this paper are the result of an iterative process whereby larger more boarder themes were compared and contrasted to express patterns of Bianca’s communication between the participant and her personal network. In the discussion we draw upon networked individualism, which is used to both describe the participant’s personal network as well as account for the interplay between CMC and their communication behaviour.

## Case – Bianca and finding the other 5%

Bianca was 20 when she was diagnosed with Hodgkin’s Lymphoma in 2006 and relapsed at her six-month check up in 2007. Hodgkin’s Lymphoma as her Oncologist informed her is one of the most treatable cancers, with a 95% success rate. With another round of chemotherapy, Bianca’s treatment succeeded in removing almost all of the cancer except one near her heart. The stem cell transplant that followed also failed to remove the cancer. Running out of options they attacked the cancer with radiation, focusing on her mantle (lower rib cage to her chin). Unfortunately, the treatment did not work and in fact the cancer spread to her sternum, her lung bases and abdomen. She was, as she described in the interviews, part of the 5% of patients with Hodgkin’s Lymphoma that do not respond to treatment. At the start of the study Bianca was waiting for a bone marrow match for another transplant and she was on a waiting list for a clinical trial. To suppress the growth of the cancer she took high doses of steroids, but the drugs often caused nausea as well as lowering immune system. This meant that leaving home or for that matter physical interaction was fraught with risk of either vomiting or infection.

Cancer and indeed her support and informational needs changed when she relapsed. Bianca recalls:

[Int.1] If I see people... I know what it was like for me the first time around, I had my friends and family and that’s great, but speaking to people who have gone through it. It was fine the first time round because you keep getting told about these odds that 95% your cured, um, well, your in remission and then five years later your cured, but the chances of relapse are really small, so you go along deluded, I guess, in some way that you’re in that 95% category. And then to find out that you’ve relapsed and that you have relapsed so quickly and that it has come back so aggressively, um, is terrifying and then you’ve only got that 5% to work with. Where

are these 5% and then you get thinking and you try find these people and that sort of what spurred me on more afterwards, people knew that I had it, obviously I don't say hello I've got cancer but it's quite obvious in my page (Facebook page) if people read between the lines, like "how's your chemo going", well chemo's associated with cancer, um but yeah, that's what really made me look beyond, I guess to find people going through the same thing, because I guess it's definitely different the second time round.

The focus of Bianca's story is what happened after she relapsed, the changes that occurred to her network of supportive ties, where and what she communicated and how this was supported by CMC. Much of Bianca's support prior and post relapse was from family, family friends and close friends with whom she had regular contact. The marked differences that relapse brought was a gradual but sustained presence of online contacts that she had made through various cancer related groups:

[Int.2] When I was first diagnosed I was not using any of the networking; I wasn't on Myspace or any of that. I think it was part way through the first time that I joined Myspace through a friend and then when I was in the (name omitted) I joined Facebook and then they took over.

As Bianca suggests in this extract, Facebook was a considerable part of how she found and made connections with other cancer patients in different locations, both locally and globally. The affect, as such, largely contributed to her ability to cope with the uncertainty of relapse and the questions that arose out of that experience:

[Int.1] I think it has been a huge positive being able to connect to someone that has had it or has had it relapse because just knowing you're not alone.

These weak ties played an important role when stronger ties were unable to provide information. To reiterate Bianca's comment regarding finding other young adults with cancer when she relapsed:

[Int.1] I know what it was like for me the first time around, I had my friends and family and that's great, but speaking to people who have gone through it

As such, weak ties link people with different social characteristics and knowledge, who are more apt to provide new information (Wellman and Gulia, 1999). In this way, online social networking tools can provide opportunities for previously disconnected people to make direct contact:

[Int.1] How I got into Myspace and through Myspace I got into Facebook and I've met people who are actually in the same boat as me that have not responded to treatment with the same cancer and similar aging and you can compare with them, "what trials is he being offered"? "What trials are working"? What have you heard about?

However, through her use of this social networking site she has also integrated other friendships and associations into this digital domain. When we interviewed Bianca, she said that she had approximately 230 'friends' in Facebook and of those she maintained regular communication with around 50:

[Int.3] Like I said, some of them are from primary school and high school that, um, that you knew, but you were not heaps close with, um, so I don't mind if they read about it that's me, I can't change what I'm going through, um, but yeah, there are some people that I do

communicate with a lot more whether they are patients or closer friends, um, others are there and you do know them, but you don't communicate, so probably about 50, it's hard to gauge

Facebook in this context operated like a network exchange linking Bianca's relatively vast network of social ties within a singular digital place. However, in the sense that Bianca's 'friends' were linked by virtue of a common thread, i.e., Bianca, the network was not determined by its locality. Rather, Bianca's use of Facebook supports Wellman's contention that "each person operates a separate personal community, and switches rapidly among multiple sub-networks" (Wellman, 2003). In this way Facebook was conducive to her way of receiving support and information, as well as giving it:

[Int.3] I'm not part of a big group though, a lot of my friends are more individual contact; I never really did fit in with the whole group thing.

We also found that MyTrac was less a single community, and rather a collection of individuals who maintained their own networks of which MyTrac was apart. Bianca revealed that her interactions with the other MyTrac members was predominantly one-to-one and therefore more oriented towards her reaching out to communicate or being directly contacted herself:

[Int.2] MyTrac is more comments on people's pages, it's weird, I guess it's because we have nothing to hide. You already know it it's written on your page

In this way, MyTrac and Facebook afforded opportunities for both focused interaction between Bianca and her network of core and significant ties as well as "crosscutting" (Wellman, 2001, p.234) that linked and integrated her social milieus.

From this description of Bianca's communication practices, it is possible to see that different technologies played different social roles and that this was mediated by her support and informational needs. In addition, the motivation to use a specific communication medium was influenced by the type of support available through particular ties linked to specific modes of communication (Haythornthwaite, 2002). However, what is particularly interesting here is how different mediums influenced, on the one hand, the kinds of ties prevalent, and on the other hand, the kinds of support she received. To best illustrate this we identified two key aspects of her communication practices, namely *bridging* and *segmenting*. Whilst bridging was clearly evident in the notion of "crosscutting" networks, segmenting emerged from further data analysis and more clearly characterized the way different communication technologies demarcated specific relational ties.

## Bridging networks

Insofar as Boase and Wellman (2006) argue that crosscutting ties links and integrates social groups, increases societal connectivity, we can see that Bianca's use of Facebook facilitated people coming together, albeit it was oriented by specific temporal events. As such, Bianca's communication through Facebook

fostered the folding in of this online network into broader communities, what we have called bridging. The following example of bridging took place when Bianca received results from a scan that her cancer had gone into remission (although remission is only properly applied after two years of no symptoms). Although what makes this particular instance unusual was the timing of her disclosure, as Bianca chose to inform the MyTrac community first via Twitter on her mobile phone, in which case the members of MyTrac replied virtually instantaneously, from multiple locations:

Bianca: Just arrived at the (name omitted) 4 my appt wit the Prof.. I've got an upset tummy, nerves. Hope news isn't 2 bad.

Fiona: Good luck Bianca!! Im waiting around at RMH for a Doc and a bed. Still not sure what's going on.

Thomas: Good luck 2 the both of u, I've gone thru 8 years of operations n pain every year, just think positive n u will get thru it. I will say a little prayer 4 u

Bianca: Really skeptical. The last scan came back all clear. WHAT! All I've had is 1 lot of steroids. This cancer is messing wit me. Another scan next wk

Bianca: all questioning it, Prof incl.. it's odd

Thomas: Take out the champagne n celebrate!! That's good news that the scan is clear isn't it?

Bianca: Test result odd. Having further tests next week. Nothing definite.

Thomas: Well I hope the further tests show up clear 2 then =). Good night n sweet dreams all.

Bianca suggested in the interview that she needed to “send something” and the members of MyTrac were new contacts that had an understanding of what she was going through and furthermore it was a smaller network and therefore easier to manage peoples expectations:

[Int.2] I didn't tell everyone straight away because I didn't want to get hopes up and I didn't know what was happening, but I wanted to send something and then I thought, I'll send to Twitter, but then it cut out part of my message, so then I had to rephrase it because everyone thought I was in remission. "No I'm not!" So I had to resend it, but it was good and it was good to have that feedback, I wasn't expecting it

She then reflected on the response, and reconstituted the information for a different, wider community on Facebook through her ‘status bar’:

[Int.3] I did tell people and I have had it on Facebook that it's all clear at the moment, AT THE MOMENT! So people do know that the last one was clear, but I just didn't go through my whole phone like I used to. Like say, if I got a good result, I'd go send to that person and that person that person... and I'd just go through the majority, but because there were still so many questions and it's only one scan and I'm getting scanned again next month...

However, the affect of this was quite different, Bianca notes that her friends on Facebook understood the significance of her good news differently:

[Int. 3] Yeah, like some did (understand it), but they got excited because at least finally it was some good news for me, I think that was the other reason, they were just really glad that finally something has gone my way because so much has gone against me. To have something positive happen for once (was good)

In this case, the audience was not only much larger than on MyTrac, but she did not differentiate between network members, and as she later stated – [Int.3] *If*

*they don't want to read it, don't go on my page.* The medium, in this instance reduced the boundaries between networks and linked network members through their common interest in Bianca's wellbeing. This also supports Granovetter's (1973, p. 1376) claim that "the more local bridges in a community and the greater their degree [of density], the more cohesive the community and the more capable of acting in concert", although in this case the medium was a significant player in enabling her community to act in concert.

## Segmenting Networks

In the sense that Bianca used Facebook to momentarily bridge her networks, we also found that the communication medium as well as other temporal factors segmented them, whereby demarcating the strength of relational ties. This was evident from our interviews where illness and treatment played an important role in determining the mode of communication as well as people with whom she communicated. She remarked that while she was in hospital for chemotherapy and radiation she was often too sick to use her computer to stay in touch with people:

[Int.3] It's whether you've got the energy to and sometimes you are just sitting there and I just want to go to sleep or I just can't be bothered doing this, or you just don't have the heart for this. It's not so much bringing it all back, you don't have the energy, it's almost like it's too hard and you say it can wait, it will be there when I check it next, so you don't go on. When I was in the (name omitted) I didn't check my internet unless I was really bored and I felt alright, because if you're being sick and your tired, or you've got visitors or something it's really not ideal.

In this instance, not only did less significant ties recede to the background, but the mode of communication was also minimized and therefore the type of people she communicated with. In this case the medium not only reflected the relational bond between Bianca and her communication partners, but also momentarily reduced the size of her network. This was revealed in two separate conversations with Bianca. The first concerned her father and the importance of using her mobile phone to bridge the gap between times of absence:

[Int.1] When I was in for the stem cells [...] Our (referring to her father) form of communication would be on the phone, we'd speak everyday, but it's still not the same because he's not there and as much as he'd want to be there for you he can't because he's got to work

In contrast to the need to sustain contact with her father, her commitment to less intimate ties, such as other patients she met online, became momentarily less important:

[Int.1] I used to email updates to people but I sort of just... people were relying on that and they were just waiting for an email and they would contact me and I thought, "it's so impersonal" and then I gave up on that and with all the radiation (it became too difficult)

What this suggests is that the communication medium can play an important role in not only affirming the significance of a particular tie, but also the medium

can segregate networks and enforce the strength of relational ties and the members' place in the network. This was also evidenced where Bianca used more than one communication modality to support communication with core and more significant ties. On a daily basis, Bianca used a combination of mobile phone and instant messaging software (i.e. MSN) to communicate with particular network members. In the follow extract Bianca talks about how she communicates across channels to her best friend and the role these mediums played:

[Int.3] Um, say I talk to someone though text or I see them in person or whatever. I went and saw (name omitted) yesterday and she sort of said I will be online later, so if you are online we will chat, so sometimes you will continue conversations, or if you left a comment on someone's page and then they logged onto MSN and then you would start following on from that, um, it's just a way of communicating. After having it for so long, you don't even think about it, you're in that generation that you've grown up with it, like I've had MSN since year 8, so you've got a fair few contacts on that

However, moving between mediums was not simply about physical or temporal constraints, but a mixture of finding the right medium to support the emotional and informational content of the relationship. For example, of the young adults with cancer she had met online she established three significant relationships with women who have also not responded to treatment. The most intimate of these lives in the UK and they maintain regular communication through phone messaging, MSN and Facebook. Also, through the study and her use of MyTrac, Bianca became close with one of the other participants, Louise, who also had Hodgkin's Lymphoma, but had not relapsed. Bianca's interaction with Louise during the study was initially through MyTrac, but as their friendship became more intimate they communicated through MSN and SMS as well some interaction through Facebook:

[Int.3] I guess initial common ground was Hodgkin's lymphoma, same thing, and then we added each other to MSN. Sometimes we don't even talk a whole lot, or sometimes we talk about everyday things or stupid things that have happen or if we're watching TV while we are talking to each other, we'll talk about that, there are different wink things you can do that are quite amusing to just annoy the crap out of each other. Sending them and always "ding ding", and then all of a sudden it comes up and all of these people are hammering (referring to the emoticon) and doing these things on the screen. I don't know, it's just amusing, but we get along really well. Like if she is online we pretty much speak, um, I guess most days if not every couple of days

Insofar as the medium needs to support the informational and supportive content of the relationship, the content itself needs to reflect the multiplicity of the relationship. This was also embedded in the type of medium used to communicate, but also how she demarcated someone's relational significance:

[Int.3] I take it as it comes, if someone is interested, whether it's online or...It is a lot more personal when you speak to someone in person or on the phone, but there are some people where your form of communication with them is online that's the basis... I guess that's why

they're not I guess your close friends because that's the only form of communication you have is the online stuff

This was again reinforced when we asked Bianca about another member of MyTrac. What was interesting about Bianca response was that she suggested there was equivalence between the nature of her relationship with this young person and the mode of communication:

[Int.3] But yeah, I sort of spoke to him, but again it's just someone to speak to in that sense it's not, um, it hasn't gone any further like with MSN or any other networks as a form of communication.

Bianca's use of one-to-one (email, mobile phone, MSN), one-to-many (Twitter), and many-to-many (Facebook, MyTrac<sup>2</sup>) forms of communication enabled her to build and maintain her personal network that was not only distributed over and between physical and virtual space, but was amenable to the many temporal and physical constraints of her illness. Furthermore, the medium was an important agent in changing the characteristics of her personal support network as well as reinforcing specific relational ties.

## Discussion

From this case study of Bianca's personal support network, we derived three key findings that describe the socio-technical relationship between communication technology, support and informational needs, and specific social ties:

- i) In this context computer mediated communications are not exclusive to the maintenance of online relationships, but mediate networks of "core", "significant," and new ties (primarily online) over time.
- ii) The social engagement between the subject and members of their social networks is dynamic with different modes of communication predominant at different points in time and different relationships significant at different points in time depending on state of illness, treatment and context.
- iii) The interplay between CMC and different ties influence the characteristics of the network, which is characterized by bridging and segmenting networks.

In the following, we analyse these findings using networked individualism (Wellman, 2001).

---

<sup>2</sup> Both MyTrac and Facebook encompass individual and group communication modalities. Our categorization schema is based on Bianca and may change for other users.

## Networked individualism and personal networks

With the increased mobility of both people and culture brought about by the proliferation of new technology driven communication– mobile phones, internet – people have access not only to diverse forms of information, but also new relationships and opportunities for sociability and support that they might not otherwise find in their local support networks of core friends and family members. Authors such as Wellman (1999, 2001) and Castells (2001) have argued that society and people more generally have moved away from centralized and geographically located communities towards “social networks organized by shared interests rather than by shared locality” (Wellman, 1996, p.5). Networked individualism (Wellman, 2001, p.248) suggests that each person maintains their own “personal community” of multiple, thinly-connected, and partial communities, which they can switch between kin, neighbours, friends colleagues and other specialized relationships (Wellman, 2001, 2003). This social arrangement provides the basis through which individuals seek and maintain relationships that afford amongst other things support, information, social identity and belonging (Wellman and Gulia, 2001; Wellman, 2003). Rather than fitting into the same group as those around them, people potentially accesses a vast social network that spans and intersects local and global localities, mediated and face-to-face. Boase and Wellman (2006, p.720) have stated the core characteristics of networked individualism as:

- i) Relationships are both local and long distance.
- ii) Personal networks are sparsely knit but include densely knit groups.
- iii) Relationships are more easily formed and abandoned.

Firstly, the data presented provided evidence that Bianca’s personal support network is not limited to any single group or setting. Rather her relationships spill over into multiple, partial communities that comprise, as Boase and Wellman suggest, *both local and long distance relationships*. Furthermore, these were supported through a suite of communication mediums that afforded different types of relationships and interactions. For example, those relationships with a high social / emotional commitment were often supported through the use of multiple technologies, than is indicated by just using email for example (Davis, Vetere & Ashkanasy, 2008). This, as Wellman argues, refocus attention from fixed groups to “active networking” in order to find support, sociability and identity (Wellman, 2001, p.234).

Secondly, Bianca’s use of one-to-one, one-to-many, and many-to-many modes of communication changed in response to external factors linked to illness and treatment, as well as internal social dynamics between herself and her relational ties. As such, her communication practices support Boase and Wellman’s assertion that people communicate between *many sparsely knit networks and densely bound groups*. However, it is important to recognize that the medium

itself delimits the potential range of the audience as well as demarcating roles, drawing different relationships to the foreground, while necessarily allowing for others to fall to the background. Licoppe and Smoreda (2005, p.317) argue that different communication tools “provide new resources to negotiate individual timetables and social exchanges, making it possible to adjust roles, hierarchies and forms of power in relational economies.” Although we would add the division of roles and relational ties was more clearly evidenced, where the technical constraints reinforced tight boundaries and individual / group sentiments (Wellman, 1996), for example where the audience was smaller and either one-to-one or one-to-many.

Thirdly, whilst we agree with Boase and Wellman *that relationships are more easily formed and abandoned* online than face-to-face, we feel that is was subtler than what they suggest. It was unusual for Bianca to entirely sever a tie, rather weaker ties, or those that provided specific types of information or support, fluctuated in their presence. We feel that the notion of bridging and segmenting describes the rhythms of her relationships, whereby the interplay between events, timing, and her support and informational needs mediated the significance of different relationships; although she was communicating regularly with her more core ties (i.e. her parents and close friends). Furthermore, the immediacy of the communication technology to both send and receive responses was an important agent in this process. For example, the asynchronous nature of her messages on Facebook gave her control over the timing of her disclosures and the audience to whom she communicated. This also allowed non-active members to respond, which has the potential to change their relational significance to the individual and others in the network. Wellman has discussed this in terms of a general reciprocity, whereby comments made in a publicly accessible domain is potentially seen by the entire group and moves to solidify group sentiment and foster positive reward of its members (Wellman & Gulia, 1999, p.176). Also the nature of the disclosure, whether it is to a single person or the group can connect previously disconnected people through their mutual interest in the individual, turning an “indirect tie into a direct tie” (Wellman, 1996, p.6).

This movement between different types of ties and support has also been explored in the work of Foth and Hearn (2007), who studied the communication and social interaction between residents of three inner-city student apartments in Australia. They proposed the concept of “communicative ecologies” (Foth and Hearn, 2007, p.751) to capture the interplay between online and offline, global and local as well as collective and networked social communication. Their study found that communication between residents of these apartments moved between small groups and networks depending upon purpose and context. Foth and Hearn’s (2007, p. 768) concluded on the one hand that “individuals in networks give rise to emergent collective behavior” and on the other hand that peer-to-peer communication encapsulated this idea more so than the use of public forums. The

latter findings supports our argument that one-to-one or one-to-many modes of communication more clearly reinforced tight boundaries and individual / group sentiments. This is significant because it raises questions about the use of, for example, forums in online peer support sites that attempt to encourage group collaboration/sharing. Insofar as different mediums enable different levels of social interaction, they also signify different levels of sociability. Depending upon the context in which they are used, their use, either by an individual or a group can demarcate social and relational boundaries. As such, the relational significance of communication technologies is an important aspect of collaborative communication.

## Limitations

This paper is limited by the reliance upon one case study; as such the findings are idiosyncratic and highly dependent upon the experience and interpretations of one person, as well those of the researchers. Other social factors such as gender, socio-economic background have also been neglected, however they require further analysis; a fertile ground for future papers, or indeed studies.

## Conclusion

Networked individualism provides a valuable tool to unpack personal networks and the independency between people, technology and relationships albeit it also depends upon the socio-relational context in which they function. Bianca's story provides clear evidence that the internet not only supported interaction with online groups, but incorporated an array of people from all aspects of her life; from core intimate ties which she regularly interacted with physically and virtually, to a larger set of significant ties that fluctuated in their presence in her life, to many more weaker ties that she has met through online groups as well as on Facebook. While the study of group social dynamics and behaviors are an important area of research, personal networks and networked individualism attempt to explore the factors that constrain and influence individuals and the various ways they access resources (both social and material) through different social ties. As such, this tension between the actions of individuals and the characteristics of the networks, including the communication mediums that support them, is an important aspect of personal networks that influences the way support is understood in this context.

Finally, the study of personal networks in CSCW and in particular the use of CMC by people living with illness and how they access support and information must consider a number of factors. On the one hand, it is important to consider the temporal aspects of illness and how they influence the support and information needs of the individual, while on the other hand, the motivation to

use a specific communication medium is also influenced by the type of support available through particular ties linked to specific modes of communication. Furthermore, researchers should bear in mind the way communication technologies demarcate relational ties within personal networks, whereby influencing the type of ties available and support prevalent over time.

## Acknowledgments

We would like to thank all of the participants of the study for their generosity of time and in particular, Bianca, for showing us the capacity of the human spirit to survive despite all adversity. We would also like to acknowledge our funding partner, Cancer Australia, and research partners David Thomas, Penny Schofield, Kate Thompson, Gavin Dyson, and Giselle Withers, as well as Telstra, for providing equipment and technical support; without which the study would not have been possible.

## References

- Boase, J., Horrigan, B. J., Wellman, B. & Rainie, L. (2006) *Pew Report: The Strength of Internet Ties*. Washington, Pew Internet and American Life Project.
- Boase, J. & Wellman, B. (2006) Personal Relationships: On and Off the Internet. In Perlman, D. & Vangelisti, L. A. (Eds.) *Handbook of Personal Relations*. Cambridge, Cambridge University Press.
- Bleyer, W. A. (2002) Cancer in older adolescents and young adults: Epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Medical and Pediatric Oncology*, 38, 1-10.
- Bleyer, A. & Barr, R. D. (2006) Highlights and Challenges. IN Bleyer, A., M, O. L., Barr, R. D. & Ries, L. (Eds.) *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. Bethesda, MD, National Cancer Institute.
- Bowker, N. (2008) Participating in the World (Wide Web): Social Connections for People with Disabilities IN Holland, S. (Ed.) *Remote Relationships in a Small World*. New York, Peter Lang.
- Castells, M. (2001) *The Internet galaxy: reflections on the Internet, business, and society*, New York; Oxford, Oxford University Press.
- Davis, H., Vetere, F. & Ashkanasy, S. (2008) Towards Social Connection for Young People with Cancer. *Proceedings of the 19th Australasian conference on Computer-Human Interaction: Designing for Habitat & Habitus*. Cairns, Australia, ACM.
- Ettinger, R. S. & Heiney, S. P. (1993) Cancer in adolescents and young adults. Psychosocial concerns, coping strategies, and interventions. *Cancer*, 71, 3276-80.
- Foth, M. & Hearn, G. (2007) Networked Individualism of Urban Residents: Discovering the Communicative Ecology in Inner-City Apartment Buildings. *Information, Communication & Society*, 10, 749 - 772.
- Granovetter, M. S. (1973) The Strength of Weak Ties. *American Journal of Sociology*, 78, 1360.

- Greenhalgh, T. & Taylor, R. (1997) *Papers that go beyond numbers (qualitative research)*. *BMJ*, 315, 740-3.
- Haythornthwaite, C. (2002) Strong, Weak, and Latent Ties and the Impact of New Media. *The Information Society*, 18, 385-401.
- Høybye, M. T., Johansen, C. & Tjørnhøj-Thomsen, T. (2005) Online Interaction. Effects of Storytelling in an Internet Breast Cancer Support Group. *Psycho-Oncology*, 14, 211-220.
- Kavanaugh, A., Zin, T., Rosson, M., Carroll, J., Schmitz, J. & Kim, B. (2007) Local Groups Online: Political Learning and Participation. *Computer Supported Cooperative Work (CSCW)*, 16, 375-395.
- Licoppe, C. & Smoreda, Z. (2005) Are social networks technologically embedded?: How networks are changing today with changes in communication technology. *Social Networks*, 27, 317-335.
- Marsden, P. V. (1990) Network Data and Measurement. *Annual Review of Sociology*, 16, 435-463.
- Mynatt, E. D., O'day, V. L., Adler, A. & Ito, M. (1998) Network Communities: Something Old, Something New, Something Borrowed. *Computer Supported Cooperative Work (CSCW)*, 7, 123-156.
- Munkvold, G. & Ellingsen, G. (2007) Common Information Spaces Along the Illness Trajectories of Chronic Patients. *Ecscw 2007*.
- Nardi, B. A., Whittaker, S. & Schwarz, H. (2000) It's Not What You Know It's Who You Know. *First Monday [online]*.
- Preece, J. & Maloney-Krichmar, D. (2003) Online Communities: Focusing on Sociability and Usability IN Jacko, J. & Sears, A. A. (Eds.) *Handbook of Human-Computer Interaction*. Mahwah, NJ, Lawrence Erlbaum Associates Inc. Publishers.
- Rice, R. E. (1994) Network Analysis and Computer-Mediated Communication Systems in Wasserman, S. & Galaskiewicz, J. (Eds.) *Advances in social network analysis: research in the social and behavioral sciences* Thousand Oaks, California, Sage Publications.
- Thomas, D. M., Seymour, J. F., O'brien, T., Sawyer, S. M. & Ashley, D. M. (2006) Adolescent and young adult cancer: a revolution in evolution? *Internal Medicine Journal*, 36, 302-307.
- Walsham, G. (1995) Interpretive case studies in IS research: nature and method. *European Journal of Information Systems*, 4, 8.
- Wellman, B., Quan-Haase, A., Boase, J., Chen, W., Hampton, K., Isabel Isla, D. D. & Miyata, K. (2003) The Social Affordance of the Internet for Networked Individualism *Journal of Computer Mediated Communication*.
- Wellman, B. (2001) Physical Place and Cyberplace: The Rise of Personalized Networking. *International Journal of Urban and Regional Research*, 25, 227-252.
- Wellman, B. & Gulia, M. (1999) Virtual Community as Community: Net Surfers Don't Ride Alone. In Smith, A. M. & Kollock, P. (Eds.) *Communities in Cyberspace*. London, Routledge.
- Wellman, B. (1996) For a Social Network Analysis Of Computer Networks: A Sociological Perspective On Collaborative Work And Virtual Community. *Proceedings of the 1996 ACM SIGCPR/SIGMIS Conference on Computer Personnel Research*. Denver, Colorado, United States, ACM.
- Wellman, B. (2007) The Network Is Personal: Introduction to a Special Issue of Social Networks. *Social Networks*, 29, 349-356.
- Woodgate, R. L. (1998) Adolescents' perspectives of chronic illness: "It's hard". *Journal of Pediatric Nursing*, 13, 210-223.

Yin, R. K. (2002) *Case Study Research: Design and Methods*, Thousand Oaks, California, Sage Publications.