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The identity of the heart patient in the context of the gift economy: HeartNET and media framing

Lynsey Uridge
Edith Cowan University

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By

Lynsey Uridge
Masters Science (Information Science)
Grad. Dip. (Information Services)
B. Health Science (Health Promotion) Honours

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Abstract

This health communication research examines the identity levels of the heart patient on a therapeutic website HeartNET through an empirical investigation of site interactions as manifestations of a gift economy. The thesis also explores the media's representation of heart health in both television and print.

This research utilised a longitudinal qualitative ethnographic and netnographic approach involving twenty-six participants who completed two in-depth interviews. The first one-on-one interview occurred during the early stages of the participants' heart journey, explored their heart story and use of interactive technology for heart health support. The second interview occurred six to twelve months later, and investigated changes in the participants' heart health status and their media awareness. Data obtained through onsite postings, in-depth interviews, and asynchronous and synchronous interactions on HeartNET, resulted in an analysis of the rich insights into the lived experiences of people affected by heart disease.

The heart patient has to cope with an unknown and disrupted future which may be complicated by a lack of understanding by their significant other and extended network. Interactions on HeartNET indicated a change in participants' attitudes toward their heart disease. The gift of time, information and support were commodities that were shared freely. Over time however, a change in focus was evident. As members became more independent their posts would shift to a focus on independence and healing (or wellbeing) rather than focusing on the disease.

Another key finding among the non-HeartNET members was the importance of volunteering and how it became an integral aspect of many recovering heart patients' lives. As peer supporters this volunteering role appears to support the extension of social networks and complements professional health services.

Findings from this research have shown that the media often portrays heart disease as a lifestyle issue and the participants of this research felt the media considered they were 'to blame', even though the majority of them had a healthy, well-balanced lifestyle prior to their heart event. An analysis of newspaper articles indicates that the use of the Heart Foundation brand name, or a passing mention of

heart disease, was often used to raise the salience of the newspaper article, particularly in terms of its title.

This research provides valuable insights into the heart patient's journey as each individual recreates and re-identifies as a heart patient. Most importantly, this research allows participants' voices to be heard.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

(i)   incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;

(ii)   contain any material previously published or written by another person except where due reference is made in the text of this thesis; or

(iii)   contain any defamatory material.

Signed:

Date:

13|1|2015

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One cannot talk about HeartNET without acknowledging Leesa Costello and Gerry Atkinson. Both individuals have been an integral part of the Project. To Leesa, thank you for creating the site and then passing it on to me. I appreciate your help and encouragement and I am pleased to say HeartNET has continued to grow and develop, and is now a significant site for people worldwide who are seeking support to deal with their heart health. Gerry you were an amazing man, an actor, a gentleman and a heart patient who spent countless hours, counseling tirelessly people on HeartNET and through the Heart Foundation. To both Gerry and his wife Jill,

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HeartNET and its members have been part of my life for a long time now and everyone is an inspiration. If my PhD shares your stories with others then I have done what I set out to do and provided a voice to tell your amazing stories.

I dedicate my PhD to my Dad Bruce Uridge and to my older sister Toni Chambers. Rest in peace and know that you are will always be missed.

And boys, the computer is now yours!

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CHAPTER ONE:
INTRODUCTION

1.1   Introduction

This research was supported by a tripartite agreement between Edith Cowan University, the Australian Research Council (ARC) and the National Heart Foundation (WA Division). It was funded through a national competitive ARC Linkage Project grant. The research involved an ethnographic investigation which examined the construction of the self as a heart patient in the context of a therapeutic website (HeartNET) and investigated interactions on the website as manifestations of a gift economy. The original objectives of the project were to:

- evaluate the role of interactions on HeartNET by individuals in the early stages of assuming an identity as a cardiovascular patient;

- identify whether media representations or health messages about cardiovascular disease influence interactions with others on HeartNET;

- apply the theory of the gift economy to HeartNET participants; and

- assess the influence of HeartNET in negotiating a positive self-concept.

This thesis argues that online support such as that provided by HeartNET, provides a strong example of the gift economy in action. While the role of the Internet as a communication medium is firmly grounded in the twenty-first century, there are still many people who do not have access to the Web or alternatively, do not want to be involved in online support. This research involved the members of HeartNET and their interactions both online and in the offline environment. It also explores the role of HeartNET in the gift economy and considers a comparative population who do not utilise online support following a heart event. The research analyses the media's portrayal of heart disease and argues that the reality of living with the disease differs significantly from that constructed in the media. This thesis provides a snapshot into the lives of people with heart disease and offers some insights into the reality they jointly create through their online interactions in a web-based therapeutic community.

1.2   History of HeartNET

HeartNET originally began recruiting participants through the Heart Foundation's Western Australian (WA) division database for the first PhD research commenced in 2005 by the previous HeartNET Australian Postgraduate Award Industry (APAI) recipient Dr. Leesa Costello. While the Heart Foundation database provided access to several hundred individuals, predominantly 'baby boomers' born between 1946 and 1964, few people volunteered to participate in the research. Eventually participants were sourced through doctors' surgeries and extensive media campaigns. When initial recruitment was completed, patients were invited to attend 'meet and greet' sessions at the Heart Foundation to get to know each other. Few people attended and those who did "felt overwhelmed and were reluctant to engage" (Bonniface, Green & Swanson, 2006, p. 97). Participants were divided into two groups, one of which was offered the opportunity to join an online or virtual community. However, issues arose almost immediately. Participants were reluctant to post on the public bulletin board forums, preferring instead to leave private messages for each other. This was inferred by Bonniface, Green and Swanson (2005, p. 14) as evidence that a "pattern of invisible interaction was symptomatic of a generation that felt most comfortable with using the Internet for e-mail, and were unfamiliar with discussion boards". HeartNET was closed, redesigned and re-launched with access available to anyone who wanted to participate.

While I had a background as a research student, and had been working as a librarian, I was apprehensive about taking on the moderation role on HeartNET. Initially Leesa Costello remained on HeartNET to show me its operation and to provide training in the moderation role. I took on the role of moderator full-time, some six weeks after starting my PhD journey. I was also assisted by Gerry Atkinson, who had many years experience both as a lay counsellor and as a heart patient. A number of the inaugural HeartNET members also went out of their way to 'show me the ropes' and gave me lots of encouragement, advice and support. Originally an outsider wishing to gain insights into the lives of HeartNET members, I soon became an integral part of the community as its moderator. I was a member, but also not a member, since I was there for reasons other than my own heart health. This insider-outsider relationship was complex and challenging as I was constantly

renegotiating my role and relationships on HeartNET as moderator, PhD candidate and researcher (Jewkes & Letherby, 2001).

I had initially been concerned about my acceptance onto the site by the HeartNET members. The previous moderator had developed the site, recruited many of the members and was actively involved on HeartNET when I arrived to take over the role of moderator/PhD candidate. I felt something of an outsider. I was conscious of Neil Drew's assessment of the importance of undertaking participant observation research. He reminds researchers that they must not be like a seagull or "a researcher who flies into a community; craps all over everything and then leaves the community to tidy up the mess" (Drew, 2006, p. 40). This is one aspect of HeartNET where I am proud to say no seagulls have taken roost. All research undertaken on the HeartNET site has been completed appropriately and significantly, I "have vested a genuine ownership in the [HeartNET] community and stay[ed] for the long haul" (Drew, 2006, p. 41).

1.3   My Interest in the Research Topic

I trained as a Registered nurse and a Midwife and then spent almost 20 years nursing in New Zealand, Scotland, and both metropolitan and remote Western Australia. During my nursing career I worked in coronary care units and medical wards, often nursing patients who had been admitted to hospital following a heart event. After the initial treatment they would go home in the care of their family members and that should have been the last we saw of them. Unfortunately a few would return with an exacerbation of their heart disease. They would again be sent home in the care of their family with a 'shopping bag' full of medications, an appointment with their general practitioner or specialist, and an expectation they would learn how to cope. Not all of them managed. They would sometimes return with spurious symptoms and fears about the future, and often concerned that every twinge or minor pain was the precursor to the 'big one' that would result in their demise.

Fortunately the Heart Foundation in Western Australia now presents all people affected by heart disease with a manual *My Heart – My Life* that informs them about heart disease and its prevention and management (Heart Foundation, 2013). When talking with many of the cardiac rehabilitation nurses in the course of my research, it

became evident that a significant proportion of people still get their health information from watching television shows such as *The Simpsons*, or *Home and Away*. This finding is supported by the United Kingdom's Heart Foundation, which determined that many people based their knowledge of the signs of a heart attack from watching Hollywood movies or television shows (Hope, 2008).

This research project fulfilled many of the hopes I had when contemplating further research. It allowed me to draw upon my nursing, health promotion and information science backgrounds, while also addressing my interest in the use of the Internet and the role of support in an online environment. My Master's thesis had investigated the role the Internet played for parents of children with disabilities and special needs, and while many of the parents used the Internet for information and bibliotherapeutic purposes, none of them had actually joined support groups (Uridge, 2007). It seemed a natural progression to further my studies as the moderator and PhD candidate during the second phase of the HeartNET project.

Rheingold (1996, p. 413) describes how he immersed himself within an online community, where he spent nearly seven years:

> Participating in a wide ranging, intellectually stimulating, professionally rewarding, sometimes painful and often intensely emotional ongoing interchange with dozens of new friends, hundreds of colleagues, thousands of acquaintances. And I still spend many of my days in a room, physically isolated. My mind, however, is linked with a worldwide collection of likeminded (and not so likeminded) souls: my virtual community.

This was certainly similar to what occurred to me on HeartNET. As previously indicated, I had decided I could complete my PhD on HeartNET while remaining objective and not getting too involved. I believed I could treat it as a job where I would moderate the site by checking in first thing in the morning, maybe again at lunchtime and prior to heading home. I would head home, and change my role from PhD candidate and moderator of HeartNET into that of wife, and mother to two boys. I would them make one final check of HeartNET before retiring for the night. I soon realised that remaining objective and detached was not an option. I became immersed in the site and many an evening I would be online long after my family were asleep, reading people's posts and sharing in their stories as they expressed their pain, sorrow or delight. This was much like Rheingold, when he writes about

how his active participation in the WELL had become an integral and necessary part of his family's daily routine and where they grew "accustomed to the fact that I sit in front of my computer early in the morning and late at night, chuckling and cursing, sometimes crying, about something I am reading on the computer screen" (Rheingold, 1996, p. 416).

I would often read a post and perhaps leave a comment, then get to bed late, only to be up first thing in the morning with a cup of tea in hand, back on HeartNET to read how people were, and to discover whether they had dealt with the issue they had raised the night before. Rheingold (2001), states that people log onto online communities because:

> There's always another mind there. It's like having a corner bar complete with old buddies and delightful newcomers [… instead] of putting on my coat, shutting down the computer, and walking down to the corner, I just invoke my telecom program and there they are (p. 157).

I remember my parents staying with us from New Zealand early on in my PhD journey. While they were sitting at the kitchen table I was on HeartNET moderating the site. My Dad commented to my children that I seemed to spend far too much time on the computer to which one of them replied "yes, she does, but that's her job!" I had quickly become immersed in the online world of heart patients, and to my children, family and friends it was now an integral part of my daily life. This is similar to the findings of Correa, Hinsley and de Zuniga (2010, p. 217) who found that "Internet users go online to communicate with others and that for many the Internet is part of our everyday lives, and who we are guides how we use it").

1.4 Background to the Research

HeartNET was created over eight years ago, prior to the take-up of Web 2.0 at a time "when the Web we now know, which loads into a browser window in essentially static screenfuls [was] only an embryo of the Web to come" (DiNucci, 1999, p. 32). HeartNET was created during the later years of what might be constructed as Web 1.0 (Allen, 2011) and its members were restricted to passive viewing of content, unlike DiNucci's 1999 vision where the:

> Web will be understood not as screenfuls of text and graphics but as a transport mechanism, the ether through which interactivity

happens. It will ... appear on your computer screen, ... on your TV set, ... your car dashboard, ... your cell phone, ... hand-held game machines, ... maybe even your microwave oven (DiNucci, 1999, p. 32).

Web 1.0 limited interactivity, whereas Web 2.0 provides "interfaces [which] are based on technologies that allow [it] to perform significant computational activities on the client greatly enhancing the user experience" (Pandrini & Ramilli, 2012, p. 706). Unlike many of the more interactive websites available, HeartNET only provides its users with access to a chat room and a bulletin board which encourages some interactivity between members. However, it does not have the facility to produce or "actively encourage user contribution, interaction and even full production and distribution of user-generated content" (Macnamara, 2010, p. 34) which are options familiar to social networking sites like Facebook and MySpace. However, even though HeartNET was created prior to current technology that allows the tracking of visitors, guests frequently appear on the site, and as such, the HeartNET visitors whether as a lurkers or readers, remain a constant presence.

1.5   Research Aim

The current investigation examines the construction of the self as a heart patient in the context of a therapeutic website (HeartNET) and investigates interactions on the website as manifestations of a gift economy. Utilising data obtained through onsite postings, in-depth interviews and interactions on HeartNET, the objective of the research is to explore identity creation by cardiovascular patients and the role HeartNET plays in the construction of the self as a heart patient. The graphical representation of the interrelationships between these data can be seen in Figure 1.

A secondary study of the media messages that resulted in HeartNET interactions has also been undertaken. HeartNET members sometimes comment on news items they have read or seen, and then use the site to discuss the impact of these stories. This study investigates the lived experience of HeartNET members and their response to the mass media's portrayal of heart disease.
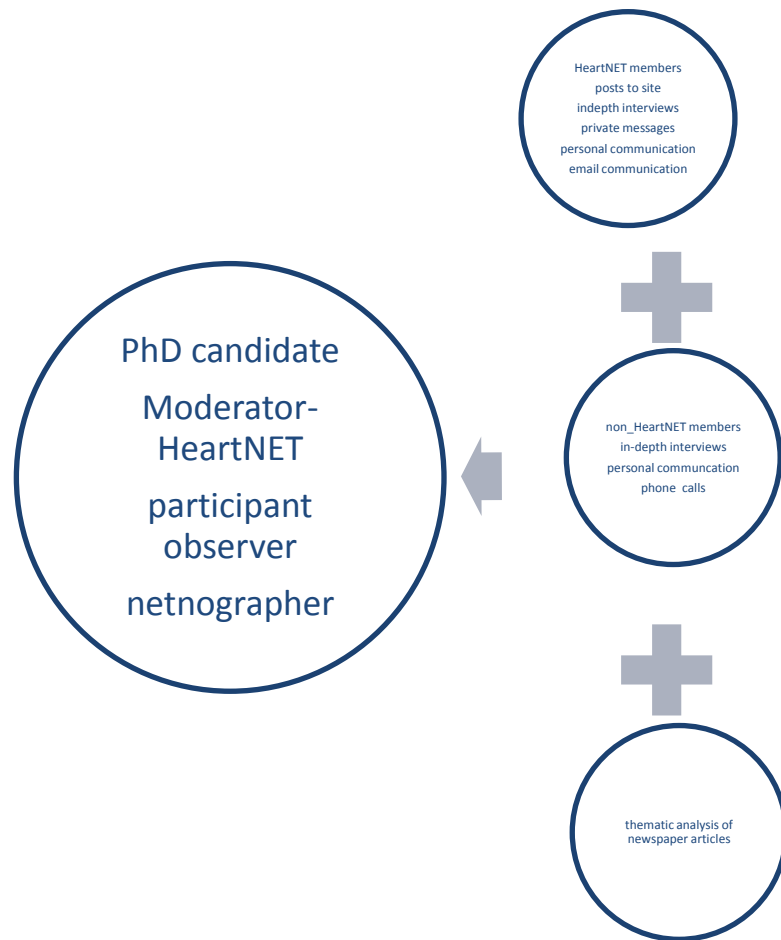
Figure 1: Graphical representation of the interrelationships between data used for PhD research

Heart disease is a major burden on Australian health care providers. As the Australian population ages, Cardio Vascular Disease (CVD) becomes more likely. People who have had a heart event often report their overall health status as being lower than those without heart disease (ABS, 2006a). This is because healthy people take their abilities for granted by building "their self-concepts and identities around what they can do" (Corbin, 2003, p. 257). When people experience disruptions to their health, they may need to reassess their lives. Sometimes people identify roles that need reconstructing by finding meanings in their new roles, relationships and self-identity, while still dealing with their ill health (Rittman, Boylstein, Hinojosa, Hinojosa & Haun, 2007).

This research is significant because it provides insights into the importance of empathetic communication for people living with heart disease. It will assist the

National Heart Foundation Australia (WA Division) in its provision of services, thus contributing to better health outcomes for heart patients. The research contributes to the literature available on heart health, the gift economy and the provision of health care services by health promotion professionals.

1.6 Research Questions

To address the overarching research aim four sub-questions were determined.

1. Does HeartNET have an impact on people with newly diagnosed cardiovascular disease and are these people more likely to adopt a positive identity than new patients not participating on HeartNET?

2. Can the interactions on HeartNET be constructed as part of the gift economy?

3. Is the development of a heart patient identity via HeartNET a benefit when it comes to processing and internalising media messages about heart disease?

4. Are there identifiable stages that occur when a person develops an identity as a heart patient within the context of a therapeutic online community?

1.7 Significance of the Research

There is clear evidence that people affected by chronic diseases find it beneficial to utilise social support. Due to the asynchronous nature of online support, people with chronic illness can participate at leisure and "develop responses at their own speed" (White & Dorman, 2001, p. 696). While the majority of users are based in Australia, there is an international contingent of members. By its very nature, an online group may well span the globe and this is the case with HeartNET. This allows members of HeartNET to "draw from a wide variety of perspectives, experiences, disabilities and points of view, while at the same time promoting a feeling of universality" (White & Dorman, 2001, p. 694). The international and global scope of this research is one aspect which makes it significant.

This PhD utilises members of HeartNET, a locale that meets many of the criteria that Rheingold (1993, p. 5) describes as an online community which has "social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling to form webs of personal relationships in cyberspace". The members of HeartNET are predominantly

individuals with similar or common health-related interests or conditions, "who interact and communicate publically through … the Internet or through other computer based bulletin boards, allowing social networks to build over a distance" (Eysenbach, et al., 2004, p. 1). This is especially significant for people who are marginalised or restricted due to poor health or isolation.

Cummings, Sproull and Kiesler (2002) believe that support and information should ideally come from friends and family. They also believe however, that "even if a person does have compassionate friends or family members, and skilled caregivers, these relationships are almost always circumscribed over time, by expectations of reciprocity, or by reluctance to discuss personal situations" (Cummings et al., 2002, p. 78). To address this need for support, many people seek self-help through books, support groups or via online communities. Such online support is described by Cummings et al., (2002, p. 79) as offering the "possibility of encountering many different perspectives on a problem, of finding people with similar experiences and pain, and, at the same time of communicating in comparative privacy and psychological safety."

Informational and emotional support is evident in many online communities. Coulson, Buchanan and Aubeeluck (2007, p. 11) researched the use of online support for people affected by Huntington's Disease (HD) and found that "providing emotional support to others appeared to be an important function of the group with members typically acknowledging the feelings of others and validating them by reiterating their own similar views and experiences". Often older members of support groups would provide emotional support to new members, and then, over time and as new members became comfortable on the site, this support would wane. Coulson et al., (2007) explained that something similar happened within the HD community. They noted that one possible reason for this could be because "the need for this type of support was addressed simply by participating in the bulletin board" (Coulson et al., 2007, p. 12). HeartNET provides a reasonably safe outlet for its members to share their health issues and to benefit from the experiences of others in similar situations. Thus, therapeutic sites provide users with additional support when required.

1.8   Structure of the Thesis

This thesis is divided into nine chapters including the introduction.

Chapter one provides the reader with information concerning my interest in the topic, the background to the project, the significance of the research, and an overview of my research journey as the moderator of HeartNET.

Chapter two focuses on the relevant literature and is divided into three main sections. The first section outlines the role of the Internet as a communication tool. The second section outlines the role of the Internet as part of the gift economy and HeartNET's involvement in the gift economy. Chapter two also examines the media's portrayal of heart disease and how it portrays people with heart disease. It is interesting to note that people with heart disease often find media reports to be less than credible and usually have a "quirky or feel good" component to them (Picard, 2005).

Chapter Three discusses the methodology used in this research, in particular the appropriateness of the use of participant observation and netnography. Netnography is an approach which can be "applied to the study of online cultures and communities" (Kozinets, 2010, p. 6). It is also a valuable data collection tool as it allows the researcher to collect and analyse text-based information and images from an online environment (Garcia, Standlee, Beckhoff & Cui, 2009), while also meeting people face-to-face where appropriate (Kozinets, 2010). In this chapter, the research aim and objectives are identified and the significance of the research is outlined in detail.

Chapter Four describes the key features of the HeartNET site and provides a brief history of the creation of the site and the functions of HeartNET prior to my taking up the role of moderator and PhD candidate. Each of the main features of the site are identified and discussed in detail, providing an insight into how members of HeartNET utilise the site. This chapter also addresses the sense of connection that many people find on Facebook and provides examples of how interactions on Facebook took over the social support role that HeartNET had provided. Social gaming, especially on sites such as FarmVille (FarmVille, 2009) and Fish World (Fish World, 2010) are also explored. Members of HeartNET left HeartNET and joined Facebook. However, several of the members who identified as prolific game

players on Facebook ultimately returned to HeartNET as it provided a safer and more supportive environment.

Chapter Five defines the gift economy in the online environment, examines the role HeartNET plays in the gift economy and describes how participants' use of the HeartNET bulletin board usually met their needs. This chapter also describes the role of the moderator and how the moderator's role is an integral part of HeartNET's structure. It also identifies the role of the gift economy in the wider world, the role of volunteering (an activity in which many of the non-HeartNET members are involved), and considers the argument that volunteering in various roles may be the result of feeling a need to reciprocate in some way following their heart event. This chapter also outlines the role of friendship and the sense of community that people develop in their volunteering role following a heart event.

Chapter Six takes a different focus and begins with a letter written by Lasnick (2007) which addresses how she feels while living with a chronic, debilitating illness. This is a letter from the disease to the person who has the illness and was posted on the HeartNET site. The letter elicited a strong response from HeartNET members and prompted many of them to relate to their own reality of living with heart disease. This chapter identifies the four health related personas that Charmaz (1987) believes people may assume following the onset of chronic illness. The chapter concludes with Lasnick's letter (2007) replying to her disease.

Chapter Seven outlines the role of the media as a source of information for the wider public. It is divided into three sections, with section one outlining how the media portrays heart disease in both print and television. The second section analyses HeartNET members' posts to the site about the media and subsequent discussion that arose. This section also identifies some of the key factors that both HeartNET members and non-HeartNET members have identified as critical to the media portrayal of people with heart disease.

Chapter Eight analyses the role of newspapers in portraying heart disease and provides a content analysis of articles that appeared in the *West Australian* and *The Australian* newspapers over a four-month period. While the content analysis is interesting, it also highlights some of the discrepancies between what the media states and HeartNET members' stated experience of living with heart disease.

Chapter Nine draws together the research findings. It provides recommendations for the Heart Foundation which may result in the continuation of the HeartNET website as a valuable health communication tool for people affected by heart disease. It also suggests possible avenues for future research in the field of heart health communication.

1.9   Summary

This chapter has identified the use of online support such as that provided by HeartNET is an example of the gift economy in action. It provided an outline of the history of the Internet as it related to online communication on sites such as HeartNET. The moderator's interest in the research topic and the background to the research was discussed. The significance of the research was identified and a summary of the structure of the thesis was provided. The next chapter identifies key literature relating to online communities within the gift economy.

CHAPTER TWO:
LITERATURE REVIEW

2.1   Introduction

The focus of this chapter includes literature related to the history of the Internet; the gift economy; the use of online communities; identity, grief and humour; the social worlds people live in; and the role of the media in heart health.

Cardio vascular disease (CVD) describes heart, stroke and vascular diseases, and currently affects 3.4 million Australians. It accounts for 34% of all deaths and is one of the leading causes of chronic and disabling disease, affecting one in five Australians and two in three Australian families. Every twelve minutes an Australian dies from CVD (Heart Foundation of Australia, 2013). Advances in diagnosis and the treatment of heart disease and stroke have included effective medication for addressing elevated blood pressure and cholesterol levels, an increasing number of specialist health care providers, and better coronary care units. These initiatives have all contributed to reductions in fatality rates and improved survival times for individuals affected by a heart event (Australian Institute of Health and Welfare, 2009). Following a heart event an individual may turn to friends, family or medical professionals to seek information, advice and support for assistance in the processes involved in re-identifying themselves as a diagnosed heart patient. Others may choose to look beyond their social circle to utilise the Internet and access online support groups such as HeartNET, which is a West Australian-based, members' only, national support group that provides participants with an opportunity to communicate with others experiencing similar situations. The members who actively participate in online interactions by sharing their stories, helpful hints, support and encouragement soon become part of what French sociologist Marcel Mauss (1990) originally identified as the "gift economy", which will be discussed in detail later in this chapter.

2.2   History of the Internet

A brief history of the Internet is included here in order to place HeartNET in context within the gift economy. While computers have been in use since the 1940s, it was not until 1969 that the first network of separated computers was set up by the

United States (US) Defence Department to assist in research of a communication strategy which might survive an initial attack in a war (Chandler, 2000). Scientists from Bolt Baranek and Newman Inc. (BBN) were responsible for installing the first Advanced Research Agency Network link, known as ARPANET, between two computers at the University of California's Los Angeles Campus (UCLA) and at Stanford University (Green, 2010, p.21). This networking innovation eventually used two protocols, the Transmission Control Protocol (TCP) and the Internet Protocol (IP), which allowed data to be transferred on what is now known as the Internet. According to the Defense Advanced Research Projects Agency (DARPA, 1981, para. 4), the TCP was created with long term goals as "it … [was] essential to provide [a] means of interconnecting them [computers] and to provide standard interprocess communication protocols which … [could] support a broad range of applications". Since its inception, the Internet has continued to grow and evolve with the Federal Networking Council (cited in Kahn & Cerf, 1999, para. 2), describing the Internet "as a dynamic organism that can be looked at in myriad ways. It is a framework for numerous services and a medium for creativity and innovation. Most importantly, it can be expected to evolve". Originally limited to college campuses and research laboratories during the 1970s and 1980s, it was not until early 1990 that computers which had the capacity for the Internet became a consumer commodity in the West (Chandler, 2000, para.10).

Over the past twenty years, computers have become more user friendly, and as a result the Internet and World Wide Web have become integral parts of many people's lives (Korp, 2006). According to the Australian Bureau of Statistics (ABS) Multipurpose Household Survey (MPHS) in 2008-2009, 72% of Australian households had home Internet access with almost two thirds of these households having broadband connectivity (ABS, 2009, para.1). Moreover, the proportion of Australian Internet users with dial-up access is rapidly diminishing. Currently, 92% of Australian households access to the Internet via non dial-up connections (ABS, 2010; 2014). This contrasts with 2005-2006 when 51% of the Australian population had dial-up access and only 48% had broadband Internet access (ABS, 2006b).

The term "the gift economy" was first used by Mauss (1925) and has been elaborated on by anthropologists such as Veale (2003) to explain the growth of the Internet and the sharing of information found within it. Participants in the digital gift

economy initially included programmers who contributed their software for free, which encouraged others to do the same.

2.3   Gift Economy

Traditionally, gift giving research was based upon work undertaken by theorists such as Mauss (1925), Malinowski (1926) and Caplow (1982), who explored the use of gifting from a social exchange perspective. Mauss, a French sociologist and anthropologist, is recognised for his contribution and exploration of gift exchange amongst what were then termed 'primitive cultures'. His 1925 book *The gift*, explores gift exchange within cultures and identifies the reciprocal nature of gift giving. He describes three obligations associated with the exchange of gifts:

- giving – the first step in building social relationships;
- receiving – accepting the social bond; and
- reciprocating – demonstrating social integrity (Mauss, cited by Komter, 2005, pp. 116-117).

Malinowski a Polish anthropologist also explored tribal communities and the role of gift giving. He found that "the chain of reciprocal gifts and counter gifts, … in the long run benefit both sides equally" (Malinowski (1926, p. 68). Caplow (1982) identified the tenuous link between gift givers within relationships that may be insecure, especially when the parties accept that the information transfer cannot be guaranteed. Gregory (1982) argues that gift giving is the opposite of commodity exchange in that these exchanges establish qualitative relationships between people. Sahlins (1972) agrees, and recognises that givers and receivers do not keep records of their interactions and are often unaware of any imbalance that may result from the interactions that take place. Belk asserts that in many cases the gift exchange seen in online communities is more social than economic and may involve *agape love* (Belk, 2007, p. 128), which can be identified as "altruistic love that is patient, kind and undemanding" (Djikic & Oatley, 2005, p. 205).

Belk (2007) believes the Internet leads to a global community of sharing and communicating, and that the giving of a free flow of information provides equality of access. He outlines several motivations for giving including:

- paying back the benefits previously received;
- the motivating effect of feeling part of a group of kindred spirits;
- the fact that the sharing of secrets and self-disclosure deepens and reinforces relationships;
- paying back for prior good fortune;
- a feeling of shared identity with others including the feeling of a sense of moral obligation; and
- sharing with others with whom there is empathy, because the donor has identified that they are in need of assistance (Belk, 2007, pp. 133-135).

However, Belk (2007, p. 136) suggests that "ironically we are becoming more likely to share our deepest secrets, insights, information and loyalties with someone we know only by an online pseudonym than we are with our partners or with other members of our families". Many people faced with a medical diagnosis find that family and friends may struggle to provide continuing support. Therefore, turning to the Internet and accessing online forums for additional support may provide users with a way to communicate and connect with others in like situations. No two online health communities are the same and some sites are more successful than others.

The Internet remains an example of the gift economy. As a result of the early culture of shared information, the use of free and open software can never be fully controlled, fully commercialised or totally copyrighted (Suarez, 2004). Furthermore, support, encouragement and information is often given and received with little thought of financial gain by the Internet provider. Many individuals are eager to add to the knowledge accessible to all via Internet access, while some researchers comment that "everyone takes far more out of the Net than they can ever give away as an individual" (Barbrook, 1998, p. 2).

The World Wide Web remains an environment where "real services and real content" are readily available, although it is becoming increasingly more commercial (Veale, 2003, p. 4). Many participants in online communities are not looking to give or receive payment, but are keen to exchange information, advice and support online. Eisenstein (2011) states:

> Gifts can circulate across vast social distances, and I can receive from people to whom I have nothing to give, while still fulfilling my desire to act from the gratitude these gifts inspired within me (Eisenstein, 2011, Chapter 1, para 16).

In this way, the Internet works rather like a chain reaction whereby recipients are encouraged to pay it forward to others in similar situations (Harrison, 2006).

Users are able to access discussion boards, search different web sites and enter many online chat rooms without any financial outlay. They are contributing to the collective knowledge of site members, and encouraging co-operation among website users (Barbrook, 1998; Ghosh, 1998). Bays and Mowbray (1999) suggest that the processes of 'giving' on the Internet work in much the same ways as cookies or biscuits are given as gifts in the real world. It is not expensive or difficult to make or give cookies. Their analogy is that the time, money and effort used when giving information, support or encouragement is not personally costly, and it is these "small actions that make up what we know as the Internet gift economy" (Bays & Mowbray, 1999, para 24). An example of this form of gift giving is found on many online health sites where members frequently share information about various services available in their local community and also support each other when they are facing further medical tests or have had an exacerbation of their heart event.

Veale (2003) identifies three fundamental principles involved in exchanges within the gift economy which encourages reciprocity amongst users as the exchange of information, support and advice According to Veale reciprocity can and often has intangible rewards and these intangible rewards may eventually become tangible. However, for these principles to work the exchange of information or support must be provided freely. Even so, Veale acknowledges that there "is some expectation of return from either the gift-receiver or the Internet community" (Veale, 2003, para. 7).

Gouldner identifies reciprocity as a key norm of human nature, stating that at a minimum "people should help those who helped them" (1960, p. 171). He elaborates that this will be contingent on the need of the recipient, the resources available and the motives behind the gift (Gouldner, 1960). He argues that Malinowski and Mauss "assert or imply that the amount of return to be made is roughly equivalent to what had been received" (Gouldner, 1960, p. 172). Whereas in reality reciprocation is often dependent on "a more general norm which simply requires that one return some (unspecified) benefits to benefactors (Gouldner, 1960, p. 171). Sahlins (1965, p. 147) agrees, stating that the counter obligation of reciprocity "is not specified by time, quantity, or quality: the expectation of reciprocity is indefinite". While there is an expectation of reciprocity on online sites, the information, advice and support that is shared may remain relevant for many years, and in the course of time the

importance of the information may be "reproduced, regenerated or added to" (Weiner, 1980, p. 791).

Initially, the Internet was constructed as having "almost magical powers" (Barbrook, 1998, para. 1), whereby an individual could enter an online world and ask for and receive answers and other information, sometimes within seconds. Whereas in the past one had to seek an expert and wait for a response, which may have taken weeks or months or in some cases never arrive; now the answers can appear 'magically' within minutes. While no one denies the Internet was originally a gift economy, this is no longer solely the case as Barbrook (1998, para.3) explains, "information is shared and sold. Copyright is protected and broken ... users get for free what they used to pay for and pay for what they used to get for free."

Exchange within the gift economy begins with the creation of a product, in this case an online community, which has been made available to the online environment at large. While access to the community is free to anyone who wishes to use it, members seem to expect that if they post a message on the site, there will be some return or gifting of encouragement, support or information by other members or the moderator. Since these responses are not always instant, at times there seems to be no noticeable reward (Hovelsrud-Broda, 2000). Even so, the gift is generally received by others at a later stage, which instigates an ongoing "giving-receiving-giving sequence of gift exchange" (Veale, 2003, para. 5) that enforces the "circle of gifts", even allowing for the deferral of gratification.

This form of gift giving is not entirely without risks. There is a chance that no one will reciprocate, or there may be a frustrating delay in receipt of the gift. However, the possibility of not receiving a reply does not prevent people from communicating constantly on bulletin boards or within chat rooms. Thus a potential non-response does not appear to prevent people from contributing to the gift economy (Barbrook, 1998; Veale, 2003).). This may be why care givers and cancer survivors continue to utilise online communities even when they no longer require the support (Fehr & Gaechter, 2000). Hence, this involvement and continued interaction is critical to the development and ongoing maintenance of a site.

In the absence of direct and rewarding responses, there may be intangible rewards such as the "anticipated reciprocity" which is often found in online communities, where the expectation of advice, support or encouragement is based on

the assumption that "contribution from others will balance that of their own" (Ghosh, 1998, p. 9). Much like the analogy of the creating and giving away of cookies, Ghosh equates the gift economy on the Internet with that of a "vast tribal cooking-pot, surging with production to match consumption … the cooking pot keeps boiling because people keep putting in things as they themselves, and others, take things out" (1998, p.9).

Many participants involved in Internet-based support groups may not even be aware that their input is actually a component of a functioning gift economy. A functioning gift economy has everyone participating so it is in balance. Various issues can upset this balance including lurking, where people take value out of the site or situation without actively participating or contributing. However, according to Veale (2003), more must be contributed to the site than is removed in order to maintain the status-quo and the gifting balance within the community.

Interestingly, members of sites may also unwittingly promote the gift economy outside the support group to which they belong. This occurs when participants discuss the site of which they are members. Volunteering this information may encourage others to join the site. This dynamic will be addressed more fully in a following chapter which explores the use of online sites as part of the gift economy and discusses how members of these sites often share with each other both in the online environment and in the offline world where the research participants may volunteer in other groups. This research also identifies that for non-Internet users volunteering face-to-face in various heart-related organisations can also be a form of gift giving.

For most Internet users the online environment is an area for playing, sharing and looking for information. Assuming connectivity is easy, there is no necessary restriction in participation due to time, space or geographic boundaries. So in many cases people share and trade information online without any thought of payment. Barbrook (1998, para. 15) states that communities are "formed through the mutual obligations created by gifts of time and ideas". Thus, online environments allow connection between people and provide an opportunity for communication, social interaction and exchange (Stendal, Balandin, & Molka-Danielson, 2011). This interaction and exchange may not happen immediately. When a gift is received this may lead to a strengthening of the relationship between the giver and the recipient.

Thus "the anticipation of a future response can have a powerful impact on how and why people share their support" (Furuse, 2007, p.7).

The gift economy in this research looks at the act of giving and sharing information, support, encouragement and time, in both the online environment and as a volunteer in real world situations. The offering of advice online is different to traditional gift giving, where a tangible gift is given to an individual usually known by the gifter. There is an underlying expectation that in some way this gifting will at some time be reciprocated (Wang & Fesenmaier, 2003). Online gifting is different. Often the giver is not known to the recipient, they may never meet, and the information or advice is usually directed at a community rather than a single individual. While there is no obligation for reciprocation, there may be an expectation for others to contribute. In the long term if other members participate and contribute freely and actively, the information and advice will potentially benefit the whole community collectively (Wang & Fesenmaier, 2003). In order for the online community to continue however, there needs to be enough contributions by the members to ensure the continuation of the community, thus providing what Gielser and Puhlmann (2003, p. 275) identify as "maintenance through giving".

Coyne (2005) believes that the Internet has created a global community which allows individuals to share freely. Belk (2007) and Coyne (2005) identify this Internet based exchange as a cornucopia, where people continue to give and receive as a way of keeping a community functioning while developing deeper and more meaningful relationships. In this way altruism is "beneficial because the experience of being of service to others can reduce demoralization and boost self-esteem" (Vilhauer, 2009, p. 383).

In reality, gift economies should not work as well as they do. People who may never meet are bought together through a common bond; to share advice, help and information without any monetary or contractual interactions. This economy is described as "a gift economy … a web of enduring moral and social commitments within a defined community sustained through the giving of gifts (of goods, service, and courtesies) without any assurance of personal gain" (Bollier, 2003, p. 31).

Researchers frequently challenge the notion of gift giving and ask why it continues. It was Mauss, in 1925, who first identified that gift giving was universal across cultures. Mauss explored the practice of gift giving among tribal communities

and discerned that when gifts and services were offered there was an expectation that these would be reciprocated (Mauss, 1925). For many tribes this becomes a cycle of gifting and receiving often, with each trying to outdo the other. A gift can be important to both the giver and the receiver. When a gift is given, it is expected the gift will be reciprocated and for the receiver, that gift will always be associated with the giver (Kollock, 2002). These researchers identify gift exchange as different to commodity transactions in that there is no obligation associated with a commodity transaction. Hyde (1983) explored the differences between a market economy and a gift economy and identified a market economy as impersonal and focused on wealth formation while the gift economy focuses on relationships. Kollock agrees, stating that "gift economies are driven by social relations while commodity economies are driven by price" (2002, sect. 2, para 3).

According to Bar-Lev (2010, p. 149), it has been felt historically that "participants in gift economies must know each other, for them to feel for each other, or at least to act as if they feel for each other". However, online interactions often involve emotional responses to "traces of conversation or 'textual impressions' existing quite independently of the people who constructed them" (Bar-Lev, 2010, p. 149).

Poster (2001, p. 58) argues that the Internet cannot be a true gift economy because gifts are shared between "specific individuals" and the main purpose of the gift is "to create an obligation from a donator, or achieve recognition by a community as a donator". He asserts that sharing online is actually seen as "the economy of sharing" (Poster, 2001, p. 58). He continues that this sharing online is unique to the Internet. In most instances there is no financial gain, no exchange of products for any price and most importantly, this sharing usually does not occur outside of the Internet (Poster, 2001, p. 58).

2.4   Sense of Community

McMillan and Chavis (1986) identify four key elements that create a community. These include "membership" or a sense of belonging "or of sharing a sense of personal relatedness" (p. 9). The second element of influence includes a "sense of mattering, of making a difference to a group and of the group mattering to its members" (McMillan & Chavis, 1986, p. 9). The third element involves

"reinforcement and the integration and fulfillment of needs" (p. 9) whereby members feel their needs will be met by their involvement in the community. Fourthly, there needs to be a "shared emotional connection" where members "share a history, common places, and time together and similar experiences" (McMillan & Chavis, 1986, p. 9).

Blanchot (1983, p. 39) sees community as "loneliness that is experienced together". Nancy however, prefers to use expression such as "being together", "being in common" or "being with", rather than community (Nancy, 1991, p. 32). While Blanchot is speaking about literary communities, his theory can be related to online support communities when he states that sharing and supporting is more effective when "we [recipients] are open and vulnerable to each other" (Blanchot, 1983, p. 42-45). Montmann (2009, p. 11) identifies issues with defining the term community, highlighting that it can mean "a sense of belonging, or [to] have a local or territorial boundary". She maintinas that philosopher Jean-Luc Nancy sees community "as relational social organisation constituted not by the fact of belonging, but by the co-existence of singularity and shared experience" (Montmann, 2009, p. 12), thus providing "… interwoven, alternating, shared texts, offering, like all texts, that which belongs to no-one and which returns to everyone" (Nancy, 1991, p. 425).

While McMillan and Chavis (1986) researched farming communities, these key elements can also relate to online communities. Members of online communities can be described as individuals who maintain online communication; share common goals, interests and needs; and have the ability to harness current technology that allows them to access particular sites (Basdekis, Kliromonos, Antona & Stephanidis, 2006).

Andrews, Preece, and Turoff (2001, p. 1) define an online community as one that "consists of the people who interact socially to satisfy their own needs or perform special roles with shared purpose … to support and mediate the social interaction." Vivian and Sudweeks (2003) agree stating that "creating relationships and embedding oneself into the social structure is pertinent to the success of social networks" (p. 1435). The moderators and participants in an online community must be aware that for a community to develop, they must allow the community to evolve into something the members want, and which meets the members' needs and

expectations. The community must grow with its members and with advances in technology.

As online communities develop they serve several functions including providing a meeting place for participants and creating an opportunity for members to share thoughts, feelings and opinions in a safe environment with relative anonymity. Accessing health forums allows users to "disclose their health care concerns and issues" (Donelle & Hoffman-Goetz, 2008, p. 272), at any time, and this exchange of "textual conversation" (Burnett, 2000, introduction, para. 3) provides users with an opportunity to share health information and support with each other. There are many reasons why people connect to online communities including a personal interest in finding answers; developing social relationships with others and not just family members; looking to speak with equally informed people; and for purely altruistic reasons where the giver gains value from being able to benefit others (Butler, Sproull, Kiesler & Kraut, 2002). Following on from this type of interaction is the continued participation on the site as members take ownership and develop a shared online identity through participation. In addition, users develop a relationship of trust with other users and consumers (Barette & Becker, 2007).

Research undertaken by du Pre (2005) found that people who shared stories online about health crises were overwhelmed with responses, both positive and negative. Often members in distress received immediate replies that could encourage, give advice or offer recommendations. This immediate response was something that counselors and therapists were not always able to give while "online support potentially eliminates barriers of time and distance" (Finn, 1999, p. 221).

Online communities can also provide weak-tie support, where relationships can be developed and ultimately provide more than social support, in many cases without face-to face contact (Genoni, Merrick & Willson, 2006). The strength of the tie to the social site is often proportionate to the length of time spent on the site, the emotional intensity of the postings, and the degree of intimacy and reciprocation of contact from others (Wellman & Hampton, 1999). According to Granovetter (1983, pp. 201-233), many more people can be reached through weak-tie relationships such as Internet support groups than through face-to-face meetings. Some consider that more useful information is obtained from weak-tie Internet contacts than from stronger ties such as family and friends. Other research has found that active

participation in these weak-tie online communities allows for social exchange and an increased opportunity to participate in a global community (Wellman & Hampton, 1999).

There are several disadvantages of an online support group such as issues that arise from addiction to or overdependence on the Internet, information fraud, misinformation about the self or the group, and difficulties in conveying emotional support (King & Moreggi, 1998). The presence of lurkers can also cause issues. While some members actively post, others may read posts without leaving a comment. Additionally, most people are at differing stages of their illnesses and this fluctuation of membership may cause difficulty in sustaining an online community (Gary & Remolino, 2000).

Another issue that may arise is the identity of the people joining. Little is known about the people joining the site, and while demographic information is usually asked for, there is no guarantee the information provided is accurate (Wright, 2005). Hoaxes can abound in online sites where members can chose to be whoever they want, and this in turn can cause distress to other site members (Uridge, Rodan & Green, 2012).

Van Uden-Kraan et al., (2008) identify issues with sites that rely on asynchronous communication. As discussed in Chapter 5, often people may have to wait for a response to their post. For some this is not an issue, while for others it can cause increased stress, especially when the posts are made late at night. On international sites there may be cultural and language inhibition which can result in poor responses or no response. These cultural barriers can cause issues with site members openly discussing their medical condition or treatment (Gary & Remolino, 2000). Disinhibition online can cause people to "loosen up, feel more uninhibited, and express themselves more openly" (Barak, Boniel-Nissim & Suler, 2008, p. 4). Intimate thoughts and feelings may be shared which could lead to inappropriate responses. Often the person posting the comment may regret or feel anxious about what they have shared, and for some this may cause them to leave the site (Barak, Boniel-Nissim & Suler, 2008).

Negative postings on a site can be an issue. While it is anticipated that newly diagnosed patients or newer members will initially post negative remarks, the

moderator must be aware of this. At times, posts by other members may be seen as thoughtless, and due to the lack of face-to-face contact and the availability of verbal cues, this can lead to misinterpretation of the written word (White & Dorman 2001).

Another major factor is the digital divide. A lack of access to a computer or poor computing skills can mean a large number of people cannot access a site that may help them. Also, if people join a large site they will then have to deal with large volumes of posts to read and this can cause them to become overwhelmed and leave (White & Dorman, 2001). Given the ageing population in Australia this could be a major issue for getting people to access online, health-related support.

Moderators often play a major role on therapeutic sites and there are also issues that can arise from this role where accountability is paramount. While the moderator is aware of the ethical constraints, often the members are not. The fact that many sites span international borders means there is a 'grey' area about the local or national laws concerning accountability. For many sites, moderators have little or no training and learn on the job. This can be especially challenging if a member is seeking help during a medical crisis (Gary & Remolino, 2000), and is certainly an area requiring further research.

2.5   Identity

The Internet allows people to explore their identity by providing them with an opportunity through anonymity, to play with projections and variations of their own self-perception. Given that an individual is able to develop or enhance certain aspects of their self and portray themselves differently on the Internet, they may develop a specific online identity (Wallace, 1999, pp. 49-50). Kolko, Nakamura and Rodman (2000, p. 5) construct the Internet and in particular cyberspace, as "a semi blank slate upon which users write ... a blank webpage, an empty chat room, an unformed public policy – individuals are responsible for how they work with the empty space". It is this interactivity and involvement that encourages the creation of online identities that may be fluid and possibly non-gender specific, but easily identifiable by their creator or creators as a construction of their self-identity.

Identity is defined by Little, Paul, Jordens, and Sayers (2002, p. 171) as "the sense of personhood that places each of us in a social context". Similarly, Woodward

(2002) believes that personal and social identities are linked. She claims that developing an identity is not a linear process, but is affected by many things including our own perceptions, our position in our world and contact with family, friends, colleagues and sometimes strangers. This identity is relational and is constantly evolving to incorporate new thoughts, feelings and connections, including how we are named and seen by others (Woodward, 2002, p. xii). Social identity is influenced by the way we are seen by others (Willson, 2006) and our own perceptions of ourselves, and this is particularly relevant to newly diagnosed heart patients. In addition, the individual will be influenced by events and experiences so that no two identities are the same (Abelson et al., 1998). Individuals need to know who they are and where they can position themselves within both their real worlds, and for the purposes of this research, their virtual worlds (Howard, 2000).

Using the anonymity of the Internet allows individuals to express and develop different versions of their self. Goffman (1959) identified that an individual has an inner self and a public self. While Markus and Nurius (1986) expand on this sense of self and investigate the existence of "possible selves" and the potential desire of an individual to explore variations of identity. All of these theorists are looking at potential, not actual identity. In contrast, Turkle (1995, p. 34) takes the concept of identity on the Internet as a mechanism through which an individual can explore their current identity, thus using the Internet as a laboratory for self-expression. This current research explores the meanings of this self-expression as it relates to online communities, the identity of the heart patient and the gift economy.

Part of the experience of becoming a heart patient is (i) finding a reason to explain the development of heart disease beyond everyday reasons of diet, exercise or lifestyle risk factors; and (ii), the process that an individual undertakes to develop new behaviours. For many individuals, new behaviours may include forming fresh ideas about their condition. Meanings are attached to these new circumstances, and the individual with a fresh diagnosis of heart disease is able to start functioning again with his/her family, friends and workplace colleagues (Stull, Starling, Haas & Young, 1999, pp. 284-292). Integrating ongoing everyday life with the identity of heart patient is not easy, and many individuals may never reconcile themselves to their new identities of being cardiovascular patients.

Chronic disease such as CVD affects individuals' self-perceptions by disrupting their beliefs and feelings about the wholeness of their bodies (Charmaz, 1995). The impact of the disease may affect all aspects of daily life, resulting in the person having to adapt to a new identity - that of a person with cardiovascular disease (CVD). This research investigates the formation of the identity levels identified by Charmaz (1987), draws upon information from both HeartNET members and non-members, and is discussed more fully in Chapter Six.

Charmaz (1987, pp. 287-289) identifies four levels of new identity construction that an individual may pass through or choose while constructing an identity as a person with CVD. These are the supernormal identity level, the restored self, the contingent personal identity and the salvaged self. She found that the majority of individuals after the onset of their illness did not want to be identified as patients, invalids or people with a particular disease or condition. Instead they "constructed their identity levels in relation to their hopes, desires and dreams juxtaposed with their expectations and definitions of their specific circumstances" (Charmaz, 1987, p. 287).

2.6   Grief and Humour

2.6.1   Grief

Many people go through a period of grieving when they are faced with any diagnosis that alters their sense of wellbeing. According to Doka (2014, p. 38), people in grief "struggle to find a meaning and to re-establish a sense of identity and order in their lives". In 1969, Kubler-Ross originally developed what is now known as the grief cycle to describe the reactions and phases individuals experience as they deal with the diagnosis of a terminal illness. She found that most people experience similar feelings and thoughts as they process the diagnosis and the subsequent realisation that they may be facing imminent death. She argued there is an order to these thoughts and feelings which are listed in Table 1. While initially formulated for people with a terminal illness, Kubler-Ross's cycle can be applied to any situation where major disruptions to general wellbeing have occurred, including being diagnosed with CVD.

Table 1: Modified Kubler – Ross Grief Cycle

Stage	Reaction	Symptoms
1	Shock	Disbelief, confusion, numbness, detachment
2	Denial	Refusal to accept facts, changes may be ignored
3	Anger	Emotional outbursts, with bottled up feelings finally released. Wish to find blame
4	Bargaining	Negotiation with God or higher power, or self. May start seeking alternative therapies and experimental medications or procedures
5	Depression	May reject everything, become tearful, pessimistic and inward-turning
6	Acceptance	Able to become actively involved in future treatment and takes ownership of condition, may return to old pursuits or activities

Source: Kubler-Ross (1969)

There is evidence that after the diagnosis of a heart event, people may experience the stages of grief identified by Kubler-Ross (1969). On initial diagnosis there are often feelings of shock and disbelief, with the individual unsure of the long term implications and effectively functioning on autopilot (Hammer, 1996). Denial may then occur, which may include emotions and thoughts and feelings such as 'this cannot be happening to me', 'there must be some mistake' or 'this is just not me'. Anger can develop with the person expressing their pent-up emotion at themselves, their partner or spouse, family, friends, medical professionals and God or another higher power. Bargaining may occur next, with the person searching for an alternative solution by asking 'what if' questions and often seeking second and third opinions, as well as accessing the Internet for information if it is available (Uridge, 2007; Hammer, 1996). Depression may occur when the diagnosis is confirmed, although ultimately, the person may accept the diagnosis and return to pursuits and activities they enjoyed prior to their heart event. Uridge (2007) found that many parents of children with disabilities and special needs initially rejected or refused medical treatment and withdrew until they were able to absorb and face the new reality of life with a child with a disability. Much the same is thought to happen with people facing a diagnosis of heart disease. This research explores the range of stages people newly-diagnosed with CVD experience over time as they re-identify themselves as people with CVD.

While the grief cycle is written in a linear fashion, this may not reflect an individual's experience. The individual may construct their feelings, thoughts, behaviours and emotions as occurring in a chaotic and unpredictable way, and as responses to new or remembered health threats. Olshansky (1962) conducted research into how parents dealt with the diagnosis of a child with a major intellectual disability, and theorised that chronic sorrow or "grieving without finality" occurred when these parents had to deal with the loss of the dream of a perfect child. It may be that something similar happens when a person has to face the reality of a diagnosis of heart disease and the subsequent disruption to their previous healthy life. The person must deal with the loss of their normal future and cope with their new identity as a heart patient and with the possibility of a disrupted or shortened future. Olshansky suggests that people need to be given permission to grieve as and when they require. According to Parrish (2010, p. 1) "chronic sorrow is a normal reaction to a living or unending loss of self or other due to permanent injury, disability, or illness". Rossheim and McAdams (2010, p. 478) agree with Parrish, seeing grief and chronic sorrow as a "realistic response to sustained loss". While psychological interventions are beyond the scope of this research, utilising support and providing individuals with an opportunity to tell their story in an online environment can assist individuals to "revise their perceptions of their experience in such a way that they are able to recognise and identify with their personal tragedies" (Rossheim & McAdams, 2010, p. 479).

2.6.2   *Humour*

Humour is often cited in research as being good for heart health. The humour-health hypothesis identifies the direct or indirect link between humour and health (McCreaddie and Wiggins, 2008; Martin, 2004). Martin explored the direct link between physiological changes and "positive emotional states which accompany humour and laughter" (2004, p. 4), and also determined that health may indirectly improve due to a reduction in stress and may "indirectly benefit health by increasing ones level of social support (Martin, 2004, p. 5). However, while Kuiper and Nicholl (2004) agree that humour does have a positive effect on health outcomes, there is limited empirical evidence to support this finding. They contend that distancing oneself in some way from the situation by using humour resulted in "less fear of

death or serious diseases including cancer or cardiovascular problems" (Kuiper & Nicholl, 2004, p. 57).

Participants in a breast cancer support site often shared jokes which played a part in the recovery process. Høybye, Johansen & Tjørnhøj-Thomsen (2005) found that postings "sometimes contained remarks that would elicit laughter, bring relief to both the writer and the reader" (p.216). It was found that these posts provided distance from the event and the sharing was seen as a gift or an opportunity to share laughter establishing "a shared social world where people laughed at the same thing" (Høybye et al., 2005, p. 216). Members of sites can share jokes and create scenarios where humour provides an opportunity for members to share painful or difficult issues in a relatively safe environment.

There are various patterns of humour that can be identified online including those used to conquer adversity and strengthen social ties. Hearne and Nielsen (2004) found that after sharing a difficult or trying time with others, responses were frequently humorous with the rewriting of similar experiences or anecdotes seeming to alleviate tense moments by cementing a continued sense of community for all. De Koning and Weiss (2002, pp. 2-3) state that "the positive effect of humour comes from a 'cognitive shift' which leads to a change in affect." Humour can also assist in alleviating the heartbreaking and intense moments experienced during communication with others which are often felt by people following heart events.

Interpersonal humorous stories may help create a sense of community. Hearne and Nielson (2004, p. 70) suggest that "humour depends on a shared cultural code that is both defining and binding". Baym (1995, p. 3) concurs, stating that humour is "embedded in shared knowledge, shared codes and shared emotional significances." This is certainly evident in many online communities where members share with others both the heartbreaks and highlights of their ongoing journey with heart disease. These shared messages are often treated with humour and a degree of what Freud (1928) identified as rebelliousness against the possible outcome:

> Humor is not resigned, it is rebellious. It signifies the triumph not only of the ego, but also of the pleasure principle, which is strong enough to exert itself here in the face of the adverse real circumstances (Freud, 1928, p.217).

In face-to-face settings individuals are usually able to identify cues for humorous exchange including a wink, nod and smile or nudge, all of which are comparatively easy to identify. This is not always possible in the online environment where cues are mainly expressed by written text such as "lol lots of laughter"; "ROFML rolling on floor madly laughing" or even a simple statement such as "ha-ha." Baym (1995, sect. 4, para. 6) argues that humour can be a response to other posts or a reaction to previous discussions. Recognition of shared humorous responses leads to a unification within the group; while reference to past events creates an enhancement of group identity, resulting in the "creating of a social context despite the impersonal elements of the medium" (Baym, 1995, sect. 5, para. 7).

Humour online can also allow an enhanced perception of individuality, with each person expressing themselves through the written word by contributing and adding online to a post or thread. Given that body language cues are missing in an online environment, such communication can lead to conflict, misunderstandings and distress as the cues usually seen in face-to-face communication are not apparent. There is a dichotomy apparent here. While in some cases humour can be constructive, alternatively it can be destructive. Either way, humour can be an effective communication tool within an online community. McCreaddie and Wiggins' (2009) research identified that most research into the use of humour comes from a psychological perspective. There has been little research on the use of humour in online therapeutic settings and this research takes an alternative approach to the psychological one by exploring the role of humour on HeartNET.

2.7   Online and Offline Social Worlds

Many researchers actively investigate the culture of online communities which, due to advances in technology, now allow social connections unheard of fifteen years ago. Information is available in different formats with digital information able to be sent, stored and shared seemingly instantly and providing "many-to-many communication that transcends both space and time" (Herring, 2001, p. vii). This is a

far cry from previous communication methods such as the telephone, telegram, fax and letter writing (snail mail). Information can be created, processed, distributed and responded to in very short time frames. Green, (2010, p.6) also underlines the value of the online activity of "searching", whereby information can be accessed online and disseminated to other parties, or added to "through the creation of new knowledge." Silver and Garland (2004) identify the culture of the Internet as a by-product of the stories and knowledge that are shared and stored on it. Kolko, Nakamura and Rodman (2000, p. 5) construct the Internet and in particular cyberspace as "a semi blank slate upon which users write ... a blank webpage, an empty chat room, an unformed public policy – individuals are responsible for how they work with the empty space"

There are many reasons why people access online communities via the Internet. These reasons include communicating with friends, family, and colleagues on a global scale, and the seeking of companionship and information (Barkardjieva & Smith, 2001). For instance, the Internet provides those people who are socially isolated or those with a disability, with a means of communication and connection that in the past would not have been available. For many people, the use of the Internet for investigating health-related issues can be empowering. People are able to communicate with others through websites and at the same time create an identity within the various groups to which they belong (Korp, 2006).

The Internet expands the context of one social dimension to many, which allows the "user to spread their social relations across multiple means of communication and social contexts, blurring locational and medium specific definitions of worlds" (Haythornthwaite & Kazmer, 2004, p. 91). This expansion of opportunity provides Internet users with chances to enter multiple social worlds regardless of time or place. Haythornthwaite and Kazmer (2004, p.89) identify the temporal aspects of the online-offline dichotomy, including the "priorities, needs and rewards involved with managing multiple worlds". While evidence supports an integration of the online world within the offline activity, rhythms such as using chat rooms and support sites are still comparatively new to some people, and their characteristics need to be identified, explored and integrated. This may include identifying and dealing with behaviour cues and conventions which are often absent online (Zhang, Saltuklaroglu, Hudock & Kalinowski, 2011). These must be

identified before friendships can be developed or discarded, or new communication strategies explored. The online environment opens a whole new world in which users can explore, communicate and play.

For any community to be effective there has to be active participation, including the sharing of ideas, thoughts, concerns and opinions. When online, people initiate conversation and create and sustain relationships with seemingly unknown others as a means of maintaining a sense of community (Haythornthwaite & Bregman, 2004). To sustain current communities online participants need reading and writing skills to function successfully, as without these and other skills communication is affected. Haythornthwaite and Bregman identify three consequences of computer-mediated communication. Firstly, the emphasis on reading, writing and expressing oneself in text; secondly, the presentation of the self in text; and thirdly, the continued presence of written thoughts and feelings which remain available to others as long as the site, community or chat-room log remains active. In fact the long term presence of the written word online has been described by Erickson (1999, para.4) as a "persistent conversation" which may be "searched, browsed, replayed, annotated, visualized, restructured and recontextualized." According to Bregman and Haythornthwaite (2003), this conversation can be "renewed or reused". What makes this text-based conversation differ from verbal equivalents is that it is often "generated in the context of ongoing interaction among participants as they create and attend to previous utterances" (Bregman & Haythornthwaite, 2003, p.122). Responses to online conversations or posts may be immediate or may occur days, weeks or even months after initiation of the posting. While many see this persistent conversation as disadvantageous, Erickson and Herring (2005) construct it as a positive means of having large-scale global conversations that can persist for as long as the site remains active.

Creating an identity is both a public and private process. Identity is an integral part of our self-concept and "that part of the self by which we are known to others" (Altheide, 2000, p.2). An individual claims publicly, an identity which has been received and established through interactions with others. Privately, an individual tries out "different facets reflecting different aspects of self" (Gackenbach & von Stackelberg, 2007, p.56). The introduction of the Internet has provided individuals with the means to create and experiment with a multitude of personality attributes

and identities if they wish. What may be constructed as dysfunctional in the offline environment can be seen as "extensions of the self" online (Gackenbach & von Stackelberg, 2007, p.56). The Internet increasingly allows individuals to explore new selves and create new personae.

Research undertaken by Valkenburg, Schouten and Peter (2005, p.383) asked a cohort of 600 teenagers if they had experimented with their identity online in chat rooms and found that half the group had done so. The reasons given included "exploration (to investigate how others react) ... and social facilitation (to facilitate relationship formation)". This investigation and development of different possible identities may have an adverse effect on others online where some of these identities may be perceived as malicious or predatory. This was the case in an early example of misleading identity online. Julie, a physically disabled woman, appeared only able to share her thoughts and insights online, as a result of social and mobility restrictions associated with her disability. While she gathered a committed circle of female friends online, in reality Julie was a male psychiatrist who was fascinated by the insights women provided in their interactions (Stone, 1991). When Julie's true identity was discovered it caused much distress, hurt and betrayal for many of the parties involved. What may have started out as a prank or an exploration of a new self, deteriorated into an online community rocked by cynicism, outrage, distrust and suspicion (Uridge, Rodan & Green, 2012).

2.8   Media

The media plays several roles by providing information, entertainment, "creating meaning, setting agendas for individual and societal discourse, and influencing behaviour" (Grilli, Ramsay & Minozzi, 2009, p. 2). Health information is easy to find in the media with many magazines and newspapers having dedicated health sections dealing with health topics and research (Clarke, 1999). However, while much is written about health this can often be misleading, inaccurate and unreliable (Larsson, Oxman, Carling & Herron, 2003). When reporting on public health issues, the media can play an important role in providing health information.

Australia has close to two thousand media outlets, including television stations, mainstream and local newspapers, radio stations and magazines (Social Change Media, 2005). There are twelve daily newspapers and two national newspapers in

Australia, with little diversity in ownership of the Australian press. Television, print and social media assist users to improve their general and political knowledge and their public and community awareness (Schoenbach, 2004). While the Internet provides health information to many, *The Australian,* a national newspaper, remains a dominant agenda setter for news in Australia and has been considered more influential as a key reference source than the Internet (Australian Press Council, 2006). However, there have been rapid changes in the media landscape and how people access their information due to an increase in the use and access to online and social media. Walther et al., (2010) identify that a person can now "examine the NYTimes.com while chatting about its content with [a] friend via Instant Messenger, [or] one can draw political news from a blogger, and post an individual reaction on their blog as a comment" (p. 18).

The ready availability of online information now means that "traditional mass media or interpersonal sources may be less likely to be easy-going starting points for information seeking. The search engine puts a virtual encyclopedia on every desk" (Walther et. al., 2010, p. 23). Gerhards and Schafer (2010) see the media as a strongly regulated form of communication which is being superseded by the ready access to information via the Internet which is now "increasingly considered as a legitimate information source and is, in part, superseding the old mass media" (p. 145). Walther et al., (2010) and Gerhards and Schafer (2010) believe further debate is required to determine if Internet communication is better than traditional media. It may well be that there will be a place for both.

Investigations of health information found in the media have demonstrated several areas of concern. These include the brevity of information found both in television and print media. Television health reports are usually less than a minute and print stories are typically fewer than 500 words per item. Many stations and newspapers do not employ full-time health journalists and may rely on sensationalism and hyperbole to add impact to the information reported. There is also a risk of commercialism with many reports including links to private health providers or pharmaceutical companies (Schwitzer, 2004, pp. 0576-0577). Other issues relevant to health reporting include the fact that story selection is more likely if it has a "quirky or feel good element" or portrays a "cute child" in need of treatment, as opposed to items focusing on health policy (Picard, 2005, p. 604). There is also likely to be more emphasis on local research, because people are more

interested in what is available in their home environment. Alternatively, coverage maybe so technical that it is difficult for lay people to understand the implications of what the media is reporting.

Research shows that 75% of the general population pays a "moderate amount" or a "great deal" of attention to media reports (Johnson, 1998, p. 87). Newspapers often carry stories that show the latest medical research sometimes based on findings from medical journals (Entwistle, 1995). Bonevski, Wilson and Henry (2008) confirm previous findings and emphasise the importance of ensuring that the information provided is of the highest quality. Johnson (1998, p. 92) asserts that a newsworthy story will make an impression on the reader regardless of its origin and accuracy therefore it "may be very helpful, but if it is not [accurate] then it may be very misleading". Readers found "illnesses that heavily affect the lives of patients and their families" were more newsworthy according to Caspermeyer, Drazkowski, Watson and Sirven (2006, pp. 300-306). These authors found this impact was irrespective of the "medical or scientific value physicians might assign the information" (Caspermeyer, et al., 2006, p. 300-336).

Although, the majority of health reports may be presented accurately and give a balanced view, health breakthroughs sell newspapers, and sensationalising a story can create a "national media feeding frenzy" (Ransohoff & Ransohoff, 2001, p.185). Balance in reporting a news story is therefore vital (Bubela & Caulfield, 2004). Editors and journalists need to decide if the story is worthy of headlining or not. Pirkis et al., (2001, para 2) found that when the media reported on mental health issues they were only deemed "newsworthy" if they were "offbeat, curious or bizarre". There are times when the "representation of illness in the media […] plays an important role in determining community understanding and acceptance of those affected" (SANE Australia, 2009, para. 1). This is especially true for stigmatised members of the population who are stigmatized, such as those with mental health issues.

2.8.1 *Medical reporting in the media*
The media is known to be a primary source for health information and the quality of media reports can differ dramatically, which has an impact on the general public (Cullen, 2013). Favourable publicity can lead to increases in the utilisation of health services while unfavourable reports lead to a decline. For example, when

Kylie Minogue was diagnosed with breast cancer this "generated a 101% increase in never-screened women booking for mammograms" (Bonveski, Wilson & Henry, 2008, p. e2406). In contrast, the reports of hormone replacement therapy (HRT) impacts on heart health led 28-40% of women using HRT to drop their treatment (Schwartz & Woloshin, 2004). Research undertaken by Shuchman and Wilkes (1997, p. 976) found that when incomplete data was released by the American Heart Association that "6 million persons in the United States who were receiving channel blockers for hypertension might be increasing their risk of heart disease by 60%" (American Heart Association, 2014), this led to an immediate reduction in the number of people taking the medication and increased patient contact with health care professionals. The report was later found to be inconclusive. However, incomplete data and poor management by both researchers and journalists led to unnecessary distress.

Medical stories compete with general stories for space, which leads to stories often needing to "reflect established news values such as the size and impact of an event, its relevance to readers, and strength of human interest" (Entwistle, 1995, p. 922). Wallington, Blake, Taylor-Clark and Viswanath (2010, p. 491) found that some journalists chose to avoid using "angles that may be seen as controversial by reading or viewing audiences", while other journalists utilised an angle for the story that would be most likely to grab readers' or viewers' attention and evoke a range of emotions (e.g. joy, delight, anger, etc.). Journalists state that "medically worthy information is not necessarily newsworthy" (Entwistle 1995, p. 921). Many journalists see reporting on health as no different from any other reporting role. Even so, Schwitzer (2005, p. 0576) believes that "journalists have a special responsibility in covering health and medical news […] readers and viewers make important health care decisions based on the information provided in our stories". Research has shown that a significant proportion of viewers get their health news and information from television. The problem with this is that most stories are no longer than 45 seconds (Schwitzer, 2005). As with any reporting, it is important that sensationalism is avoided and that misleading, misinformed and incomplete or biased, information is not reported. Mudur (2005, p. 215) believes that providing a context for every health report is crucial, especially when advances in health care are made available.

2.8.2   *Gender stereotypes*

Cardiovascular disease is typically reported in the media from a masculine perspective, even though it now affects women equally (Curry & O'Brien, 2006). Many media reports depict females and males in gender specific roles which may result in viewers "constructing a gender meaning from the advertisement" (Curry & O'Brien, 2006, p. 1971).. In fact, to many, heart disease in women "was not something they took seriously or personally, largely viewing it as a 'man's' disease" (Long, Taubenheim, Wayman, Temple & Ruoff, 2008, p. 3) and stereotypically, heart-related advertising was portrayed as masculine. This finding was backed by research undertaken by Carey and Grey (2012, section 3, para. 8) whereby:

> Too many women do not think of heart disease as a "woman's disease," so they often fail to appreciate the relevance or benefit of seeking out and participating in clinical trials. Furthermore, investigators have historically focused efforts on enrolling men, as this disease was once considered a "man's disease." Result interpretation and application in the clinical setting has classically been applied on the premise that results are gender neutral.

Carey and Grey (2012, section 2, para. 9) determined that the majority of women studied were more likely to utilise their obstetrician as their primary care giver and due to this speciality, they tended to emphasise "breast and reproductive health, not heart disease risk reduction". Due to the misperceptions that females are protected against heart disease due to hormones, or that breast cancer causes more deaths than heart disease (Armstrong, Carpenter & Hojnacki, 2006, p. 739), there are fewer women in heart studies and fewer clinical trials (Maas & Appelman, 2010). The American Heart Association reported in March 2014 that:

> while many Americans may think heart disease is a man's disease, it is in fact the No. 1 killer of women, and sometimes affects them in different ways. Yet, as this helpful new report points out – only one-third of participants in cardiovascular clinical trials are women, and fewer than 31 percent of trials with women report outcomes by gender (American Heart Association, 2014, para. 3).

Van de Weyden and Armstrong believe "media coverage provides an essential link between the providers and users of health care" (2005, p. 188). Readers acknowledge they find information from the media to be less trustworthy than their health care practitioners, but admit that media sources are "still an important textual resource for health information, possibly because they are immediately available and

because they use accessible language to deal with complicated information" (Hellyer & Haddock-Fraser, 2011, p. 14).

2.8.3   *Online media*

When searching online databases for recent research on how the mass media reports heart disease to the general public, over six hundred thousand web references were revealed. However, the first sites were predominantly statistics based and most were related to research prior to 2005. There is clear evidence that people find the Internet "a valuable and effective way to communicate, especially about health related issues" (Zrebiec & Jacobson, 2001, p. 154). This was confirmed by an Australian Communication and Media Authority (ACMA) survey which found that around 46% of all online queries were looking for travel, or health and medical information (Australian Communication and Media Authority, 2009, p. 2). Reinfeld-Kirkman, Kalucy and Roeger (2009, p. 422) indicate that individuals who report they have a chronic medical condition are more likely to search for health information on the Internet, with men and single people looking for information online less often than women or those who are married or in a de facto relationship.

While many people avidly search the Internet for information (Andrews, Preece & Turoff, 2001), the quality of the medical news available scored poorly when evaluated by Smith, Wilson and Henry (2005). They found that reports were lacking pertinent information such as the "benefits and harms of interventions, [and failed] to mention costs of treatment … or to obtain independent expert commentary" (Smith et al., 2005, p.192). The researchers felt there may be a degree of "immediacy" in reporting online that compromised quality.

2.9   Summary

This literature review discusses the significance and impact of heart disease on the general population and notes that heart disease is still identified as the main cause of death amongst all Australians. A brief history of the Internet has been used to explain how this medium has significantly changed the ways in which many people communicate. As discussed, while there is much current debate within Australia about high-speed broadband connectivity, the digital divide and users' access to the Internet, advances in technology and improved accessibility mean that users are becoming more proficient at finding the health information they require online.

Thus, the literature shows many people have integrated their use of online support groups and communities into their daily life, providing members with an opportunity to share common interests, ask questions, and seek, receive and give support and information.

The concept of the gift economy is identified and explored from a social perspective, with an emphasis on the reciprocal nature of gift exchange. While people within this gift exchange are often unaware of any imbalances that may result, the literature reveals that gift exchange in an online environment where information and support are freely shared, helps provide equity of access.

The remainder of the literature review explores the construction of online communities and their effectiveness as a means for communication, along with the opportunities these interactions offer for members to share thoughts, feelings and opinions in a relatively safe and anonymous environment. The literature review also explores the notion of identity formation and how the Internet allows people to develop their sense of self through interactions online.

A diagnosis of heart disease can evoke multiple emotions. Some people experience grief, others chronic sorrow. Dealing with ill health meanwhile, can disrupt people's perceptions of, and beliefs about, their bodies. Four ways in which an individual may choose to reconstruct themselves after a medical diagnosis are identified and elaborated on later in this thesis using examples from the HeartNET community. Roles considered include the supernormal identity, the restored self, the contingent personal identity and the salvaged self. This typology would appear, from the data to be presented, to have particular relevance to heart patients.

The final section of the literature review explores the role of the mass media as an 'agenda-setter' and its continued influence as a key health information reference for many people. Issues discussed include mass media inaccuracy, credibility and the use of quirky or feel-good elements and sensationalism to sell stories. Evidence is also presented about gender stereotypes and heart disease that are perpetuated through the media, and how celebrities or role models are often used to sell a story or highlight an issue.

The following chapter discusses the methodology used to undertake this research and to address the research questions. It provides an overview of the

ethnographic approach, netnography, which was the main approach utilised when researching online and offline interactions among members of HeartNET.

CHAPTER THREE:
METHODOLOGY

This chapter provides a detailed description of the broad methodological approach taken in this thesis. The research process employs a qualitative netnographic approach to investigate how HeartNET members live and identify themselves as heart patients. It also identifies whether media representations of heart messages on HeartNET influenced interactions between members of the site.

The chapter identifies the rationale for choosing a netnographic approach, followed by a discussion of the research procedure which includes the difficulties experienced in the recruitment process. An outline of the structure of the data collection is described and the chapter concludes with an overview of the data analysis.

3.1   Introduction

A multi-method approach has formed the basis of this research. Interactions on HeartNET have been analysed, an initial questionnaire which helped with the formulation of the in-depth interview questions, and an analysis of the print media's portrayal of heart disease. Additionally, the research used access to a small control group. The multiple approaches and interpretations helped me achieve a fuller understanding of the "phenomenon from different perspectives and … [the] technique of triangulating different sources of data [which] helps to achieve methodological rigor (accuracy and credibility) of the study" (Aldiabat & Le Navenic, 2011, p. 9). Results have been fairly presented from the "perspective of the participants who have experienced the phenomenon" (Aldiabat & Le Navenic, 2011, p. 10). Streubert and Carpenter (1999, p. 17) point out that it is the "quotations, commentaries and stories [that] add to the richness of the report and to the understanding of the social interactions".

This research comprises over seven years of participant observation in HeartNET, plus face-to-face meetings, in-depth interviews either in person or over the telephone, and numerous interactions on HeartNET via postings on the bulletin board, chats in the chat room, personal and private messages and email interactions.

It was determined early on that a netnographic approach to this research was an appropriate research method. Netnography is "participant-observational research based in online fieldwork [using] computer-mediated communications as a source of data to arrive at the ethnographic understanding and representation of a cultural or communal phenomenon" (Kozinets, 2010, p. 60). It also provides a "written account that results from field work studying online, using computer-mediated or Internet-based communications" (Beckmann & Langer, 2005. Abstract). The current research into HeartNET predominantly investigated online interactions, however, like many other ethnographic studies, it also involved the researcher making offline contact with participants using what Garcia et al., (2009, p. 55) identify as "multi-modal social worlds as research settings". A key component of the second iteration of the HeartNET research is the fact that the moderator had access to a captive population of HeartNET users (Bryman, 2012). This access to historic postings on the discussion board and chat room provided a valuable source of data for this research. Seale, Charteris-Black, McFarlane and McPherson (2010) argue that collecting and analysing online posts gives the researcher access to the immediacy of the posters' experiences, and an insight which is not influenced by the interviewer or the moderator.

3.2   Ethnographic Research

Ethnography is a research methodology that studies the social interactions of a specific group or community with the aim of providing insights into people's views and actions, as well as the nature of the location they inhabit, through the collection of detailed observations and interviews (Reeves, Kuper & Hodges, 2008, p. 512). Key features of an ethnographic approach include exploring particular phenomena, working with structured data similar to that used within grounded theory, and analysing the data obtained using primarily "verbal descriptions and explanations" (Reeves et al., 2008, p. 512). Netnography encompasses both online interactions and face-to-face interactions and "the culture (or cyberculture) shared between and among them" (Bowler, 2010, p. 1271). It provides an opportunity for researchers to study online communications between members of specific groups or communities and allows these researchers to understand members' "perceptions, imagery, attitudes, and emotions" (Isupova, 2011, p. 3).

Adler and Adler (1987) identified a typology of membership roles for researchers undertaking ethnographic research. Firstly, peripheral researchers are those who are involved on a daily basis with members of the group under investigation, but have a "marginal role or are least committed to the context" (Adler & Adler, 1987, p. 13). Secondly, active researchers are those who become involved with activities, have a functional role as well as an observational role, but do not commit to the wider members' values and goals. Thirdly, complete member researchers are those who are already members of the group under observation or become fully immersed in the research. Over time, as the moderator and researcher I became an active member of HeartNET while still maintaining "role awareness" and "periodically withdrawing from the setting" to maintain my research role and objectivity (Adler & Adler, 1987, p. 13).

With the introduction of an online or virtual ethnography, Kozinets' netnography, researchers have a methodological framework for interacting in online communities (Kozinets, 2010; Reeves et al., 2008).This allows the ethnographer to "discover phenomena … meaningful to the host community … that would have been missed if the research had followed a positivist orientation of investigator control" (Whitehead, 2005, p. 6). Utilising participant observation of the group being studied necessitates the researcher becoming directly involved in and engaged with the culture under study. This was certainly the case on HeartNET. As the moderator, I immersed myself in all aspects of this site and could be found on HeartNET at any time of the day or night, clearly visible to all members and guests who accessed the site. In fact, the visibility of site engagement meant that one proviso when undertaking research on HeartNET was that, while all moderators appeared on the site as themselves; only pseudonyms and nicknames were encouraged for HeartNET members.

Ethnography provides multiple ways of seeing things from an insider's perspective, with Wolcott (1999, p. 137) arguing that "every view is a way of seeing, not *the* way of seeing". Hine (2000, p. 21) elaborates by stating that "ethnography is a way of seeing through participants' eyes". Another major aspect is the creation of friendships during the ethnographic/netnographic process. Coffey (1999) and Rabinow (2007) expand believe that friendships enhanced their fieldwork, shaping the "identity and experiences of both the researcher and the informant beyond the

parameters of the field" (Taylor, 2011, p. 7). In fact, Powdermaker (1966, pp. 261-262) noted that in many of his fieldwork experiences there were always one or two people with whom he developed an "exceptionally close friendship ... who provided the deepest communication". He believed this contact and friendship allowed him to make sense of many aspects of the group with which he was involved.

Insider research is defined by Kanuha (2000) as research undertaken by researchers who are members of the group under investigation. Asselin (2003, p. 100) expands on this definition by arguing that the researcher "shares an identity, language and experiential base with the study participants". The insider role however, can have inherent problems. For instance, the researcher and participants can find "themselves caught between loyalty tugs and behavioural claims" (Coghlan, 2007, p. 297). This was something that I needed to remind myself about constantly; especially when I was participating in HeartNET events. I felt free to move from my role as participant observer, moderator and researcher, but at times would catch myself thinking that some of the information disclosed, especially during social gatherings, was what Pruulmann-Vengerfeldt, Tatsi, Runnel and Aljias (2012, p. 305) identify as "undiscussable". This could be a comment made on the spur of the moment, or that people shared because they had invited me as a guest to the gathering, not as a researcher. While I maintained my role, over time acceptance into a group like HeartNET can provide a "level of trust and openness in your participants that would likely not have been present otherwise" (Dwyer & Buckle, 2009, p. 58). This situation has a range of ethical implications.

Coffey (1999, para. 17) sees the ethnographer becoming an "insider or native over time". She continues by suggesting that an ethnographer's roles and relationships with the culture they are studying changes over time. She elaborates on the differences between researchers who are relative strangers when they commence their research, and those who have some awareness and enter the research from a "position of knowing – where the researcher already possesses some of the esoteric knowledge and an empathetic self" (Coffey, 1999, para. 18). When I took on the role of moderator, HeartNET members quickly became aware of my nursing background, even though I clearly stated I was no longer registered and had not worked in that field for more than ten years. My previous occupation appeared to give me as moderator, an insider view in the sense that members responded to me as if I had

layers of professional expertise in addition to the researcher role, even though I had only recently started on the HeartNET site. I would be contacted and asked what I thought about certain things and would then refer members to their general practitioner (GP) or health professional. Coffey discusses this overconfidence and trust that ethnographers are often given by participants, where at times the researcher does not know what to do with the information divulged. Carter, a researcher and ex-police officer, investigated prison culture. He identified the difficulties an ethnographer can be placed in, where one "welcomes the opportunities it afforded and the acceptance it implied, while being extremely wary of the level of familiarity and loyalty it assumed" (Carter, cited in Coffey, 2009, para. 32).

One challenge faced by many ethnographic researchers is identified by Dwyer and Buckle (2001, p. 58) as "role confusion". This was something I became aware of during my time as moderator of HeartNET. While I was able to maintain a degree of objectivity, I was often challenged by some of the HeartNET members about whether I was on HeartNET as a researcher or as their 'friend'. While I always saw my role as that of researcher/moderator, it became clear that some members of the site saw me as more than that. The reasons I was on HeartNET and the role I played became blurred over time. I would be asked to attend functions, parties, coffee mornings and evenings and, if these events conflicted with my own family life, I would later hear that I had disappointed the person who had invited me. At times there was an expectation that I would address in some way the disappointment caused by my lack or absence. Dwyer and Buckle (2009, p. 59) state that the "core ingredient is not insider or outsider status but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience" . I always attempted to act in these ways, but am left wondering if I fell short of this mark for some of the HeartNET participants.

3.2.1 *Netnography*

In an early edition of his ground breaking book, Kozinets (2002, p. 64) says that netnography is "based primarily on the observation of textual discourse". Using a netnographic approach allows researchers to study communities or cultures that have arisen from computer-mediated communication. Researchers in online communities "watch text and images on a computer screen rather than watching

people in offline settings" (Garcia et al., 2009, p. 58). Since participants communicate online, the netnographic methodological approach identifies the researcher role in an online setting as that of a "participant–experiencer" whereby the researcher adopts the role of "active contributor to the group being studied" (Walstrom, 2004, p. 175). This allows the moderator and researcher to "experience what it is like to participate in the group [HeartNET] by reading and posting messages to the group" (Garcia et al., 2009, p. 58). While Kozinets identifies netnography as a less intrusive way to investigate social cultures, Langer and Beckman (2005, p. 192) believe that "netnography provides researchers with the opportunity to gather 'a thick description' of the life worlds of consumers."

Kozinets (2010) indicates that in the early stages of online interaction "the online experience [is] often more like the reading of a book than the sharing of a conversation" (Kozinets, 2010, p. 7). Kozinets states that the people who participate in online sites are real people who have created real communities. Members can feel a very strong sense of connection. Indeed, this is the reason why people keep returning to the community. Such connections can lead to meetings in real life. Even though site rules and protocols suggest that people keep their identities private, self-revelation is a natural progression as friendship and intimacy develop.

There are many advantages to using a netnographic approach when undertaking research into online communities, including the fact that researchers are provided with continual access to the users of the community, and for the most part, remaining unobtrusive while still observing members "in a context not fabricated by the researcher" (Kozinets, 2002, para 6). Disadvantages include limitations due to a "narrow focus on online communities, the need for researcher interpretive skill, and the lack of informant identifiers present in the online context that leads to difficulty generalising results to groups outside the online community sample" (Kozinets, 2002, para 7).

3.2.2 *Participant observation*

Bowling (2009, p. 387) identifies participant observation as a "qualitative observational technique which involves the observer (researcher) in the activities of the group being observed". Some research is covert, but this was not the case on HeartNET. Researchers have always identified themselves and at no time was their role concealed or covert actions undertaken. This prevents the risk of site members

becoming distressed as a result of thinking they had been deceived. It also provides legitimacy. Pope (2005) found that an observer's presence as a participant was legitimised if there was a credible organisation sponsoring the group or site. This is the case for HeartNET which is situated on the Edith Cowan University server and supported by the National Heart Foundation WA and Australian Research Council funding.

Bryman (2012) identified four key study methods used by qualitative researchers to investigate online interaction. All involved immersion in the environment under study, to differing degrees. These four methods are:

> Type 1: The study of online interactions on blogs, websites, and discussion boards with no involvement. Often the "researcher lurks on the peripheries without identifying themselves" (Bryman, 2012, p. 663)
>
> Type 2: Where researchers study online interactions with minimal interaction. The researcher may play some role on the site, but still overtly or covertly analyses the interactions.
>
> Type 3: Where the researcher studies the online interactions and offline interactions. While similar to Type 2, the researcher is also involved in either online or offline interviews.
>
> Type 4: Researchers study both online and offline interactions and are also involved in online or offline interviews. Most importantly, the researcher plays an active role in the offline world of those being studied and attends activities as well (Bryman, 2012, p. 663).

As a Type 4 researcher, I was quickly immersed into the running of HeartNET and within about six weeks of taking on the role of moderator, I was invited to a breakfast at Simone's house, a participant on HeartNET. I was initially reluctant to attend. However, I accepted the invitation believing that this would lead to developing a relationship with the active members on HeartNET. I had been asked to contribute bacon and fresh bread. I knew little about dietary restrictions for people with heart disease, so spent some time at the deli counter looking at various types and cuts of bacon and determining which I thought was the healthiest, i.e. had the least amount of fat on it. On arrival, I produced healthy bacon with little fat. Simone looked me in the eye and asked "Where's the fat? Bacon doesn't taste right if there's not fat!" With much laughter the breakfast continued. This was my first introduction

as researcher to learning, observing and in turn, understanding the reality of life with heart disease as lived by many CVD patients.

Mann and Stewart (2000) identified the creation of mutual trust as a key component for researchers who wish to develop a relationship with their project participants. This is especially important when participants need to commit to long term involvement in the research process. It allows the researcher to return to participants for clarification and elaboration on key points and if necessary, confirmation of issues that may be identified throughout the research process as it progresses. Attending social events hosted by HeartNET members helped me to build this kind of trust.

While participant observation is mainly concerned with observing group members and recording activity, there is also a need to utilise more

> than one source or method of data collection […] with fieldworkers relying on other forms of information such as documentation […] mass media coverage, and [discussions] with respondents which may vary in formality from casual conversations to tape-recorded interviews and routinized surveys (Waddington, 2004, p. 154).

It has always been the intention of this research project to allow the members of HeartNET to tell their own stories and to give them with an opportunity to voice their own experiences through the use of verbatim, first person accounts of their experiences.

3.2.3   *Ethical considerations*

Before undertaking this research, I was required to obtain ethics clearance from Edith Cowan University's (ECU) Human Research Ethics Committee and to ensure that the research undertaken met the guidelines outlined in the *National statement on ethical conduct in human research* (National Health and Medical Research Council, Australian Research Council, & Universities Australia, 2007). An application was forwarded to the ECU Ethics Committee outlining the research that would be undertaken on HeartNET and I included a Risk Assessment of Potential Issues Associated with this Research (Appendix 1), which assisted me in anticipating and addressing issues that might arise when interviewing participants who may be vulnerable and marginalised due to their health condition.

When people are interviewed about their health conditions, there is a possibility that reliving their heart events can cause undue stress. This was something I was concerned about, and as I was aware of this possibility I stayed with any participant who expressed distress until they were comfortable and reminded them to access their health care team if they had any concerns. I also provided details of a phone-based helpline. If I was concerned about them, I rang the next day to ensure they were all right. I also kept the research team informed.

3.3   Recruitment Process

Following ethics approval I began active recruitment of participants for this research. Initially it was hoped that I could recruit patients via the National Heart Foundation WA (NHFWA) division database, Perth metropolitan hospital cardiology outpatient clinics and via the HeartNET website. It soon became clear that this was not possible. The contact person at the NHFWA resigned and it proved difficult to recruit through the Heart Foundation. As part of the Heart Foundation involvement in the recruitment process, a poster was designed and printed to assist in publicity via community notice boards in local shopping centres and in West Australian public libraries. Immediately after it was printed it was discovered that it did not conform to the revised NHF branding statement, and as the research was supported by the NHFWA, the Heart Foundation requested the poster be redesigned. This meant that the initial poster had to be recalled and a new one developed. Ultimately a poster was reproduced in conjunction with the NHFWA and ECU graphic designers which conformed to all requirements, but this false start and subsequent change resulted in a significant delay in getting posters delivered.

I also spent many hours in consultation with the cardiac rehabilitation nurses attached to the two major hospitals in the Perth metropolitan area to see if posters could be placed in their offices and the cardiac outpatient clinics. While I had hoped to spend time in these clinics and talk to anyone interested in participating in the research, this suggestion was eventually refused by the consulting team. Since the research was not medically based or attached to a medical school, the researcher was unable to satisfy the requirements of the Hospital Ethics committees and therefore, they did not allow recruitment through their cardiology departments or approve the placing of posters in any cardiology clinics or wards.

An article also appeared in the metropolitan and some regional community newspapers with a request for people who were interested in sharing their heart story to get in touch with me (*Please share your stories*, 16 June 2009). This article appeared in approximately nine community papers and resulted in two people offering to participate in the research. Unfortunately, due to the community newspapers' copyright restrictions, it is not possible to include a copy of the article in this thesis. I also attempted to recruit via community seminars and various Lions Clubs and Rotary meetings.

Existing HeartNET members were also recruited to participate in this research. Since its inception members have made over 10,000 postings to the HeartNET site and these postings were investigated as part of the data collection and analysis, and to identify the existence of potential interviewees.

It proved a constant difficulty to find newly diagnosed heart patients. Many people with a heart condition were already well past their initial diagnosis when they registered on HeartNET and had commonly experienced previous heart events. A number of factors affected recruitment. Firstly, there were some issues of misdiagnosis. Often people would come onto the site and say they had been diagnosed in the emergency department with a specific heart condition, only to discover via a follow-up appointment they had another diagnosis not related to CVD. While others wanted to participate, but then found their heart condition precluded them from continuing. Some also felt they needed to complete medical treatment or were unable to deal with being part of a research project while they were recovering from their immediate heart health issues. The challenge was to recruit people with a new diagnosis who were still coming to terms with their identity as a CVD patient.

Initially I aimed to recruit twenty eight (28) people for this research. Due to recruitment issues, the final number of interviewees was twenty-six (26) and included fourteen (14) active members of HeartNET and twelve (12) non HeartNET members. These participants were given an information letter (Appendix 2) to explain the nature of my research and a screening questionnaire (Appendix 3). If they met the criteria and expressed an interest in participating I would then contact them to set up an appointment to interview them at their convenience.

To ensure all data collected from postings to the HeartNET site and in-depth interviews remained confidential, all participants and their interactions were de-identified. All quotes that have been used throughout this thesis have been assigned a pseudonym to ensure participants' identities remain protected. At times gender has also been changed and where towns, places or Australian states have been identified these may have also been altered to ensure anonymity and confidentiality is maintained. In places where information has been divulged that could be seen as sensitive in nature, I also ensured the participants consented to the use of the material in the research and made certain that my supervisors and the research team were informed.

After completion of the twenty six in-depth interviews, the audio files were transcribed. The pseudonym assigned to each interviewee is the pseudonym that has been used throughout this thesis. To ensure this research conforms to Edith Cowan University's *Policy on the conduct of ethical human research* (Edith Cowan University, 2007) and the *Australian code for responsible conduct of research* (National Health and Medical Research Council, 2007) all data will be stored and destroyed five years after the completion of the research in the appropriate manner.

3.3.1   Research process

The current research was divided into five distinct phases. In the first phase I moderated the HeartNET site, attended coffee mornings and breakfasts, and became an integral part of the HeartNET community. The second phase involved the recruitment of participants and in-depth interviews when participants first entered the study and again nine to twelve months later. The third phase involved netnographic data collection and an analysis of the postings to the HeartNET site. Phase four involved collecting media articles over a three month period to analyse how cardiovascular disease is portrayed in the *West Australian* and *The Australian* newspapers along with an analysis of HeartNET postings on the site regarding media issues raised in the print media. The fifth and final stage involved an analysis of the data and writing the thesis. While each of these phases has been reported in a linear fashion, the researcher was often involved in several phases at the same time.

3.3.2   Moderation

The HeartNET website has been available to members since 2005. I had some experience in moderating an online site prior to starting my PhD, as I am involved in

the moderation of several non-health-based sites. Initially, I had a six month period where the previous moderator was available to answer any queries and to suggest methods of response where I was unsure about what to do. Ultimately however, I took on the role of moderator with the assistance of a lay counsellor, Gerry, who was also involved in the Heart Foundation and a heart patient. Moderation is an integral part of the HeartNET site and over time the participants accepted me as their new moderator.

The moderator's role is clearly defined on HeartNET. The two main functions of the moderator are to ensure users are offered support without offering medical advice and to encourage members to help and support each other, which in turn helps build a sense of community (Williams & Cothrel, 2000, p. 38). There has been much research conducted on the role of the moderator (Preece, Nonnecke & Andrews, 2004; Preece, 1998). Williams and Cothrel (2000) have identified several key strategies that moderators can use to help create a sense of community in an online support site like HeartNET. These include "clarifying but not editing or policing interactions", where the moderator reads and maintains the site and only makes changes to a post when the post "contains personal information, or deliberately attacks other members" (Williams & Cothrel, 2000, p. 83). The moderator must also learn to understand and address the needs of site members and this occasionally involves meeting or communicating with the author of a post to make sure the moderator understands what the author is actually saying. This is especially relevant in an online environment where many of the "feedback cues that are used in face-to-face communication" are missing (Basdekis et al., 2006, p. 42). Encouraging the members of the site to "keep the conversation going" also allows the moderator to ensure that members' interactions are centre stage, by encouraging interactions, but not taking over or using the site for the moderator's personal benefit. The moderator must also show a 'human side', and it is helpful if he or she is able to draw on personal experience when assisting or supporting site members (Williams & Cothrel, 2000). One issue that is often difficult for a moderator is to allow members an "opportunity to vent" (Williams & Cothrel, 2000, pp. 83-84). Although interactions on HeartNET are monitored to reduce the risk of personal attacks which may escalate into 'flame wars', the moderator also spent several hours a week on site responding to queries and ensuring the site ran smoothly.

3.4 Data Collection

3.4.1 In-depth interviews

Prior to commencing any in-depth interviews' I ensured the participants read the contents of the in-depth interview information letter (Appendix 4) and asked them to sign an in-depth interview consent form (Appendix 5). This occurred at first contact and again six to twelve months later, as it was important to establish that interviewees were prepared to participate in the study. They were also reminded that they could stop the interview at any time and then asked if they wished to proceed.

Data collected in the first in-depth interview provided the researcher with information about the participant's heart story, the impact of their heart disease and about the support structures they had in place. Final questions were related to heart health information and advertising (Appendix 6). This data provided valuable insights into the "*life-world* as it is lived, felt, undergone, made sense of and accomplished" by the participants of this research (Polkinghorne, 2005, p. 138).

The second in-depth interview (Appendix 7) asked participants to tell me about any changes to their heart health and they were asked to discuss how this had affected their daily life. They were also asked to discuss issues related to the media. During the interview I encouraged the participants to discuss their heart stories, and at times I had to bring them back on topic. Over a period of around sixty to ninety minutes I was able to capture the "richness and fullness of the experience" (Polkinghorne, 2005, p. 137) which would not have been available if the participants had only completed a questionnaire. The use of one-on-one interviews also maintained participants' dignity as the discussion was related to "the personal and private dimensions of people's lives" (Dare, 2009, p. 47).

One challenge faced in recruitment and subsequent interviewing, was finding suitable participants for the research which was designed around investigating the formation of a heart patient's identity during the first six months following a heart event. It soon became apparent that some heart patients were able to seek support immediately, while others could "only articulate a story about suffering long after experiencing it" (Charmaz, 2002, p. 303). However, many of those who had experienced their heart event a long time previously could recount every minute of that event as though it had 'happened only yesterday'. In fact, while interviewing

participants I would often have to pause and wait for them to gather their thoughts, and allow them to regain their composure, before they could continue telling me their heart story no matter how long it was after their first heart event had occurred. Often, participants would hesitantly discuss their feelings, look away, pause and re-focus while they thought about their experience, then take a deep breath and continue. Sometimes, with tears in their eyes, they would recount something poignant that had happened, but if given the opportunity to stop, they would shake their heads vehemently and state "No I need to tell you this!"

For one participant, Penny, discussing her heart event elicited a physical response. She mentioned how she could feel her heart racing: "Sorry I can even feel a physical response to it … Now I feel teary now" (Penny,☏). I wanted to stop, but she was adamant that we should continue. After her interview, I admitted to Penny that she had frightened me and I was poised to call an ambulance if it was required. She laughed and told me the emergency services were on speed dial on her phone and she knew most of them by their first names. This bought home to me how significant participants' stories were and how important it was to them that I allow them to tell their complete stories. Sharing these stories meant that "meanings [would] emerge [that helped] clarify the collective power of people striving to be understood", while at the same time people came to terms slightly more with their new found identity as heart patients (Charmaz, 2002, p. 305).

I consider myself fortunate to have been able to immerse myself into the HeartNET community. I was readily accepted as the moderator and went on to develop ongoing relationships with many of the HeartNET members, which has given me valuable insights into their everyday lives. Many times during the interview process I would stop and think about how willing these people were to tell me their heart story, along with explaining their heart health's subsequent effect on their lives and lifestyles. Often HeartNET members would comment on how ordinary their lives were. Not so. The interactions I had with participants demonstrated the extraordinary feats people can achieve when they have to deal with ill health, and the rich detail that emerges when people are given the opportunity to talk about themselves and tell their story.

3.4.2 Archival data

HeartNET data collection often involves what Kozinets (2010, p. 96) describes as "archival interactions". This involves the collection of online interactions that the researcher is not directly involved in, or online communication initiated and instigated by the site members without any prompting from the researcher. To date, there are over 10,000 postings on HeartNET. The moderator reads new posts every day and any issues or topics relevant to this current research are identified, flagged and then analysed for relevance. Markham (cited in Kozinets, 2010, p. 106) believes that all participants' posts should be "presented exactly how they appear on screen, in the original font, without any corrections of spelling, grammar or punctuation". Markham also believes that when a researcher alters a participant's posting they "literally reconfigure these people" (Markham, 2004, p. 153). To the best of the researcher's ability, direct quotes have been presented verbatim in this research. The only time quotes have been changed is to de-identify names and places or to explain jargon or terminology specific to the HeartNET website and its members.

On HeartNET, netnographic data collection allowed me to "endeavour to understand the people represented in these interactions from within the online communal and cultural context in which they are embedded" (Bartl, 2009, p.3). Immersion into the HeartNET community meant that I could "become sensitive towards the attitudes and the communication mode of the community members" (Bartl, 2009, p.3). The data collected was predominantly "archival data, elicited data and field note data" (Kozinets, 2010, p. 98).

3.4.3 Elicited data

According to Kozinets (2010, p. 98), elicited data is material "co-created by the researcher and the participants." This includes private messages, chat room interactions and any private communication between site members and the moderator/researcher. There are two methods of eliciting data netnographically. These methods are through communal interaction, and through interviews. HeartNET provides an ideal venue for communal interaction as demonstrated by the thousands of posts to the site since its inception in 2004. Over time, the researcher has initiated and responded to many HeartNET posts. It has become obvious that developing and creating relationships on the site led to valuable and insightful perspectives from HeartNET's members.

3.4.4 Field notes

Field notes represent my observations of the community and its members, and the interactions that occurred (Kozinets, 2010). The use of unstructured observations helped to provide me with insights into situations that arose during the course of the study. Observations offer an overall picture along with context and insight into the environment under review (Mulhall, 2003). Over time, the use of keywords and jottings allowed me to identify areas that needed to be elaborated upon or explored in more depth (Emerson, Fretz & Shaw, 2011). I often took observational notes, as a means of ensuring I didn't forget important factors or to remind me to ask participants to elaborate on some of their insight.

3.4.5 Issues raised in the print media

When I took on the role of moderator from the previous incumbent, one of the issues identified was how the print media portrayed people with CVD. To determine how heart disease was portrayed I conducted a content analysis of articles published during the period from March 1 and June 30, 2010 in the *West Australian* and *The Australian* newspapers. These articles were obtained from the *Factiva* database. A keyword search was undertaken for any articles that included words such as heart disease, cardiovascular disease, heart attack and the Heart Foundation. Once the articles had been downloaded they were read to determine if they pertained to local, national or international research and also whether the item was a feature article or a general article. Specific criteria were also used to determine if the newspaper articles were relevant to the study. Articles had to mention the keywords, appear during that time frame and be in those particular newspapers to qualify. In total 110 articles were obtained from both papers that met the criteria. On further examination they were then categorised as relating to lifestyle, political or medical issues.

The reporting of health stories in the media can have an impact upon and potentially influence the ways in which people gather health information and make decisions about their health. Media reports can influence decision-making about seeking health care. Depending upon how a story is reported, it has the potential to raise people's hopes about possible cures or alternatively cause distress or alarm (Leask & Chapman, 2002). Health reporting can influence "individual health behaviour, health care utilisation, health care practices [and] health policy" (Larsson et al., 2003, p. 324). The findings from this content analysis will be discussed in a

later chapter, but there was clear evidence that many of these articles focused on lifestyle as a key factor in heart disease or used the Heart Foundation's name to give their article or activity credibility. There was little evidence to suggest the more weighty scientific articles were discussed in the HeartNET forum by people who might have been perceived as a key readership; that is, those with active or recent heart disease.

3.5   Data Analysis

Like many netnographers, I spent months immersed in the HeartNET environment, reading, responding and involving myself in the community. While my role was observational initially, there was also a participative component which allowed me, in time, to call myself 'a HeartNETter' (a termed coined by the members of HeartNET who would meet offline on a regular basis). According to Bowler (2010), it is this immersion and participation in the life of a site that is an integral part of netnography. In his seminal work *Netnography: Doing research online,* Kozinets (2010) describes several key components of netnographic data analysis. These include utilising a systematic and rigorous process, keeping accurate records, keeping research in line with the objectives and remaining immersed in the field of study while seeking an understanding of the emerging story of the participants (Kozinets, 2010; Bowler, 2010). Through analysis of the material provided on the HeartNET bulletin board and via in-depth interviews and interactions with the research participants, the researcher was able to investigate the "lived experience of the consumers" (Langer & Beckman, 2005, para 3). It is this long term engagement and interaction with members that "allows for a deeper understanding of meaning creation" (Hine, 2000, p. 23).

Over time, I immersed myself in the HeartNET community, meeting with member's offline and speaking to interstate members via phone or email. It gradually became clear that I was observing "how people in their everyday life understand the … world and how they represent it to themselves and to others" (Lippuner, 2004, p. 2). Using this information allowed me to determine where there were areas that needed further investigation. It often seemed that what professionals in the health field thought was relevant or important did not appear that way to the heart patients.

Listening to the interviews and reading the transcripts several times provided insight into the importance of some issues and helped me identify common threads that necessitated further investigation. Ultimately, I was able to identify a range of areas of relevance to people experiencing life as a heart patient.

Throughout this study I have ensured the members of the site have been de-identified and names of towns, cities or states have been altered. However, the moderators have not been de-identified, so throughout this section where the moderators have been cited they have been referenced as themselves.

3.6   Summary

This chapter outlined the research methodology utilised in this project, it also described the methods used to obtain the rich insightful data required to address the research aims. The use of in-depth interviews and an analysis of the postings on the HeartNET website provided an opportunity to show the social context of everyday life for someone living with heart disease.

Issues identified during recruitment such as difficulties recruiting participants, and time delays were discussed. While I found these issues stressful at the time, they proved in the long run to ensure that I had access to participants who provided relevant and richly insightful data.

The next chapter describes the history of HeartNET and then highlights interactions on the forums available to HeartNET members. It concludes with an insight into the role Facebook and various gaming sites had on HeartNET's viability.

CHAPTER FOUR:
HeartNET

4.1   Introduction

This chapter describes the history of HeartNET and then explores the use of social gaming sites by HeartNET members. It then examines the interactions on the HeartNET bulletin board and website. There have been over 10,000 posts to the site within the last seven years and examples of interactions have been chosen for analysis on the basis of the response elicited. These posts showcase the emotional depths experienced by newly-diagnosed heart patients and also highlight the relief these individuals experience when they find a site that addresses their needs. This confirms what Bonniface (now Costello) found during her time as the first moderator of HeartNET - that people with heart disease felt confident to share their thoughts and feelings and "appreciate the opportunity to communicate online with people going through similar experiences, … [creating] a virtual community of mutually supportive recovering participants" (Bonniface, Green & Swanson, 2005, para 4). HeartNET posts provide insight into how participants "interact, discuss problems, and offer support" to each other without "physical person-to-person contact" (Willson, 2006, p. 4).

The aim of this chapter is to highlight the different forums available to members of HeartNET to read or use at any time. Some of the forums are used regularly, while others only when needed. All but one of the forums is moderated and inappropriate or offensive material is removed.

While members make every attempt to make their posts fit the themes of the forum, sometimes they don't. While this may cause concern to the person making the post, it is not the policy of HeartNET to remove these postings. The moderator would rather see a person posting their thoughts and fears on the site than worry about where it has been placed. As stated previously the participants have been de-identified, quotes from posts by HeartNET members have not been altered, and all spelling and grammar remains as originally posted. I have in places opted to add words or an explanation to ensure the subject matter and the context are understood.

4.2   History of HeartNET

HeartNET was launched in 2005 as a tripartite project between the National Heart Foundation (WA division), Edith Cowan University and was funded by an Australian Research Council (ARC) linkage grant (Green, Bonniface & McMahon, 2007). Participants who were active within the Heart Foundation were approached and asked to join the newly developed HeartNET site. The initial goal was to compare those participating on HeartNET with matched non-HeartNET members. Within three months, all interactions had ceased and the HeartNET site was struggling to remain viable. The decision was made to close the site, re-create it, and open it to anyone affected by heart disease. It was then that HeartNET began to thrive and develop a sense of community. Green, et al. (2007) argue that the inaugural members invited to join HeartNET were well established as heart patients, whereas, the second iteration HeartNET site members were recently diagnosed. This may have meant "that they were actively reconstituting their identities as heart patients, and … in effect, the people who joined the relaunched site were 'learning' to be heart patients" (Green, et al., 2007, para 11). The second stage HeartNET site went live in 2005 and is still running in 2014. In May 2007 I officially took on responsibility as moderator and PhD candidate for phase II of the Heart Foundation (WA Division), ECU and ARC research.

Since I acquired these roles HeartNET has continued to grow. It currently has members in every Australian State and Territory, and some international members. Links have also been forged between Heart Support Australia and in 2009, with the Hearts of Salford, an online support site for people living with CVD in the United Kingdom. Many of the HeartNET members are also members of other support groups including those related to Marfan's Disease, and Crohn's Disease, and they bring their expertise from these areas to the HeartNET site.

Members of HeartNET are actively involved in sharing their insights and experiences with others who have been affected by CVD. This may involve chatting in the chat room, sharing thoughts and experiences on the bulletin board, sending messages of support and encouragement privately, or meeting face-to-face at HeartNET's regular social gatherings. HeartNET members are actively involved in Heart Foundation events from sharing their heart story, actively participating in the annual memorial service or speaking about their experiences to others. The

moderator is frequently contacted by members of the Heart Foundation when people are needed for radio or newspaper interviews and several HeartNET members' heart stories appear on the Heart Foundation's website. Members of HeartNET join together on an annual basis and offer assistance during the Heart Foundation's Doorknock Appeal, while at other times they may also be actively involved in radio interviews about heart disease, HeartNET and the Heart Foundation.

Sharing personal experiences is important and the exchange of information between people in similar situations has been found to be therapeutic for people with health problems (Patsos, 2001, p. 805). It is this sharing of experience, resources, ideas, coping strategies, hints and information, support and time that is an integral aspect of online communities. Finding support from others with CVD may have an impact on the health outcomes of a person who is newly diagnosed with heart disease, allowing them to develop a more positive self-image after a heart event. It was anticipated that these interactions would add to the understanding and knowledge of those touched by heart disease, thus benefitting those involved. It is not only heart patients that gain benefit from this reciprocity, but the moderators, researchers and other health professionals involved with the site.

4.3   Accessing HeartNET

The first contact online searchers have with HeartNET is the front page which gives them an explanation of what HeartNET provides once they enter the site (Figure 2).

Figure 2: HeartNET home page. (Source: www.heartnet.com.au)

As an online health community supported by ECU and the Heart Foundation, it is important to ensure that people accessing the HeartNET site do not experience harm. One significant risk identified was that members might change their medical or treatment options after visiting the site and/or conversing with other HeartNETters. As a result, members see the following message each time they login to HeartNET:

> It must be stressed that any discussion on medical matters and rehabilitation must be treated with caution. There has [have] never been two cases of cardiovascular disease that are entirely identical. One patient's experience is never the same as any others. Any medical or health-related information which HeartNET members might seek to rely upon should be discussed with their physician before making any changes to health behaviours (HeartNET, 2012).

After reading the welcome, visitors can click on the Guest link to enter and explore the site or login if they are already members. On entering the site they will find the main notice or bulletin board (Figure 2). By following simple links HeartNET members can access the site at their leisure.
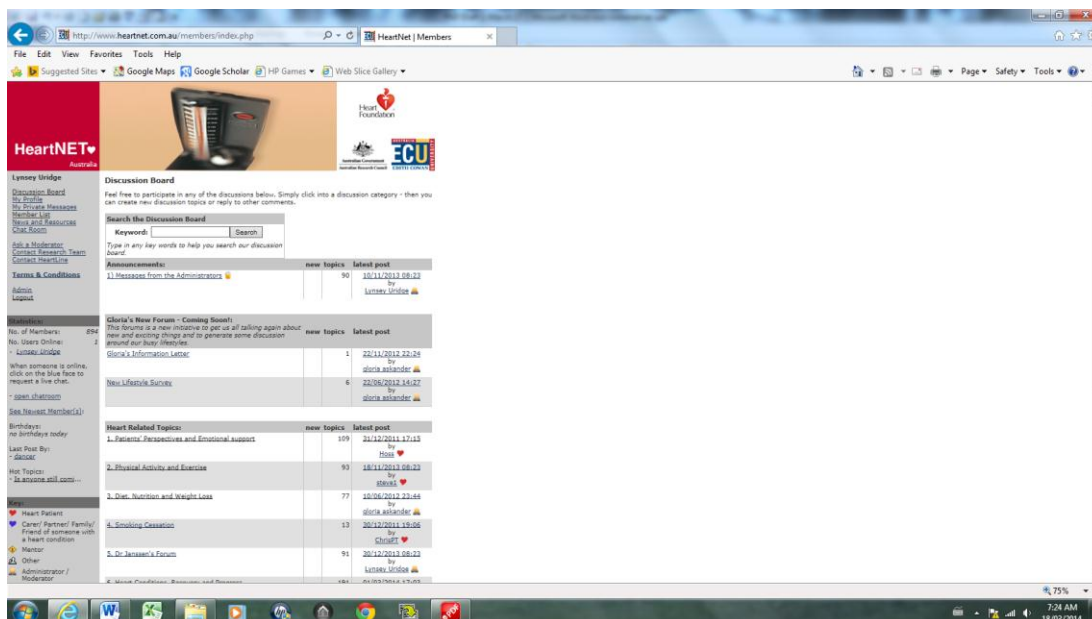
Figure 3: HeartNET bulletin board (Heart Foundation, 2013)

The main bulletin board of HeartNET is the most active component of the site and comprises four primary sections: announcements; health related topics; meet and greet; and other issues. Each of these sections has discussion threads where members can contribute and discuss "queries or concerns with each other and the moderators" (HeartNET, 2012). Some of these forums are well utilised while others may remain dormant for several months before someone posts to them or responds to another's message. Different coloured envelope icons are used to denote when new postings have occurred, with yellow for a new post and purple for a private message, These icons contribute to the site's interactivity with members able to see at a glance if new posts have been made to any forum. The interactivity on HeartNET is cyclical and over public holidays and the Christmas period, activity on the site diminishes. At one point there was a marked decrease in the number of posts to HeartNET. This caused some concern, since the most prolific users were no longer coming onto HeartNET as often. When questioned, these members responded that they were now participating actively on Facebook, playing games or farming virtually. This move to social networking sites will be discussed later in this chapter.

The following section analyses the interactions on the HeartNET bulletin board and identifies threads or "chains of interrelated messages" (Rafaeli & Sudweeks, 1998, p. 1) that have elicited particular responses. Examples of threads and topics are identified and elaborated on where appropriate, although some of the threads have

had a restricted range of interactions due to their subject matter. As will be seen, however, the "meet and greet" section is accessed frequently as this allows HeartNET members to update each other regularly.

4.3.1 Messages from the administrators

A message facility accessible only to the administrators is used to make special community-wide announcements. It is designed for one-way communication only and all general members are locked out. If members wish to respond to any messages posted by the administrators they do so by posting to the general forum or via private messages. The following examples show how the moderators announced changes to the moderation team as one study ceased and another began:

> A BIG announcement – HeartNET Phase II
>
> HeartNET has received 3 additional years of funding as a research project into online support for heart patients. As such, the site will remain under ECU's control and we will be making further improvements (as previously discussed). However, it is important to point out that HeartNET is a self-sustaining community – one which requires members to interact responsibly online and to support each other. While we have moderators …. the site is administered with minimal intervention and as such it is up to all of us to ensure the success of HeartNET in the future. … I think there are exciting times ahead. My involvement (as I've said on countless occasions – LOL) will eventually phase out as will Gerry's. However, a new PhD student will be coming on board to take the community to a new level of development and research. (HeartNET Moderator, 2007,⌨)

Messages posted here by the administrators include issues such as maintenance to the site, changes to the terms of service and the introduction of new researchers or upcoming research. This facility informs members of administrative issues and is the first place administrators post if there is a change in the way the site operates. Gerry, a long term Heart Support Australia volunteer used an administrator's message to announce his 'retirement':

> To HeartNETters all, as the walrus says in Alice in Wonderland, "The time has come ...." Yes it has for me. HeartNet will always have a special place in my heart because I've been there from the very beginning and what a wonderful journey it has been. But just like any old salt the time has come for me to drop anchor. This does not mean that I won't up anchor every now and then and visit briefly. I have been so privileged to be part of what has been a truly remarkable exercise which started as a project and that is now

a substantial 'centre' for any and everyone to share moments of friendship and comfort for we all speak the same language – that of the heart patient. I have made so many friends from all States and internationally as well, both on this site and as a result, personal contact via phone and PM…. Keep asking questions and expect answers and if you are not satisfied seek a second opinion. To Leesa I say it was a wonderful moment when I heard [Heart Foundation member] mouth the words, "We know just the man for you to meet," and we became a team. To all at ECU who stayed the early flounderings and provided support without which HeartNet would have disappeared in the ether, thank you. And of course [Heart Foundation CEO WA] who had faith in spite of the misgivings of others. HeartNet owes you a lot. And Lynsey, I know HN is in very safe hands – good luck. So for the final time this old owl tips his hat to you all. Au revoir. (Gerry, Moderator, HeartNET, 2009,⌨)

Gerry was an integral part of HeartNET and as an experienced lay member of Heart Support Australia had been part of the moderation team from its inception. When I became moderator he was a significant mentor, not only to the other moderators, but to HeartNET members as well. Gerry was in a unique position as he was a heart patient of long standing, an orator, mentor and Heart Foundation representative. He was able to bring all these roles to the HeartNET site and would impart wisdom and caution at times to both moderators and members alike. It was a sad day when he left HeartNET, however, both Leesa Costello and I still keep in regular contact with him.

4.4   Heart Health Topics

The second section of the HeartNET bulletin board is where members identify, address and elaborate on heart related issues.

4.4.1   Patients' perspectives and emotional support

Research undertaken by Barrera, Glasgow, McKay, Boles and Feil (2002, p. 638) found that many people find it more convenient to participate in an online environment than in a face-to-face environment. They argued that this may be because participants feel more valued for their online participation and contributions, rather than feeling judged for their physical appearance or degree of disability. Members of online groups often experience a powerful feeling of community with some participants developing an emotional attachment to the chat rooms and websites they visit regularly. This sense of community may be due to the online

network which provides participants with a means of support that is not available from more traditional support providers such as family and friends (Parr, 2002; Wright and Bell, 2003). It can be especially valuable for new heart patients to talk to someone who is already an experienced member of the heart patient community.

Macias, Stavchansky-Lewis and Smith (2005, p. 211) found that asynchronous chat rooms and message boards provide a variety of information and emotional support. Parr (2002) described how the use of Internet support sites and chat rooms allow participants to "gather resources in order to rewrite their own illness experiences" (p. 91). The very nature of a message board allows members to access "multiple sources of information and diverse viewpoints about issues as well as providing diverse solutions to the issues discussed" (Wright & Bell, 2003, p. 42). According to Braithwaite, Waldron and Finn (1999, p. 126; Wright, 2002), there are different types of supportive behaviours that may be found within online communities. These include emotional support (concern) and informational support (advice and suggestions). As will be seen later in this section, the HeartNET site provides both emotional and informational support to its members.

The time delay that occurs in asynchronous communication online may be a disadvantage for some, especially those wanting an immediate response to their situation or problem. For others however, it can be advantageous as it allows them time to assess critically the statements posted and then to respond appropriately (Wright & Bell, 2003). With any form of communication some topics are 'hotter' or more interesting than others. For example, newly diagnosed heart patients may need additional support as they confront their emerging health issues and deal with a diagnosis that can be life changing. Anxiety is likely to occur when people encounter unfamiliar situations, especially if they have had no previous experience with such events. It is likely that new patients or people with unfamiliar symptoms will search for answers and information from various sources. These sources may include "self-help groups, the Internet, medical journals, casual conversations with friends or acquaintances or a meeting with someone with the same diagnosis" (Herxheimer, et al., 2000, p. 1540). Albrecht and Adelman, cited in Wright (2002, p. 197), found that emotional support was particularly important to people who felt they could not change their situation, but could only adapt to it. HeartNET provides both emotional and informational support to its participants and members.

Many recent heart patients say there is a lack of information available about the emotional and practical implications of their heart event.

> Keeping positive is not always an easy journey and i have come to a bit of a stand still in my treatment options. After 4+ years, more medications that i can poke a stick at, and numerous invasive and some not so invasive procedures my cardios have come to a halt on what they can do for me for now. So i ask where is the light at the end of my tunnel that i am not sure but i wanted to share this next challenge with you all, the challenge of not doing anything except accepting and living with it. (Caroline, 🖥)

Caroline's post elicited several responses and the majority of HeartNET members felt the same way. Emily, however, provided insight into how she had dealt with the long term implications of living with heart disease:

> try to concentrate on all the things that you are still able to do, even if it's not to full capacity and forget about the things you are unable to do now'

> Caroline I had to give up some things I love to do due to ARVD, but you know, I look at all the things I can still do...Be an active member of HeartNet, I can still see, still hear, still talk, still walk, still eat/drink for myself, toilet myself (sorry ooops), be a mother to my daughter, be a carer for my mother, be a confidant for my step-dad...these are just a few of the amazing things I can still do. Caroline

> When the light in the tunnell looks like a train coming full steam ahead at you, try hard to remember all the things you are still able to do ... and smile about them. (Emily, 🖥)

There is clear evidence that lifestyle factors such as smoking, obesity and poor exercise regimes influence the likelihood of heart disease. Even so, some of the participants in this research feel that other factors like genetics, family history or 'plain bad luck' are not sufficiently acknowledged. Some felt that health care professionals react as if their heart disease is the patient's own fault.

> And the impression I have is that it is your own fault if you have a heart attack because it's a lifestyle issue … or lifestyle issues certainly have an important place but I certainly myself have made good lifestyle choices, and I still had a heart attack. And that was one of the things that a couple of people said to me, 'so were you really eating cream cakes in secret' … they suppose that it is something that you've done wrong. (Abby, 🖭)

Sally experienced the same issue. Since she was fit and healthy prior to her heart event, people couldn't believe she had a life threatening heart condition.

> it wasn't just that all heart patients don't like exercise, because that was a lot of what I got from other people "I thought only people who didn't exercise got heart disease" and all that kind of stuff. Yeah, and because I'm little, and I'm skinny, and all of that, I also got a lot of disbelief. And yeah I'm not old and I was fit and so what, it still sucks. It sucks just as much as anybody else. (Sally, 📷)

Members of online communities such as HeartNET often discuss a sense of personal grief and a feeling of loss of control. They feel overwhelmed by their changing health status and the impact on their family life. Fran identified with this feeling, stating in her introduction to other members of HeartNET that she felt "there isn't enough support for us and we are left on our own a lot after diagnosis to find answers for ourselves" (Fran, 💻). A significant finding in this research supports Graydon (2007, p. 278) who identifies gift exchanges as having the ability to "draw people together, strengthen social bonds, impact upon social identity and roles and provide assistance." Discussing their fears about diagnosis, treatment and prognosis with others who have experienced similar situations may be helpful, especially for new patients. People often search for emotional support and practical encouragement to assist them in making sense of their current situation (Dean & Gregory, 2005). Significantly, interactions on HeartNET can allay some of the fears of the unknown, while the use of discussion forums can help, support and encourage people.

As the moderator of HeartNET I found HeartNET members used the site to share their thoughts, feelings and fears for their own and their families' futures. Encouragement and support are at the core of HeartNET. While much is written about the gift economy in an online environment, to experience it first hand on HeartNET provided the researcher with valuable insights into the importance and effectiveness of social support.

4.4.2 Emotional support

In the following communication, one HeartNET member was feeling despair. By sharing her feelings with others she was able to access comfort, advice and

support. HeartNET allowed this member to express her feelings online, which was particularly important since she felt her family did not understand her circumstances.

> … just when problems occur on the home front and you feel like you can't cope anymore and want life to be easier again. I guess I am skirting around the crux of the issue and I don't want to say much more publicly, but I feel like a black cloud is hanging over me and I am lost. (Amelia,⌨)

Accessing and contributing to an online support group provides people with a means of describing their illness experience and their interpretation of that illness as it relates specifically to them. This, in turn, allows others to read and add to this contribution from their own experience, providing both the original author and subsequent posters with a means of support they may not otherwise have (Herxheimer, et al., 2000). Members were able to respond to Amelia sharing how they had dealt with a similar situation when it occurred to them and their family.

> I understand completely the wanting to go back to the before, if only we could. Not many people understand just how much our heart conditions affect us in our everyday life. I am thinking it is mainly cos we try to protect the significant people in our life from what we are actually feeling and try to keep things as normal as possible, normal in the respect of life before the heart event or prognosis. The worry in talking to our family is we then have to cope with the limitations they put on us or, worse, they get angry with us, or frustrated. There really is nothing directly that I can do for you Amelia other than to talk with you, support you and understand you. So pleased you told us of your "black" time, keep talking and we will do what we can. We all care for you so much and we all KNOW how you feel. (Susan,⌨)

> Not much more that I can add Amelia other than there is no better solace than sharing your words and emotions with your fellow HeartNetters. The fact that you can is itself a placebo. You know you are not alone. However, if this deep sense of frustration/depression continue unabated then you do need to seek professional help but first discuss it with your GP to guide you in the right direction. (Bob,⌨)

> The one thing about clouds Amelia is that they clear eventually – even the black ones. EVERYBODY will have moments like these at some point, and as Susan mentioned, the hardest part can be keeping it to yourself... so feel free to share the load xoxox. (Chloe,⌨)

Amelia returned to the site and posted an update on her emotional feelings. She had found the support from the other members both welcome and helpful, and felt it had helped her deal with the current situation.

> Thank you all for your words of encouragement and kindness. I have these times in my life when my usual bravado and laughter leave me and that makes me feel very exposed to the darker side of my being and one of those times occurred. Fortunately, I have a much stronger part of me that usually prevails and now I am feeling more like my usual self....but thanks again for your loving words. (Amelia,🖳)

This reaction from other members of HeartNET was similar to findings from Ziebland and Wyke (2012) that "patients know what patients need to know". They suggest that there is "clear evidence that the most valued source of information was not the doctors but the other patients in online communities" (p. 221). Other newer HeartNET members also had to face the difficulty of coping with ongoing illness. Erica had to deal with several myocardial infarctions, open heart surgery and the loss of her husband all within a twelve month period. She was able to share out her fears and anxiety very openly.

> This heart thing is all new to me. This time a month ago I was told I had a heart condition. in a month I have had two heart attacks and an emergency triple by-pass… I am sooooo aware of every beat of my heart, I can't sleep at night cos I am so focused on my heart… I don't like the fact that my life has been taken out of my control, I was always the one in control. (Erica,🖳)

Emotional support was provided by members who had been in similar situations. Members were quick to respond and assist Erica by stating that they had felt similar experiences following their heart event.

> I know what you mean by having trouble getting to sleep but try to remember as long as you hear your heart beating your alive.& the pain does fade to just a memory. It just takes time. (Fred,🖳)

> And as for listening to your heart. I've been listening to mine for the last 24 years and I usually whisper a silent 'thank you' most mornings to it for doing such a good job. (Bob, 🖳)

> First month is always the hardest, it sucks and your world is spinning out of control well thats what if feels like anyway, but you will get throught it, you will adjust and you will regain control it just takes time. (Penny, 🖳)

Three members of the site, all with varying heart conditions, were able to relate to Erica and provide her with emotional support about a situation that felt out of her control, and to which her family and friends were unable to relate. She found the online support encouraging and posted an update on her feelings acknowledging the support she had received.

> "certainly feel a lot better this morning…I read a few post and threads a day and you all are an amazing lot of people" (Erica, 🖥).

It is this awareness of others and their interactions on the HeartNET site that helps members to feel comfortable about sharing their emotional experiences in a safe and non-threatening environment. Braithwaite, Waldron and Finn (1999, p. 126) identified several outcomes resulting from participation in online communities, including allowing other members to take on the role of helper, finding others in the 'same boat', and the initial poster finding and experiencing support. According to Ziebland and Wyke (2012, p. 232), knowing that others have experienced similar situations such as isolation, fear and anxiety, provides reassurance that a member's "experiences and reactions are normal".

4.4.3 Informational support

HeartNET members who when searching for information have found sites they consider relevant or which have provided them with the information they are looking for, will notify other HeartNET members online. Wright (2002, p. 197) found that "informational support may help people experiencing health problems to feel more in control over their situation … will help them make better decisions about coping with illness". Sonia, known by other HeartNET members as the site's 'librarian', would frequently share information about sites and articles she found that related to heart disease, diet and other relevant issues. This is similar to the findings of Genoni, Merrick and Willson (2006, para 8) who found that senior members such as Sonia were willing to use "their particular knowledge or skills" to explore issues and provide relevant information.

Susan was concerned that following deterioration in her cardiovascular health, she might be taken to the closest hospital rather than to the hospital her cardiologist wished her to go to if she had a repeat heart event.

I went to the cardio today and as I expected would happen I'm to have an angio. He said he will put me as urgent and to expect to hear from the hospital sometime next week. He was really peeved off that he wasn't told I was in [a rural and remote hospital]. He said that in future I'm to be transferred to the [regional base hospital] regardless of my troponin levels because my condition is too unstable. I'm to take it easy till I have the angio and if I get pains that won't go after two sprays I am to call an ambulance and insist that I be taken direct to the [regional base hospital]. Wonder if I can do that??? Guess if it happens I'll find out eh. (Susan,⌨)

Within two hours this member had a reply from a HeartNETter on the site who worked in the emergency services, with the answer to her query and concerns.

Susan, ring the ambulance communications centre phone number should be in the book; if not contact your local ambulance station, or ring your local police who in your case will divert you through to [regional base hospital] they have the direct number for the Ambulance. The ambulance service can list your name, address etc. on their data base with the required instructions i.e. being transported to the [regional base hospital], directly to the crew.(Sam, ⌨)

Members who responded after this post said they had been unaware this was something they could do to ensure they received the treatment they required quickly and efficiently. Without access to HeartNET they might not have received this relevant information.

Research undertaken by Seale, Ziebland and Charteris-Black (2006) found that although information on public sites was visible to all, both genders shared intimate information about themselves. This can also be seen on HeartNET, where members post about intimate feelings and issues with other members responding. One such posting was entitled "this one is for the girls only… OK this is secret woman's business so boys please go away. haha" (Lucy,⌨). It related to a member's legitimate concern over dealing with a fairly personal issue. After having had a pacemaker inserted into her chest cavity, she was experiencing difficulty finding comfortable brassieres. She asked the women on the site who had pacemakers or defibrillators fitted what they had done to relieve this problem.

OK this is one question I have wanted to ask for some time but it's a bit embarrassing … bras I have noticed that since my heart complication I find that I can't wear bras for any great length of time because I get chest pains as if there is too much pressure on

my heart even though the bra is well fitted and by no means tight.
(Lucy,🖥)

There were several responses with practical advice such as how to wear a bra only for the time required, as well as how to sleep more comfortably at night, as Lucy's post went on to discuss her difficulty in sleeping on her left hand side which she now found uncomfortable. While several members responded and acknowledged that it was an issue that they had also experienced, one male member suggested various alternatives:

> Oh ok I know I'm a boy … but I have a degree in fashion design so I may be able to help her … one suggestion … have you tried getting a bra more like a corset with straps … but nowhere near as tight … I forget what you call them … but when I find a link for one I will show you what I mean. (Ben,🖥).

Soon after, he returned and posted the link to the site that catered for people who had difficulties with pace makers and comfortable bras.

> … and below is an American website with some sort of heart patient designed bra that is getting rave reviews … ohh the thing you are looking for is called a cardio thoracic bra … for the link below … [URL provided]. (Ben, 🖥)

Information from support sites such as HeartNET can provide peace of mind, reduce feelings of isolation and vulnerability, fill information gaps and provide participants with feelings of mutual support (Dickerson, Boehmke, Ogle & Brown, 2006). Much has been documented about the possible untrustworthiness of online information, so it is necessary to ensure that information is relevant and balanced. This role, in part, is jointly managed on HeartNET by the moderator and the members. Entwistle et al., (2011) express caution about the validity of online information. They urge online community users to be aware of atypical experiences and information that appears to be biased, inaccurate or sponsored by commercial interests. Often members would contact myself or Gerry and ask for our input or alternatively, some took it upon themselves to research the topic and would then come back on site with their findings.

4.4.4   *Physical activity and exercise*

Originally started as a bulletin board for members to communicate about their exercise strategies, over time the focus of this area has changed. It is now used by many of the male members of the site to journal their exercise regimes. While

members may post their achievements in this section and see it as a means to motivate others to take up some exercise or physical activity, they sometimes forget that HeartNETters may be restricted in the exercise they can undertake by the severity of their heart disease. Members responded to exercise-related postings even if they had previously communicated that any degree of physical activity was difficult with their heart health, although they did initially appear to be impressed by the prowess of the athletes on the site and often responded positively.

It became apparent over time that several of the male members of HeartNET had become increasingly competitive with each other and described their exercise regimes in great detail. One of the first threads in this topic was initiated by Sam who posted that he was planning to compete in a number of forthcoming triathlons and decathlons. Each thread involved exercise regimes, successes and failures, and comments by members also undertaking exercise regimens and those who would like to do so. Sam's posting included a dialogue about his first bike ride in several years and how good it felt to be able to get back into cycling.

This prompted several of the women to comment on the fact that they had never learned to ride a bike.

> I didnt learn to ride a bike either, was never taught or given the opportunity (no bike)! One time during my 30's I decided this is silly. So I borrowed a bike and a helmet(thank goodness) got on and free wheeled down the driveway(not so hard I thought elatedly!!) then it came to my first turn onto the road...yep there I was in all my glory sprawled over the road near the kirb...a car was going by and I just lay still like road kill(lol) until they went by before I got up and limped back up the drive wheeling the bike with a somewhat red face and dented ego!! I am so embarrassed to admit this but I am laughing my head of as I type this!! One thing I learned is that when we get older we DONT bounce well..ha haaaaa. (Karen,⌨)

The thread became somewhat side-tracked as members regaled each other about their biking mishaps. I had also thought I was one of the few people around who had never learned to ride a bicycle, mainly because my parents believed it was dangerous to ride a bike around the hills of Wellington. It was gratifying to know I was not the only adult who lacked this skill. Sam finally intervened and brought the discussion back to his successes and training sessions.

While Sam took his training sessions to an elite level with running, cycling, and swimming sessions, he would also come onto HeartNET and post about the pain and soreness this exercise regime caused him. Initially given sympathy by his fellow HeartNETters, he now gets little sympathy or empathy from any of the members, so he now posts rarely about his pain levels.

The first "Triathlon, Duathlon or any other Athlon" thread began in 2008. In four years, the seventeenth episode of this thread was initiated in the latter half of 2012. It is still one of the main threads in terms of activity, with frequent posts about exercise regimes, competitive successes and training adventures or mishaps.

4.4.5   *Diet, nutrition and weight loss*

Diet and nutrition are important factors in the continued wellbeing of people who have a diagnosed heart condition. For some, their heart health means losing excess pounds, becoming fitter and taking on some form of exercise and movement. The Heart Foundation recommends "that adults include at least 30 minutes or more of moderate-intensity physical activity on most, if not all, days of the week. It's never too late to start being active" (Heart Foundation, 2013, para 1). The Heart Foundation has various activities and resources available to encourage people to become more active both in their home surroundings and in the community.

Diet and nutrition are also a key component of improving heart health and HeartNET members are constantly sharing and swapping recipes. Often this may involve modifying the recipe to ensure it is heart healthy.

One significant post started with a member of HeartNET asking how the other members' diets had changed since they had joined HeartNET. For many there had been no dramatic changes while others had to reduce their sodium intake or start using cholesterol-reducing margarines or spreads. Several HeartNET members had used a well-known weight loss club. Some experienced dramatic successes, but the majority like Sandra had minimal success. Her response is below.

> I know that's why [weight loss club] is so popular (as well as their brilliant points plan idea including being able to "buy" points through exercise) is that they have regular meetings where they [provide] education, share hints, support members, do weigh-ins and so forth so they cater to a variety of motivations people have. For the past 9 weeks or so I was on a strict [weight reducing plan] and lost some weight (but not quickly enough and with Easter eggs

around falling off the wagon a little). … Also Internet support really is going to be the way of the future especially considering varying working hours as it provides a forum that you can log into anytime (Sandra, 🖳)

After some patchy progress, Sandra vowed that she would persist and to date she has lost a significant amount of weight. Gary had other health issues that necessitated him avoiding all forms of caffeine. He successfully altered his diet to accommodate this:

Since changing my diet to reduce stomach acid production by stopping eating chocolate, fatty and spicey foods and stopping alcohol and coffee (all difficult to digest and common) I went from 98 kg to my weight now of 79 kg. This is over a 6 year period. I do however believe that the support that is offered by Heartnet has helped me tremendously with my heart related issues, but my diet was already 'fixed'! (Gary, 🖳)

Sonia found she had to contend with cultural issues. As an immigrant, she had embraced most parts of the 'Australian way of life', but still struggled with wintertime and craved the foods that she was used to eating in her home country. She identified herself as a 'foreigner' who still reverts to her familiar diet over winter as it reminded her of home:

[European] food in wintertime has mashed potatoes with carrots and onions, served either with pieces of bacon or smoked hot sausage (rookworst). Either that or mashed potatoes and sauerkraut, with bacon or rookworst. Fat was supposed to keep you warm, seeing that they tell us the planet is heating up, the trend might disappear completely. Green pea soup is another favourite over there, especially when there's ice on the canals and people can do their favourite wintersport – skating. I can just imagine, they won't be good for a slimming diet. (Sonia, 🖳)

When I first became the moderator of HeartNET I was surprised at the number of recipes on the site. Many of these recipes had been modified, as members often craved their pre-heart event foods, but knew that they were no longer an option in their original form. Connor had been craving Hollandaise Sauce, a "creamy sauce of melted butter, egg yolks, and lemon juice or vinegar" (Edmonds Cookbook, 2005). He asked for alternatives. While some HeartNET members commented on the fat, salt and butter content, and suggested he find an alternative or not bother using this sauce, another came up with an alternative low fat, low salt recipe which received the HeartNETters' tick of approval.

A change to a heart healthy diet can result in weight loss, but this isn't always the case. At one point Fred decided to put away his scales. He posted that this was proving to be a successful weight loss strategy and the next time he weighed himself he had lost around 10 kilograms. Rhonda also decided to put away her scales because "our scales just sit there and don't get used cause I don't like what it tells me" (Rhonda,⌨).

When Sam asked members what they did to maintain their heart health he received varying replies. Sam and Colin trained daily, Bianca had a healthy diet and lifestyle, but had to work at reducing her stress levels while Fred struggled to maintain a healthy lifestyle, but had managed some changes. Shona went back to nature and had found this a therapeutic way to de-stress.

> I have gotten back in contact (something I enjoyed many yrs ago on a bigger property) with making compost, throwing around top quality horsey and chooky poo, to produce a vege patch that is the envy of all my family and friends! There is something cathartic about getting ur hands dirty and producing top grade veges that family and friends enjoy as well as urself …Thought I would share this experience cos it may fan a flame in someone elses life here … destressing doesnt have to mean spending megabucks for the benefits. A few days ago we had gale force winds that for a number of days ... drove every one nutty and especially me cos it wasnt nice and in fact tiring to be in such wind for to long ... along with a banging gate that I finally secured … by the end of the day I was not my usual self! Grumpy as! Then I realised it was cos I hadnt had my time in the garden early in the morning (which really sets my day on a great footing..) tis my think time, my balance & right perspective is reset as I commune with nature! (Shona,⌨)

Alternatively Jeremy had found getting a pet helped him to get out of the house and become more active, because he now had another creature that relied on him.

> But a good thing was the kids after constant nagging convinced us to get a dog. Needless to say the novelty wore off quickly and she became my wife's and my responsibility. I found you cannot remain stressed if you are patting a dog, and she reminds you in no uncertain terms when it is time to go for a walk and get some exercise. (Jeremy, ⌨)

Many found that focussing on a short term goal proved successful, while sharing it with others was also helpful. Sam believed starting the changes and setting short term goals in turn led to long term benefits.

That way your focusing your energy to a specific target. Naturally of course, once you achieve that goal, you need to focus on a new one. They don't have to be world mind blowing event, just something that takes you out of your comfort zone and gives meaning to your efforts. For some that may be fitting into a size smaller clothing, for others it may mean doing the marathon. Somewhere between doing nothing at all and competing in the worlds most tortuous event lays where you should focus your energies. That somewhere is only known to one person. ... (Sam,⌨).

The value of a thread like this allows for conversations to be structured and "to facilitate communication among strangers with similar informational needs" (Rau, Gao & Ding, 2008, p. 2768). Users can access the site at their leisure, read the posts and if they feel the need, to respond. An additional bonus is that readers have access to people who have knowledge, information and expertise, and in the case of the participants on HeartNET who were trying to stop smoking, experience in the challenges that this caused.

4.4.6   Smoking cessation

There is clear evidence that continued tobacco usage is a major risk factor for people developing heart disease and "nearly 40% of all the people who die from smoking die from heart, stroke or blood vessel (cardiovascular) disease" (New South Wales [NSW] Government, 2012, para 1). The Australian Bureau of Statistics, (ABS) identifies tobacco consumption as one of the "largest single preventable causes of death and disease in Australia. It is associated with an increased risk of heart disease, stroke, cancer, emphysema, bronchitis, asthma, renal disease and eye disease" (ABS, 2013a).

Many HeartNET members have struggled with quitting smoking and discuss at length on this thread the strategies they have used in their attempts to stop. For some, like Sam and Frances, giving up 'cold turkey' was their preferred option. Cold turkey refers to how "drug addicts will try to 'kick the habit' without any help and to deal with the symptoms or cravings as they arise" (Barringham, 2009, p. 7).

Frances describes her journey to give up smoking.

> Giving up smoking for me was extremely difficult. I had only lasted 36 hours maximum before the craving for a cigarette was too strong. I had a warning from my Doctor that the pains in my chest were not good and I had to stop smoking. As I had only just bought a carton of cigarettes I decided to use them as a "weaning" tool, so

for the next week I smoked as usual but told myself that these were the last cigarettes I would be smoking until finally I smoked the last cigarette in July, 1991. I haven't smoked another cigarette since! Perhaps this way of giving up might help others – it worked for me and I am so glad I no longer smoke. (Frances,⌨)

For many, the fact they had had a heart attack was sufficient impetus to make them give up and stay away from smoking. Many shared similar stories to those below:

After i flat lined, and they bought me back with the jumper leads. i haven't had the slightest urge for a smoke since. The doctor said I died, and a non smoker came back. Might sound funny, but I suppose it's something good that came out of my attack. And to be honest, I dont miss smoking, and the wallet also feels a bit fatter for not smoking..... (Simone,⌨)

I smoked for 25years, had the excuse that I didn't want to put on weight so I kept smoking. I too haven't had a smoke since the night of my heart attack, 42 weeks ago. I do still get urges, but do not miss smoking one bit. Like Simone got the fright of my life and I want to stay around for my 3 little kids. Guess what no weight gain either, I kept cut up strawberries in the fridge if I got the urge for a smoke I would have strawberries instead. (Colin,⌨)

I haven't had a smoke since 7/11/05 when I had my heart attack. But... it isn't rocket science, smoke and I'll have another attack which could be fatal, quit and I'll probably live long enough to not only be a problem to my children but a problem to absolutely everyone!!! (Mark,⌨)

Not everyone was quite as successful as these members and some shared how they had tried to stop smoking many times. They felt that if they were still smoking they did not deserve to get treatment. Whether this was due to embarrassment or comments made by health professionals is unclear, but it remains a major area of concern. I found it stressful to listen to people say they would not go back to see a specialist about their heart health even when they were clearly unwell. Susan gave up smoking for several months, but went back to it. Now she says she will not go back to her cardiologist until "I've stopped smoking because I figure why the hell should he look after me when I am not doing anything to help myself" (Susan,⌨)

Fiona expressed similar feelings. She smokes more than thirty cigarettes a day and has chosen not to seek ongoing medical treatment, because she feels that her smoking makes the medical profession treat her differently. She described how she

felt every time she was asked by the medical professionals if she was a smoker or drank alcohol.

> And they asked how many do you smoke and they – and you tell them. And how much do you drink – you know well it's your bloody fault you're here so you know…Yeah and very much the attitude it is your fault, you're here… And you know really we haven't got any patience with you…This – people don't smoke and drink for fun, not now a days. We know better. (Fiona,⌨)

During her interview Fiona stopped several times to go outside and have a cigarette, and on a couple of occasions she used the time it took to smoke a cigarette to regain her thoughts and emotions. Fiona states that "she knows the big one [another heart attack] is just around the corner" and while she is scared, she feels unable to stop smoking and drinking. Fiona sees both alcohol and tobacco as tools that allow her to relax and deal with the day-to-day events in her life that threaten to overwhelm her.

Sue thought she was going to face condemnation from the members of HeartNET and from me as the moderator for her honest statement and what she termed a very 'public confession'.

> I am still smoking. I have been able to cope with all the other changes re my heart attack but just can't get a handle on not smoking. I have always loved and enjoyed smoking. Always resisted the concept of never having a smoke again… I didn't smoke for about two months after my heart attack, but when I continued to get angina I couldn't see the sense in not smoking if I was going to die anyway, as I thought. So I started again, you know the story, just one a week, then three, then one a day won't hurt. Now I am having at least ten a day. Feel such rage at having to stop smoking and cope with heart disease. Sounds wacky I know but that is where I am at now. Finding it impossible to stop smoking, drinking, eating all the foods I love AND lose weight. Have tried nicotine replacement things, they make my heart race and I feel really sick. How can I make ME want to stop smoking, life just doesn't seem to be enough. (Susan,⌨)

She was surprised by the positive comments her statement generated. She posted the following response on the discussion board. "I was expecting criticism for not being able to stop smoking. You know what I mean, wasn't the heart attack enough to make you stop!!." Sarah had avoided entering this section of the site, because (in her words) she felt "a bit of a hypocrite, cos I still have one or two, I did stop for the time I was in hossy [hospital], so I am just like you Susan :) I try to stay

out of this section [thread on HeartNET related to smoking cessation], Cos it makes me feel awful that I still do it to myself" (Sarah, 💻).

Henry, who has severe cardiac disease, was also concerned that he would feel criticised for his inability to give up smoking. He found that smoking relaxed him when he was having a tough day or, in his words:

> It was the only thing that made [makes] me feel good, every time I had a " Funny Turn" I know I should, and feel an " Outcast" these days...As Susan said, I too can't handle what I'm going thro, AND, the stress of giving up the rollies. I enjoy them too much…sighhhh :(… I DID give up 8 years ago for 7 months, but was so sick, but was really quite easy, then I hurt my bk [back], and couldn't life with the PAIN, and the WANT, NEEEEED, to have a smoke. Figured I'd give it up again soon. gawddddd 8 yrs on, an a MAJOR HA, and still haven't. I hope I don't get judged on here for it, but there it IS.... sighhhh. (Henry, 💻)

While the members who were still smoking expected condemnation or adverse comments from the ex-smokers and non-smokers on the site, this did not happen. The majority of ex-smokers who commented in this thread were able to talk about the use of 'won't power' and gave practical advice. Some stated that when they were finally ready to give up, it was relatively easy. Crystal said:

> Strangely when I finally did do it, it was okay, maybe I was just at that ready stage, not that I recognized it as such. I didn't have a moment where I said 'okay I am ready now'. I think I was really sick of the inconvenience as well as all the other things, health, cost and embarrassment to some degree. (Crystal, 💻)

Non-smokers also gave advice and suggestions on how to give up, stating that nagging did not work, to stop on the first attempt was often not possible, and that you were unlikely to ever lose the craving for a cigarette. Jon was able to describe succinctly what many other ex-smokers felt.

> I still get the occasional whiff and the old 'want one' rears its damn ugly head. And that's after over 20 years! Doesn't happen that often anymore as normally now I find the smell quite repulsive, just every now and then (Jon, 💻).

For some members their heart event was the catalyst to stop smoking. Sam believes his heart event had a positive impact on his wellbeing, because he still feels frightened "out of my wits every day of my life wondering if I will ever had [sic]

another [heart] event, even though that's highly unlikely" (Sam, 🖥). He stopped smoking after his heart event stating that:

> I had my last cigarette at [time and date] at the ambulance bay at [regional hospital], because I had one cigarette left in my packet and I thought one more nail in the coffin isn't going to kill me and I'm having this one and that was it, gave up cigarette smoking there and then and never had another one. (Sam,🖥)

Sam does admit that he often feels like restarting, but has made a conscious decision not to, as it would affect his training for marathons.

Susan, Sarah, Henry, Fiona and Jon all reported that smoking calmed them down, reduced their stress levels and made them feel better. However, medical evidence indicates that the opposite occurs. Parrott (1999, p. 817) contends that the "apparent mood benefits of smoking only reflect a process of mood normalisation: the simple reversal of the tension and irritability that build up during nicotine abstinence." This suggests that smokers actually experience slightly above average levels of daily stress. Research undertaken by the Pew Research Center confirms that smokers were less happy or healthy and more stressed than non-smokers or those who had quit smoking (Wang & P. Taylor, 2009).

While many members who still smoked expected condemnation from members of HeartNET, this was not what they experienced. HeartNET members were supportive, gave encouragement and shared their own stories on how they had either given up or were still on their own journey. It appears that some smokers feel criticised by medical authorities and this has had a detrimental effect on their health support behaviours. Fiona continues to smoke and has not sought medical advice for some months. Susan set a quit date and was successful for a time. However, she resumed smoking and has received medical attention for a further heart event in the past few months. She has placed stopping smoking on her 'bucket list'. She says she adopted this phrase from the film *The Bucket List* which outlined the steps taken by two terminally-ill men sharing a hospital ward who had compiled a list of things they would like to achieve before they died or 'kicked the bucket' (Reiner & Zackman, 2008).

The smoking causation thread remains open, but no one has posted to it in the last several months. Perhaps this is an indication of how people still struggle with quitting smoking and it may indicate

they are still concerned about how people will react if they admit to not having stopped smoking.

4.4.7   Cardiologist's forum

This forum was created when the site was set up and involved a local cardiologist coming on to the site whenever he was available. He originally posted comments and provided resources for the members to access. All the site members had their own cardiologist or health care professional monitoring their health. Some would seek a second opinion from the cardiologist and he would direct them back to their own health care professional. For others, advice would be sought regarding medication issues. One of the most prolific threads on this forum was about the risk of developing Deep Vein Thrombosis (DVT) while travelling. Theresa posted about her upcoming flight overseas asking for:

> advise on the risks to the heart of flying [overseas] and return? I will have to make that journey sometime in the future due to the ill health of my mother-in-law and am very frightened of the possible consequences (DVT mainly). I have unstable angina and am on [heart and cholesterol medications]. (Theresa,⌨)

Other site members responded with their own thoughts about travelling on a long haul flight. The cardiologist would respond and allay people's fears and provide advice that would help and result in a positive outcome. In this case he was able to provide Theresa with simple tips and ideas that all HeartNET members could use no matter where they were travelling.

> Every good suggestion has been posted except for the drinking one. It is recognised not only the inactivity on the plane makes you more prone to the development of deep vein thrombosis (DVT) but also the dry air and lower atmospheric pressure. Therefore drink plenty of water (so you will have to go to the bathroom and put in some excercise) and go easy on the alcohol (only one glass with meals?).
>
> Always carry information in English with you about your condition (latest doctors letter?) so that if you break your leg abroad the doctor knows what pills you are on and for which reason.

Simple low dose aspirin as a 'preventer' is probably advisable for all patients with cardiovascular disease who want to fly for longer then 3 hours at a go. Last but not least: if you can afford it, think about a stopover; talk about it with your travel agent. (Cardiologist,⌨)

Another issue that was constantly raised in this thread was the use of cholesterol medication which is also discussed in the media chapter in more detail. However, in this case the cardiologist was asked if the use of statins was causing additional health problems that were not associated with Ben's heart disease.

I have just done some Internet searching on Lipostat, or pravastatin sodium, and was wondering if the recent problems I have been having with fatigue may be associated with an increased dose of this drug. I am on 80mg of Lipostat as my Trigliceride levels are high, and although I am on a low fat diet and have recently lost 12 kilos in weight, they are still high. I have read a lot of drug information on the drug and have a few questions. (Ben,⌨)

Again this elicited a flurry of responses from other members who either agreed that statins caused difficulties or were unaware of these issues. The cardiologist again responded with a succinct summary of the issue from a global perspective, before giving Ben his interpretation of the need for cholesterol medication. In this case the cardiologist finished with a personal message about what he did to maintain his own heart health.

The discussion about the group of cholesterol lowering drugs called "statins" (like atorvastatin, rouvastatin,simvastatin), "fibrates" (fenofibrate, gemfibrizol) and "others" (Ezetimide) in this forum is a reflexion of the global discussion about the pro's and con's of these drugs. Some do have significant side effects, hwever the importance of a managed good and bad cholesterol and triglycerides cannot be denied. Only with lowering LDL 1 we (cardiologists) have been able to show that it is possible to reduce the amount of rubbish already buildt up in the bloodvessels ie to 'clean vessels up'. Also it has been demonstrated that the group of statins have an anti-inflamatory effect, something believed to be important in the mechanism of heart attacs. But, it cannot be denied that there are side effects as well. The pharmacists makes money out of this by advising patients on cholesterol lowering medication to take Q10 in order to counteract the side effects. Also oliveleaf extract has been advocated. My advice is to sit down with your docter (GP or Cardiologist) and ask why you would need it, what the percieved risk reduction would be, for how long you would need it etc. and ask the docter his arguments. Just having an

answer like :"I don't like those drug" needs to be substantiated so that you can make up your own mind. The field will evolve over the next few years considerably so the discussion is on-going. On a personal note: I take both aspirin and a statin as a 'preventative' measure because I believe it will reduce my risk on stroke/heart attack. (Cardiologist,⌨)

In response to this message, Ben later posted that he had chosen to take himself off all statin medication and was feeling much better. He did emphasise that he had done this against medical advice. While medication issues were beyond the scope of this research, it remains a major health issue and needs to be the subject of further research.

It was never intended that the cardiologist would diagnose patients' conditions online and over time this facility ceased to exist. He became excessively busy in his practice and it soon became apparent that his involvement was not going to be sustainable. However, the threads and posts remain and provide useful information for site members to use for reference. Since the cardiologist has left the site, any posts to this thread are referred to the Heart Foundation for a response. This change in strategy appears to have been successful in meeting the needs of members.

4.4.8   Heart conditions, recovery and progress

This thread is used frequently as there is an option to provide a monthly update on how members of HeartNET are progressing. Some months this thread is hardly used, while other months it is in constant use. Members update each other on their condition, provide information about tests and procedures they have had, and generally keep each other informed about their health. This ability to communicate with others and provide reciprocal support is important according to Thomas (2010) who found that receiving social support reduced levels of depression and was associated with long term positive effects. Taylor, S et al., (2004, p. 355) also found that "social support transactions" similar to those found on HeartNET were an effective means of reducing stress levels. For example:

> Well i had my cardio visit today, The spray is controling the angina, and he is happy with how things are going. (Bianca,⌨)

> Sounds like you will continue to get angina like I do, just make sure you have plenty of spray bottles scattered around the place. (Faith, ⌨)

HeartNET members regularly update their status, explain their absence from the site due to holidays or hospital visits, and generally keep each other appraised of their wellbeing. This confirms findings from Berkman, Glass, Brissette and Seeman (2000, p. 843) who discussed the effects that "social relationships and affiliations have on physical and mental wellbeing." They reported that while social support and relationships are important and "intimacy and attachment" are vital components of close family relationships, a degree of intimacy is also required to maintain relationships at a community level. For some, only impersonal communication occurs on a site, while for others, developing an attachment to the site and sharing personal information and reflections builds relationships with others (Rochlen, Zack and Speyer, 2004). On HeartNET, building an intimacy and a sense of trust with others online meant there was already a connection when and if members met face-to-face (Høybye et al., 2005).

HeartNET provides an opportunity for its members to login and share as much or as little as they like about themselves. The membership has remained relatively static and many of the current members have met each other offline, which indicates that friendships have developed. This has led to a degree of intimacy that may not be evident on many of the larger online support sites. According to Rheingold (cited in Fernback & Thompson, 1995, para 11) it is the "ability to network, gain knowledge, or find communion [… that provides] the social glue that binds formerly isolated individuals into a community". Having taken over the role of moderator on HeartNET, I have found that members are prepared to share their common interests, their medical history and ongoing medical challenges, and while confidentiality is encouraged, as time has progressed people have become more likely to share more intimate details about themselves. One way of alleviating the risks that are inherent with this sort of sharing is to use a moderator, who is able "to reduce the risk of harmful or inappropriate behaviours, keep topics on track and where necessary encourage active participation" (Uridge, Rodan & Green, 2010, p. 231).

4.4.9   *Carers, family and friends of HeartNET*

The ABS (2013b) estimates that there are currently a little over 2.7 million carers providing assistance and support within the broader Australian community. Of these carers, 29% are sole carers and over 68% are women. It is estimated that as the

current baby boomer population ages, the number of people who take on the role of a carer will also increase.

While the focus of this study is predominantly on the people who have experienced heart events and are recovering, it is also important to remember that family, friends and others are affected by a person's cardiac event. While the patients work at recovering, their significant others and family members also work at dealing with the emotional trauma of the impact upon their loved ones. They also go through a period of grief. Family support is important. Several partners of heart patients have also become members and they utilise the forum to share their feelings and emotions.

The Carers, family and friends of HeartNET forum regularly has posts about the wellbeing of families and friends. There is an occasional continuation of the postings to announce that someone the site members know has been taken ill and then passed away. When this happens there is an outpouring of support and sympathy from site members and moderators.

Fred, a long term site member who also had other family members on the HeartNET site, started a thread about the effects that heart disease had on family members and how they received support, if at all.

> There are over 2.6 million carers in Australia from all walks of life. They're required to, often to the detrement of thier own health & employment opportunities, manage complex health conditions, give medications handle finances provide emotional support & assist in daily living tasks such as feeding bathing & toileting. So to all you carers out there & you know who you are... THANK YOU. (Fred,⌨)

> Do you find yourself between a rock & a hard place, when a loved one has experienced any heart problem? Do you get frustrated at not knowing what to do or cope? I thought it would be good if carers could give some tips on coping to new carers here. (Fred,⌨)

Some of the HeartNET members who had joined the site as carers struggled to cope with the changed role of their partners after their heart event

> My hubby (who had a heart attack just over a year ago) has taken on a new life. He has always been active, can't sit still for long, but in recent months he is going gang busters on home renovations and now is tackling the building of a new addition to our house! He is extremely capable of all these things but my concern is that he won't/can't rest for long. My worry is that he is overdoing things. I

have even said to him that all this will be of no use to me if he isn't here. So, what do I do in this sort of situation? (Shona,⌨)

Another member Sarah described similar circumstances when her partner had a heart attack and would not allow her to take on the role of carer.

I'm in the same situation with Simon. He figures he is going anyway, why be overly diligent with diet and restriction, He thinks he would rather enjoy what he has left, selfish I guess, But I think it is their life to be selfish with, I do have my say tho lol, He can listen or not, It is ultimately up to him. I don't think I have the right to nag him to his death. Who wants to live 'longer' being nagged about your unhealthy habits & passing this life unhappy. I see his point & I see mine too, In the end (pardon the pun) It is, 'his life'. Dear Shona, My resolution is there is none, You just have to grin and bear it. Live & let live, that sort of thing, It's is bittersweet. (Sarah,⌨)

Joan was also struggling with the dual roles she had been forced to assume - that of heart patient on the one hand and as a carer for elderly family members on the other. She faced this struggle publicly on HeartNET and shared over several months the dilemma she faced with putting relatives into care, and then watching as their health deteriorated. She had finally come to the conclusion that each person had the right to make their own decisions.

As for my role as a carer, I have to also apply that same ruling to my Ma. She has the right to say yay/nay too food, drinks, medication etc, although we can support an try and twist her arm sometimes, it is her choice and her choice only to make ... I think from a carers role, that is the hardest thing to do, sit back and say nothing when you can see something is/or possibly is detremental to the health of someone you love.

What a dual edge sword for us all...

Which ever choice you make, should be right for you and hopefully you have the love and support of your family, friends and network too ... that's the key word in carer 'care' (Joan,⌨)

For Jonah, caring for an ill partner had necessitated counselling which had provided some degree of comfort. He also found support from his online friends, which was an important part of his coping strategy:

suppose the most important piece of advice I can give ... is dont keep your feelings to yourself especially as a carer ... talk to the person you are caring for ... because nine times out of ten they are feeling the same frustrations and feelings that you are!

> Caring for someone is one of the hardest and most difficult things you will ever have to do.
>
> Most important though you must know and remember that you are not alone in the quest and that there is a heap of support and guidance for you.
>
> The biggest of all things with my caring for Shanay has been the help and support of Family and friends both online and in the "real" world. If not for all of you I am quite sure i would have fallen in a heap or been in a padded stall somewhere. (Jonah,⌨)

A common theme throughout this thread is the concern partners felt for each other. While everyone dealt with this in their own way, Fred provided this advice for Shona, who was struggling with her husband doing too much after his heart attack.

> Shona, I don't know. I know some who have had heart attacks & with a few changes went on to do what your husband is doing without another incident, & others who don't listen to what they've been told & the rest is history. May I advise helping him by passing what he needs, nails, tools etc. & the occassional cuppa, that way you get to not only help but just might slow him down. Good Luck. (Fred,⌨)

Rafaeli & Sudweeks (1998) observed that most posts in group computer-mediated communication (CMC) were "predominantly factual, conversational, agreeable and supportive" (p. 9). This was certainly apparent on HeartNET with the majority of posts in these forums providing support and information. The posts also provided me with an opportunity to study these interactions as a "representative snapshot of communication in a virtual community" (Demeris, 2006, p. 183).

4.5   Meet 'n' Greet

This thread has a more light-hearted focus. It allows members to connect with new members accessing HeartNET, to chat about issues unrelated to their heart health, and by sharing online jokes and fun in an unmoderated section of the site.

4.5.1   New members – start here!

Providing an online space for people to introduce themselves and then share their feelings is important. As the moderator, I am required to activate individual membership registrations and I always direct them via email to access this part of the site first. Few do so, however, and this is certainly something that needs to be explored in the future. It may well be that new members lack confidence in sharing

about themselves or alternatively they could still be dealing with their diagnosis. However, the option is always open for them to access this thread on the forum. New members may be overwhelmed by the fairly immediate response to them on joining the site. How people experience their diagnosis or if they are feeling unsure or vulnerable, may also determine whether they access HeartNET.

Finding a support site where members are comfortable, accepted and able to share their own life story and illness experience may be helpful. Several new HeartNET members who had been newly-diagnosed used the meet 'n' greet facility to explain how difficult it was to understand their heart condition and its implications for the future.

> … i guess until I found this place I never really let myself see how overwhelmed I am with my diagnosis I just tried to pretend I was ok, … sorry I am just a bit raw with this whole situation but this place looks like it will be a god send for me. (Veronica, 💻)

> I am still a bit frazzled at the moment, I have been diagnosed with Idiopathic Dilated Cardiomyopathy and really don't know what to expect. I am on a fistful of drugs, and I really do rattle now when I walk. I have looked up information on the web about the disease, and from what I have seen I am pretty scared. (Shelby, 💻)

Members who were further on in their heart journey were quick to reassure and provide support as required.

> We are all here to help & support you through the rough times and the good. Don't hesitate to ask us anything ...Take care. (Sarah, 💻)

> … as others have said, its quite a shock to all of us when we get told our heart is the cause of our problem ... there are many of us here who are young/ish and have kids, so you are not alone. (Joan, 💻).

This appeared to ease the minds of the two new members and they were soon playing an active role on the site by joining the regular chat session and posting messages of support and encouragement to other members.

4.5.2   Chit chat

This thread provides a general chit-chat discussion area. It is intended for friendly banter. It is utilised by HeartNET members to share the highs and lows of family and community life. Titles of posts range from "Love is in the air," which was related to Valentine's Day; while other threads relate to Fathers' and Mothers'

Day, and family birthdays. One post that sparked much discussion was titled New Fangdangled technomologicallomy thingoes – Smart Phone Apps", where one of the members commented on the effectiveness of the new smart phone and some of the apps that might help people with cardiac disease to get immediate treatment if necessary.

This thread allows people to share anything including issues related to weather or physical disasters such as when major storms or floods occurred in other Australian states. Members were quick to ensure their friends and fellow HeartNETters were well and had not suffered any traumas. More personally, whenever there is an earthquake or volcanic eruption in New Zealand, one of the members will either send me a private message or ask publicly if my family is still okay.

4.5.3   Fun 'n' games

The majority of online community forums that I have contact with have a fun 'n' games thread. When it was originally set up HeartNET did not have its own fun 'n' games section, but over time due to the "popularity of games emerging on Chit Chat, we thought they deserved their own special section. Please continue to use Chit Chat for anything other than games, puzzles etc.! NOTE: This section is unmoderated – so please remember your manners!!" (HeartNET, 2012). So far this request has been adhered to and I have not been requested to moderate the site. In fact the members themselves have taken on a moderation role. The following is an example of the kind of fun and games that the members of the site have with each other. Over a period of time this cardiac comedy evolved with several members on site contributing to the story line.

> OUR OWN COMEDY SERIES... MEET THE CARDIAC'S:
>
> Here's a fun little exercise. Lets write our own comedy all about a family, oh we'll call them the CARDIAC'S
>
> I will let your twisted demented and tortured minds kick this one off, but as an idea – we could have Myra, but she's always been known as Myo as a character, the Cardinal as another [he goes by his nick name – Cardial], and there is probably a lot of infarctional fighting going on around the place as well.
>
> Knock yourselvs out folks. Lets see where this goes...

Sarah	'The Cardiacs" Scene One ... Set in rehab unit, At a local Hospital. Take One.. Myra is peddling away madly on the rehab bike. When Cardinal meanders past, with out his clothes & a glint in his eye.
Joanna	Enter stage Right The Lovely Stentosa, resplendently clad in her new titanium coat.. catches a glimpse of her lovely self in the mirror on the wall. She fails to see the "glint" in the eye of Cardial, as he approaches...
Bianca	But Myra, jealousy coursing through her veins when she realises that Cardinal is not watching her but is eyeing of the beautiful Stentosa in her Magnificent titanium coat wishes that Angio would arrive so...
Joanna	that he would plasty him all over the wall...lol
Sam	Meanwhile back in his office, the Cardinals telephone rings. "Hello" he nervously enquires waiting for the long anticipated, if not feared response "Yeah, its bloody Benedict here... You know, THE POPE – YOUR BOSS!, what the hell is going on". Cardial replies in a stammer "I I I..."
Bianca	Am waiting for Dr Defib to come and sort out the B/P and pulse's of these @#^*@# cardiacs ssorry Sir will get my clothes on and...
Sam	get back to the hospital. I have to check on those people who have been named after water courses and geographical features.
Bianca	I have checked on Mr waverock he is doing remarkable well and have changed the meds of Avon they are both in W A. And doing well.

Joanna	Mrs Yarra Mudwater,Mrs Melba Westgate and Mr Murray Bridge are responding well to the changes!
	Mr Apostles reacted badly wanting to hold his own,however 12ccs of adrenaline made him climb the walls and out the window...security are locating him now!! Hospital Legal Eagles have been notified Cardial yells "What is that infernal noise?" as the "Little River" Band, belt out a tune over the radio...hangggg on help is on its wayyyyy!...
	Throws his cup of coffee at the radio adding,"Damned that Sister Victoria Stentosa!! She will be the death of me"!!
Sam	He rises from his desk and leaves his office. In the hall he sees a falone figure that he seems to recall. The lonely man turns, and upon seeing Cardial exclaims "Ja, dis is a gud dai to see the gud father", "Ahh" Cordial replies "Mr Unda Taka, what brings you...
Bianca	I bin tuld sumbody have to come mit me today.. Cardial you know who "ja"dis is very noisy place maybe take "little river"band "ja" cardial what you think....
Colleen	"Air Supply" is calling for help...Hurry up "little river band", we need to know that help is on its wayyyyy!
Bianca	meanwhile stentosa and mr murray bridge are causing havock on the ward wondering who they can dance to if little river band and air supply have gone on to greener pastures
Colleen	In the emergency room Dr Defib is using some "midnight oil" on Sister Stentosa who is struggling with a new patient called Sassy Stent (Multiple site members, 💻)

This drama unfolded over a period of several weeks and appeared to take on a life of its own. The characters had several adaptations. When reading the transcript, a reader can see that the Australian characters have taken on deep southern accents and have used their knowledge of various Australian bands to help the authors keep the story functioning. I have found, when analysing the posts to this bulletin board and the chat room, that where comedy is involved it usually takes on a medical theme. This may reflect the fact that HeartNET is for people affected by CVD or it may also indicate members' involvement in their own heart health and thus medical themes

are more relevant to them than many other subjects. It may also reflect the findings of Høybye et al., (2005) in their cancer support site that sharing humour and laughter reduced feelings of distress and provided an opportunity to bring relief to all participants.

4.6 Other Issues

This section of the bulletin board allows members of the Heart Foundation to share issues and ideas, birthdays are acknowledged and suggestions to improve the site are also shared here.

4.6.1 *Heart Foundation events & activities*

As part of our link with the Heart Foundation several of the staff at the Western Australian Division are members of the site and access this section if they want to share details of future Heart Foundation activities and events. It is here they advertise for participants to help with the door knock appeal or to appear on the Heart Foundation website. This thread has recruited HeartNET members to participate in activities and events.

4.6.2 *Miscellaneous issues & member announcements*

This forum is similar to others, but it is here that members acknowledge birthdays, announce coming events or generally check up on each other. Activities and get togethers are sometimes organised via this area and posts acknowledge the roles that members have taken on board.

As the moderator, I highlight issues and events that are pertinent to the Heart Foundation and this includes providing links to future activities and events in all states and territories. There are also links to other forums elsewhere, walking groups and other issues that may be relevant to people living with CVD. For example, one title advertised "No honky nuts on this walk lol!!!!!" Honky nuts is a term used in Western Australia to describe the nut or seed pod of the native Marri tree (Department of Environment and Conservation, 2011). This title related to the fact that several of the members had complained about walking with the Heart Foundation as there were often tree roots or fallen seed pods that made walking difficult.

4.6.3 *Site suggestions*

This final forum allows members to comment on what they felt should happen over time on HeartNET. While many of the suggestions are really useful and are easily dealt with, such as getting the IT manager to archive private messages, others are more complex. Issues such as the speed of accessing the site have been difficult to address. As the site has grown, the length of time for some people to access it has also increased, especially for those few members who are still using dial-up connections. Addressing such issues has proven to be very time consuming, and, while it is beyond the control of the HeartNET moderation team, technological lag and access inequities are challenges of which we are aware. Many of the suggestions are beyond the financial capability of the site and would necessitate a complete overhaul of the site which is beyond the funding support provided

4.7   HeartNET vs. Facebook

The use of Facebook as a communication tool is explored in this section and provides some insight into the extent that social networking sites have been integrated into everyday life. The differences between the use of a lay-moderated site like HeartNET which encourages anonymity and the protection of personal details, is compared to Facebook where users share intimate details about themselves "and their extended social network" (Boyd & Ellison, 2007, p. 211). This section then explores the use of social gaming sites.

Facebook was created in 2004 by Harvard psychology student Marc Zuckerburg as a "computer-mediated social networking system" (Ross et al., 2009, p. 578) and was initially used by university students to maintain social ties while they experienced university life (Ellison, Steinfield & Lampe, 2007). In September 2006, "the network was extended beyond educational institutions to anyone with a registered email address" (Phillips, 2007, para, 5). In March 2012, it was estimated there were more than 835 million Facebook users worldwide with that number growing daily (Internet World Stats, 2012). As of June 30, 2014 there were 1.32 billion monthly active users (MAUs) on Facebook (Facebook, 2014).

According to Joinson (2007, p. 1027), social network sites have several functions. They provide "social and emotional support, information resources and ties to other people". Facebook provides users with social and emotional support

through the option to communicate with people already known to them or to make new contacts. With so many people accessing social network sites (SNS) and spending many hours online, it can be deduced that the sites are meeting the "personal and social needs" of users by providing a sense of connection (Raacke & Bonds-Raacke, 2008, pp. 173-174).

HeartNET moderators encourage anonymity and personal information is limited to the user-generated member profile, while Facebook users appear to place little "restriction on the nature and content of material placed on the site" (Gangadharbatla, 2008, p. 13). In fact, moderators on HeartNET actively discourage the public sharing of personal information on the site.

Privacy is another major difference between HeartNET and Facebook. It has always been HeartNETs policy to maintain users' privacy and members are constantly reminded not to publically divulge personal information. However, Debatin, Lovejoy, Horn and Hughes (2009, p. 83) found that Facebook usage was "deeply integrated in users' daily lives, through specific routine and rituals. Users claim to understand privacy issues, yet reported uploading large amounts of personal information". Park, Kee and Valunzuela (2009) noted that the use of chat rooms, bulletin boards and emails requires active participation. They examined networking among Facebook users and determined that being a member of an online group strengthened "social contacts, community engagement, and attachment" (p. 729). Dwyer, Hiltz and Passerini (2009) suggest that the main reason people join an SNS is because they need to communicate and maintain relationships which are often initiated offline, but subsequently bought into the online arena.

Many of the HeartNET members joined Facebook to keep in contact with family and friends who were on holiday. In the past people would send a postcard home while on holiday (The Advertiser, 2012). Now they choose to use Facebook to keep in touch with family and friends who are able to access photos and travel stories online. Debatin et al., (2009, p. 100) maintains that Facebook's "integration into daily life indicates that it has become an indispensable tool of social capital and connectedness with large numbers of people". Green and Jenkins (2009) describe how Facebook users who choose to "share their interactions and communicate with others online are maintaining reciprocal social relations" (p.121) and suggest that

this gives these interactions value. Amelia saw Facebook as a means of keeping in contact with family and friends and accessed it regularly.

> I rather like facebook! Never played any games. I like being able to see what my family and friends interstate and overseas are doing. Enjoy sharing photos and bits of news and reading comments. Am very sporadic in using it. Sometimes go for several days without looking, other times log on two or three times a day. To me, it is just part of modern life! (Amelia,⌨)

Sam used it rarely stating:

> I only use facebook to keep in touch with a few family members, some colleagues flung far and wide around the … Other than that, I avoid it like the plague – or a second heart attack. (Sam,⌨)

While many of the HeartNET members had been strangers to each other prior to joining HeartNET; they subsequently joined Facebook as friends and their involvement on HeartNET waned. Hei-Man (2008) suggests that "users tend to trust the site and its user more, and they are more willing to include identifying information in their profile as Facebook users tend to use the site to manage relationships initiated offline"(p. 55).

At the time that some HeartNET members moved across to Facebook, HeartNET was going through a period of turmoil. A private conflict that had exacerbated into public discord left the site members unsettled and distrustful of other members and the moderating team. Some members left HeartNET, others moved to alternate health sites and Facebook (Uridge, Rodan & Green, 2010). It would appear that the more open nature of Facebook and the advantage of knowing personal details about other users may "reduce uncertainty about other users intentions and behaviors, which is a necessary condition for developing norms of trust and reciprocity" (Valenzuela, Park & Kee, 2009, p. 878).

It wasn't until I was interviewing one of the study participants that I became aware of the HeartNET community on Facebook, as at that time I was not an active user of Facebook. Fiona was very forthright in her explanation of why she had gone across to the SNS.

> like Bianca a lot of friends from HN [HeartNET] and family asked me to join FB [Facebook] cos they were involved in games, post pics etc I resisted for a longgggggg time but got lonely (cos everyone seemed to be on there). (Fiona,⌨)

This was reiterated by other HeartNET members. Bianca agreed with Fiona explaining that "it was the interaction [that was important] as most people from H/N [HeartNET] had gone there" (Bianca,⌨).

While connection was a key factor for some of the HeartNET users, for others it was the games available through Facebook that became the major reason for accessing the SNS.

This next section explains the popularity of gaming on Facebook and associated social gaming sites. It highlights the perceptions of several HeartNET members who were willing to share their experiences while playing games such as FarmVille and Fish World. The use of games such as FarmVille and Fish World can provide a means of experiencing connectedness while exploring the interaction required for maintaining an online presence on these gaming sites. It appears that while initial contact is intensive, over time this interactivity wanes and for some it ceases completely. Creating an online persona allows people more freedom to be who they want to be, and while the moderators of HeartNET encourage members to maintain their privacy, the opposite often occurs on Facebook where users are encouraged to provide personal details to not only friends, but to friends of friends.

4.8   Social Gaming

Social gaming in the 21st century had been aided by several factors including the ability to access free gaming sites via social networking sites such as Facebook, and the use of smart phones which are now accessible to most people "as casual gaming platforms" (Greengard, 2011, p. 20). Game playing may be frivolous and time wasting to many people, but it is also seen as a means of "escape from responsibility and routine" (Callois, cited in Lisziewicz, 2010, p. 2).

The games discussed in this section are not part of social network sites, but are external applications that users add to their online profiles (Rossi, 2009). FarmVille was one of the most popular online games available and was "the top game by daily active users [DAU] on Facebook between August 2009 and December 2010" (Zynga, 2014). In 2012 FarmVille accounted for an average of 2.6 million players daily. In 2014 this number has dropped significantly to around 600 thousand DAU (Appmeter, 2014). Fish World was not as popular with around 40 thousand DAU in

2012. This number has since dropped to around 30 thousand DAU (Appmeter, 2014b). Wohn, Lampe, Wash, Ellison & Vitak (2011) identified FarmVille as a "simulation game about resource allocation and customization" (para 8), where players create their farmer persona, work in the fields or take produce to market, as well as developing in game friendships with their farm neighbours. According to Balnaves, Willson and Leaver (2012, p. 7) such games develop a rudimentary "sense of community".

For many people, playing online games provides an outlet to reduce stress and a break in everyday routine (Lisziewicz, 2010). To be an effective farmer on FarmVille one needs to work hard and to plant, harvest and replant any farm plot. Users get rewarded while playing, which then allows them to upgrade their farms, build factories, decorate their buildings, and buy more produce, seedlings and land by using the in-game profits they accumulate. Alternatively they can bypass the game playing aspect and spend real money to upgrade their farm; providing Zynga, the game designer company, with millions of dollars of profit annually (Lisziewicz, 2010).

While FarmVille players feel an obligation to ensure their farms are well tended and crops are harvested on time, there is also a perceived obligation to the friend who farms alongside them (Balnaves, et al., 2012). Farm users can assist each other with gifts such as seeds, trees and produce. This creates a sense of obligation as explained by Liszkiewicz (2010).

> The secret to *Farmville*'s popularity is neither gameplay nor aesthetics. *Farmville* is popular because it entangles users in a web of social obligations. When users log into Facebook, they are reminded that their neighbors have sent them gifts, posted bonuses on their walls, and helped with each other's farms. In turn, they are obligated to return the courtesies. As the French sociologist Marcel Mauss tells us, gifts are never free: they bind the giver and receiver in a loop of reciprocity. It is rude to refuse a gift, and ruder still to not return the kindness. (Liszkiewicz, 2010, para 9)

According to Balnaves et al., (2012) there was an intersection of gift exchanging, connection and community for the users of FarmVille. Farms were maintained, crops were tended and harvested, and gifts were exchanged in the form of resources and assistance when required. For some players "objects take on meaning based on perceived status, scarceness and emotional value. In today's

gaming universe, coveted items include homes, weapons, space stations, and yes, horse manure" (Greengard, 2011, p. 19). This became clear during one of my interviews.

Balnaves, Willson and Leaver (2012) researched FarmVille as part of an ARC funded grant on Internet social gaming. During this time Balnaves spent several hours a day on FarmVille as an "ethnographic researcher" (p. 6). Similar to Bianca he soon became immersed in the routine of farming, continuously planting and harvesting his crops, even setting his mobile phone alarm to ensure his crops did not wither and die.

> He could not rely on memory. The farm requires constant maintenance or plants will wither and die. This compelled in the researcher a certain feeling of commitment and responsibility that required continual return to the game (Balnaves et al., 2012, p.8).

Bianca chose to farm alongside her fellow HeartNET neighbours, but says she did not really communicate or chat with them. She was aware they were there, but did not consciously seek them out while she was going about her farming duties. As can be seen by the following vignette however, she was able to determine when fellow farmers were in trouble.

4.8.1 *But my crops will wither and die!*

The following is an account of the conversation I had with Bianca during her interview. Ten minutes after I arrived, her alarm went off and she excused herself. Inviting me into her office she logged onto Farmville and then proceeded to buy and sell produce for the next 45 minutes or so. Bianca had her workstation set up with pens, paper and a notebook filled in with details of all her farm purchases including the price she had received for the goods she was selling from her farms. They were all well maintained and productive, her notebook was full of the time her crops were due to be harvested, and Bianca had set her alarm to ensure that she would not forget to harvest her crops when they were at their best. Failure to do this would have resulted in a loss of FarmVille money.

Bianca kept up a running commentary about what was needed to harvest her water melon and her strawberries for her ice cream factory. She explained that she needed to plant, then harvest her crops, before taking them to the market to sell. She put the profits back into her farm which allowed her to plant something else and then

sell it on. She was interrupted frequently online by people asking her if they could work for her or if she had a particular product they could buy, and she responded either affirmatively or negatively. While checking that all her farms were well maintained, she commented that several HeartNET members were also farmers and had farms nearby.

Bianca had helped them with their crops and harvests and offhandedly commented that one of the nearby farmers was Daisy, a HeartNET member who had grapes ready for harvesting, but were several hours overdue for picking. Bianca commented that it was unlike Daisy to ignore her crops and that she would email her to find out if she was all right. Bianca then asked me if Daisy had been coming onto HeartNET lately and when I commented that "no, I hadn't seen her for a while" she wrote herself a note to send an email later that afternoon to find out if Daisy was OK. She also asked me as the HeartNET moderator to check on Daisy as well. I assured her I would and Bianca continued harvesting and selling her produce. On returning to my office I contacted Daisy only to find that she had been in hospital after having an exacerbation of her heart disease. This crop of un-harvested grapes in an online game explained Daisy's absence from HeartNET, and in an outpouring of support fellow game players on Farmville and members of HeartNET harvested her crops for her.

When Bianca completed her tasks on Farmville we continued with the interview and I asked her about her involvement on Facebook and Farmville. She was totally honest, admitted that HeartNET had become very quiet and there were several other members of HeartNET on Farmville.

> Not just farming, cos there's so many other games. And there's seven of us that I know of on there, from HeartNET. Yeah there's other games. (Bianca,📷)

Playing games was not the only reason Bianca had joined Facebook. Like many of the other HeartNET members she had joined Facebook to keep in contact with her family and friends.

> I didn't know, well I did know about the games cos Pansy was doing them, and she said to me about it. When she sort of stopped doing the games on HeartNET she said "oh I'm too busy farming or something on my other game", but I didn't really know what that was. (Bianca,💻)

Bianca was surprised that she knew so many people on Facebook. They invited her to join them near their own farms in FarmVille:

> So I joined just so I could chat to her [Pansy], and of course as soon as I joined, these people come on that, oh, shocked me. "Will you be my friend on Facebook?" you know, and then Amy, "will you be my friend on Facebook?" and Tania, "will you be my friend on Facebook?" Just so many of them, and then they said "oh come and join the farming", which I hadn't even heard about really and then I presumed that must be where Pansy farms. But there are others, you know, there's Country Life, there's fishing, Fish World where you. (Bianca, ⌨)

I had never heard of many of these games and was surprised at the amount of time and energy people were spending on these sites. Bianca admitted that she found playing these games time consuming and addictive. She said she spent a great deal of time on FarmVille, and often found her family laughing at her 'addiction'.

> But I said to my son, cos he came in, "oh you're busy farming Mum again". I said "it's really good for you, cos you've really got to work your brain. You've got to work out how long these crops are going to be in and what to plant, what you can make more money out of. Which are going to give you the best return for". (Bianca, ⌨)

Barely pausing for breath, Bianca continued talking about her own farms on FarmVille.

> And I've got all these facilities, like I think I said to you at the card thing about the ice cream factory […] Bought an ice cream factory that morning, cos I only just really started then. […] And I bought an ice cream factory, so I had ice cream making while we were at that thing. So I couldn't wait to get home and see what was happening with this ice cream that was making, you see? (Bianca, ⌨)

> [laughs] Okay. (Lynsey, ⌨)

> But now I've got, I don't know, 10 facilities that make different things. But then because you want to make ice cream, you've got to grow the pineapples to do the pineapple ice cream. […] Pineapple flavour, you've got to grow all these things and then your crop might be a four hour crop or a 12 hour crop or a two day crop, so you've got to make sure you get back to take that crop off, otherwise it withers and it dies and you've lost all that money that you've just spent planting it. (Bianca, ⌨)

> Well HeartNET can't compete, can it? [laughs] (Lynsey, ⌨)

Pretty hard. (Bianca, 📷)

Oh dear, what am I going to do? (Lynsey, 📷)

Prior to continuing the interview Bianca commented on a friend who had called her that morning and asked her to 'hide a fish'.

4.8.2 Adventure in Fish World

Bianca's friend Pauline was a member of Fish World, another online game site which involved creating a virtual fish tank, filling it with fish and ensuring they survived. Over time the fish would be fed and when they reached maturity they could be sold for 'Fish World Fishbucks'. A unique component of this game was the fact that fellow Fish World players could steal your fish. Although there appeared to be rules on how this could occur, it seemed that Pauline had a very expensive fish that she did not want anyone else to steal. She had rung Bianca just prior to my arrival in a state of distress as she had forgotten to hide her fish before going to work and was concerned that someone would steal it, if it wasn't hidden quickly. She had asked Bianca to go into her aquarium and hide the fish. Failing this, Pauline was prepared to leave her place of employment during her lunch break to return home and hide her fish!

I could not understand how anyone would actually contemplate leaving work to hide a fish, or have an employer who allowed this to happen. But this option appeared to be the only solution that Pauline could think of, had Bianca not been able to find and hide her fish.

> Well I don't know whether fish, it must be the same, because Pauline went to work this morning and then rang me up, "help! [Its] 10:00 am [and] I'm meant to hide a fish, can you please go into"… (Bianca, 📷)

I expressed disbelief:

Hide a fish? (Lynsey, 📷)

Yeah. (Bianca, 📷)

Oh okay. (Lynsey, 📷)

Otherwise it'll get stolen (Bianca, 📷)

Oh okay. [laughs] (Lynsey, 📷)

And it costs me $8 farm money, her Fish World money. (Bianca, 🎥)

Okay. (Lynsey, 🎥)

So I had to go and find this fish, which I didn't even know what I was looking for cos I don't play that game, I had no idea what I was doing. Had to find this fish and hide it so it doesn't get stolen. But there's just so many. So like, that panicked her, you know? "Oh I'll have to come home at lunch time if you can't find it. I'll have to come home at lunch time and hope it hasn't been stolen and hide it." (Bianca, 🎥)

And this is all part of a game? (Lynsey, 🎥)

Yeah because you steal each other's fish. (Bianca, 🎥)

Oh goodness. (Lynsey, 🎥)

[Another friend], she plays it, and she's always stealing Pauline's fish and Pauline's always stealing hers and this sort of thing. So that's part of the game. But it's addictive. (Bianca, 🎥)

Wohn et al., (2011) observed participants playing in Fish World and argued that the interactions they have with other players are rewarding. When helping someone there is an underlying assumption that this help will be reciprocated in the future. Fish World gives players an opportunity to be part of a larger group, described by one player as having "this kind of community of people that know each other collaborating … with these games you can send gifts to one another and help each other out" (Wohn et al., 2011, p. 6). Inter-player reciprocity is a key component of maintaining relationships on this site, and on many other social gaming sites, with players helping each other to advance themselves further in the game. It is this advancement that makes for a positive outcome for many players.

Bogost (2010) however, sees players in online games not as friends, but as a resource that needs to be cultivated to ensure advances through the game. This certainly appeared to be the case for Bianca. She would see who was on FarmVille when she entered the site and decide whether to help them with their crops or take their produce to market. In turn she would then expect farmers near her to offer to do the same. Even with their involvement on Facebook there is a core group of members who are committed to HeartNET. They remain connected to the site, its purpose and appear to value their involvement with the HeartNET community (Ren, Kraut, Kiesler & Resnick, 2012).

4.8.3 Destroyed time

Time can be lost in both playing the game and staying away from the game. Bogost (2010, para 3) identifies feelings of "obligation, worry and dread over missed opportunities". This missed opportunity time was identified as a major issue by HeartNET members who were social gamers. The gamers agreed that time was wasted and for some it was almost an addiction to remain on the site, sometimes to the detriment of their family life.

> And because of my addictive nature I did 2 games for the longest time..mainly because on one game inparticular u got to talk to the ppl who u either worked for or while they were working for u..interaction...after a time even that talk stopped cos ppl moved onto the next new game etc.. FB itself wasnt the escape but the games were, which I didnt intend to get involved with, but when ppl stopped talking,both on HN and FB, the games filled a gap cos gamers talked! I dont game now..(it was for a season).(Karen, 💻)

Other members gave similar responses when asked what took them away from HeartNET. There were a variety of responses including:

> I haven't been on HN for a while so have missed out on lots.I have become a farming tragic on facebook. What with pooter probs, moving and facebook bingo […] life has been busy. (Amber,💻)

> I am getting better at planning and organising my time, which includes trying (not too successfully) to stay off the Internet socially in favour [of] more productive work on the computer! Am making headway, but the Facebook word games are still a big lure! (Polly,💻)

Bianca, who spent hours on FarmVille, posted to a HeartNET discussion thread about social gaming and was adamant she did not need escape and could not be classified with those people who spent hours on Facebook playing games.

> For me i don't need escape!-it was the interaction as most people from H/N had gone there. but it was not what i wanted so have stopped. (Bianca, 💻)

> ye i am one of those guilty ones who dont get on [HeartNET] much since i found facebook game but am going to make a effort for thursday nite chat room […] what i am finding you dont have to be on here every day or months but when you get back on it is the same feeling that i get is one big family i have here and it does not change so what i saying is glad you are all here and hugz and kisses to everybody lov ya all xx […] and havent been on site for a

long time would like to say a big thank you to you Bianca and Fred for keeping in contact with me through facebook. (Portia,⌨)

Facebook has become a "social phenomenon and one of the largest social networks on the Internet" (Kobler et al., 2010, p. 1). It provides users with "social and emotional support, information resources and ties to others" (Joinson, 2007, p. 1027). At the same time it can allow users to feel a sense of connectedness anywhere, any time and any place. From the participants comments it is clear that Facebook, FarmVille and FishVille provided additional social connectedness and interaction.

4.9   Summary

This chapter identified the various forums and threads on HeartNET and the role of Facebook and gaming sites such as FarmVille and FishVille as a communication tool when members perceived that HeartNET was not interactive enough. It provides a snapshot of an active and ongoing community, and an insight into the interactions that occur on the site. Each forum was identified and discussed, with examples of the relevant interactions provided. As discussed previously, in some cases where new members came onto HeartNET and were unsure about their long term health outcomes, interaction with other members helped them to use the site as an alternative outlet to address any concerns or issues they were facing.

While some forums on HeartNET were used frequently and had a large numbers of threads, others were not so well utilised. Sometimes the members would find that what they wanted to write did not fit into the rigid structure of the bulletin board. Therefore, at times, the moderator would find posts on the site that did not seem to fit the forum themes.

The HeartNET members have been actively involved on HeartNET for many years. They are familiar with the site and their heart health has stabilized. When new members appeared on the site, the ' old timers' were quick to welcome them and work at helping the 'newbies' to become familiar and comfortable as they accessed the site and were encouraged to discuss their thoughts and feelings.

Chapter Five discusses the role of HeartNET in the gift economy. It provides examples from the website of the gift economy in action, where the simple act of sharing a recipe can have a profound effect on a person's heart health status. While

humour and grief were discussed in the previous chapter, these aspects are elaborated on in Chapter Five; where the opportunity to share a laugh or write a poem that expresses grief and despair with the expectation that someone will respond with support and encouragement, illustrates the gift economy in action on HeartNET.

CHAPTER FIVE:
GIFT ECONOMY – IN ACTION

> A gift is a thing we do not get by our own efforts. We cannot buy it; we cannot acquire it through an act of will. It is bestowed upon us (Hyde cited in Jenkins, Li, Krauskoppf & Green, 2009, p.xvi).

This chapter focuses on the gift economy and the relationships that develop with an investment of time and emotional compassion which can result in positive outcomes on an online community. It defines the gift economy in action on HeartNET and the role of volunteering by non-HeartNET members. This chapter explores the gift economy using examples found on the HeartNET site. It briefly looks at the historical features of the 'gift' identified by Mauss (1990, 1925) and Hyde 1983), and acknowledges that the act of gift giving in real world scenarios is different to those online, and specifically HeartNET.

The aim of this chapter is to demonstrate the gift interactions on HeartNET and the importance of volunteering in real world situations as examples of the gift economy in action. It uses examples throughout this chapter from online interactions, posts on HeartNET and data from the in-depth interviews.

Volunteering is identified as part of the gift economy whereby people gift their time, energy, expertise, knowledge and support. While HeartNET members also volunteered, the focus of the second part of this chapter looks specifically at non-HeartNET members who volunteered for hospital-based support groups and in the community. A key finding in this chapter is that an online community like HeartNET is sharing support, rather than gifting it.

The first section of this chapter discusses the gift economy and how HeartNET members contribute information sharing, humour and poetry to the gift economy through their online interactions. The second section of this chapter explores the role of volunteering by non-HeartNET members. It identifies that all participants in this group volunteered in some capacity and demonstrates how volunteering is an aspect of the gift economy in action.

5.1   Introduction

This research explores the gift economy as the act of giving and sharing information, support, encouragement and time in both the online environment on HeartNET and as a volunteer in real world situations. HeartNET members are active participants of the gift economy. They interact on the site at regular intervals sharing information and support which can be perceived as gift giving. Assigning a monetary value to this interaction is difficult, because "the artifacts [sic] one gives away (or, interpreted another way, the visible sign of one's gift of energy and time) are very complex. Their value is nowhere near as obvious as that of material gifts or exchange-economy money" (Raymond, 2000, para. 12). Rheingold (cited by Bollier, 2003, p. 30) believes that for the gift economy to function it:

> ... requires one to give something to enable and enables one to receive something ... I find that the help I receive far outweighs the energy I expend helping others; [which leads in turn to] a marriage of altruism and self-interest.

Lampel and Bhalla (2007, p. 440) identify altruism in online communities as "non-calculative generosity that is often used to explain behaviour when self-interest as a motivating factor is not in evidence". Belk (2007) asserts that any individual accessing the Internet to participate in online gaming, chat rooms, blogging, or in responding to emails, does so by "making use of these online resources [which] are a part of Internet sharing regardless of whether they make similar contributions themselves" (Belk, 2007, p. 129). This has been identified by some as altruism "bought about by the magic of cyberspace" (Belk, 2007, p. 129). People can give away support, but Belk believes that rather than gifting this support people are sharing it, as often in an online environment there is no "ritual presentation of the gift and because donors and recipients are often anonymous and unknown" (Belk, 2007, p. 132).

Pearson (2007, para 4) cites Rheingold and Kollock as arguing that the gift economy incorporates "exchanges of ideas, information, cultural product, technical assistance, and gossip [which can] be seen as formulating the basis of a gift economy". Kollock (2002) believes that people cannot rely on individual reciprocity in online interactions, as the information posted in forum threads is offered to the group as a whole. While there may be an expectation of help in the future, the

majority of interactions on HeartNET are more generalised exchanges "in which a benefit given to a person is reciprocated not by the recipient but by someone else in the group" (Kollock, 2002, p. 3). This is illustrated on HeartNET on the bulletin board and on the chat site. The interactivity of the site helps provide the social glue that helps build and maintain the sense of community. It is this interaction on HeartNET that provides what Brown and Duguid identify as "rich social networks" (2002, p. xxv), an aspect that will be discussed in the next section of this chapter.

HeartNET is unique when compared with other groups as it was created specifically as a research project and over time became a vibrant online community for people affected by heart disease. Accounts of this study therefore, add to the limited literature available about how individuals affected by heart disease interact online within a gift economy.

5.1.2   *HeartNET interactions are important*

When HeartNET members share their thoughts and feelings online, these interactions can be seen as a gift, where sharing the written word and responding to written comments or pleas in online posts makes both the writer and the reader feel as though they are providing support and encouragement to each other. The writer often assumes that if they post a comment about their health and wellbeing, that someone on the site will respond with a comment or provide a degree of support. However, this is not always the case.

Margaret, who had in the past been a prolific user of the HeartNET website, disappeared for about three months because she was moving house, had plans to renovate and once she was settled, find and start a new job. She was missed on HeartNET and occasionally people would ask where she was and wish her well. When she did return she posted a general update, and then this comment:

> I'm going to be honest here and say something.
>
> It's been a while since I've posted on the board but have posted regularly in the past and have tried to acknowledge and provide support to others in relation to their situations.
>
> The other day I posted a general update in how things were going as well as acknowledging other people's news and situations and generally wishing them the best. Yet there has been really no response to what I've posted.

I just want to share that at times things are difficult for me too. I also have a heart condition and have had incredible trouble getting it treated in spite of explaining that it seems to affect my energy levels which limits my job options. Yes it's unusual that someone in modern day Australia does not receive treatment but it happens and it's due to it being a little know and contraversial condition. Being ineligible for govt benefits if I cease earning and being self-supporting I'm in a very difficult situation so it has been important to me to get that treatment. And I have always wanted to have had my condition managed so I could continue to support myself.

So it would have been nice to have received the same level of acknowledgement and support as others. So I am feeling very much underappreciated and drained by giving but not getting any concern back. Anyhow thought I'd say how I felt. (Margaret,⌨)

For Margaret, what she perceived as receiving no support when she needed it was too much. Following this post she no longer actively participated on HeartNET. Although at times she comes on to HeartNET as a guest (lurker) to read postings, she has never posted another comment on the site. The lack of response from HeartNET members did not seem to be deliberate, and indeed members were apologetic and challenged by Margaret's post. This 'posting without a response' is what Suler (2004) describes as the "feeling of entering a 'black hole' where getting no reply at all feels like a 'black hole experience' – one that makes you wonder why your post receives the silent treatment. It can stir up all sorts of anxieties and insecurities, thereby discouraging the person from posting again" (Suler, 2004, section 3, para. 2). As the moderator, I could respond to allay a member's fear of posting and then being ignored, to defuse a potential situation or to help ensure the member returned to the site and felt supported. However, at times it is better to allow the site members to respond themselves, because it is not always the moderator a member hopes to hear from. As Margaret's post above highlighted, she had given support in the past and felt that to have this support reciprocated when she needed it would have been appropriate. Even so, as the moderator I acknowledge that failure to respond to a HeartNET member's post can lead to that person feeling unwelcome and unhappy, and cause them to leav the site.

While Margaret chose to leave, others have stayed since the site's inception. Where once they were prolific posters, they now only respond when I make a comment or use the two threads that update how the person is and how their heart journey is progressing, and the other to wish people a happy birthday.

When I first took on the role of moderator, the interactions on the site fluctuated. Public holidays would see interactions decrease and this was especially noticeable around Christmas and Easter. When conflict occurred on the site usage would increase, but members would come in to observe and leave no messages on the site. When the conflict quietened down, members would post about the quietness of the site. As the moderator I would reply, stating how important it was to write about anything:

> If you come onto HeartNET to have a look- please leave a message saying hello. The site is so quiet at the moment and I KNOW people are coming on and looking but not leaving a message- say hello please. People are genuinely interested in knowing how everyone is. Plus it keeps HeartNET alive!!! (Moderator,⌨)

Sometimes when I suggested that members should write about their daily life or activities to stimulate interactions, this would elicit a response for a time, but it was often a token gesture. Comments would be left stating that the 'person was still breathing' and others would respond in the same manner. Where there had once been constant interactions with members "chatting, joking, sharing, helping and being helped" (Bakardjieva & Smith, 2001, p. 73) HeartNET was now struggling to remain active and supportive. This clearly shows how participant interactions are needed to keep an online community functioning and that actively contributing by site members is vital.

While I had to encourage participation, an over-responsive moderator can cause other issues, such as a perception by users that the moderator is there to be 'Big Brother'. This phrase refers to George Orwell's novel *1984* which describes a fictional society where everybody is under surveillance and where all independent thought is controlled (Orwell, 1949). While working as the moderator I did not want to be perceived as 'the police' for the site, but as someone who ensures that everyone who uses HeartNET is treated with respect and compassion. However it was also important to ensure that no misleading or misinformation was placed on the site, thus monitoring is an integral part of a moderator's role. According to Medina, Loques Filho and Mesquita (2013, p. e41) the role the moderator plays on a site can be a "gift given to its members".

As the Internet expands, so does access to online health communities. These communities provide users with opportunities to gain insights into their condition

and to share their own experiences. In turn, these communities can have "a positive effect on people's ability to learn about and manage the implications of chronic disease" (Malhotra & Stockdale, 2008, p. 26) in a safe and semi-moderated environment.

The following section provides various examples of the gift economy at work on HeartNET by outlining the ways in which information and practical tips can assist in building and maintaining heart health. It explores the role of task-oriented posts defined by White and Dorman (2001) as the messages left by members who are seeking information, problem-solving or discussing general subject matter. It will also look at the socio-emotional posts to the site which White and Dorman (2001) identify as posts "discussing feelings, friendships, chit-chat, poetry and art" (p. 700).

5.2   The Gift of Information

HeartNET offers a range of communication opportunities including the gift of information and support. In addition to the bulletin board, chat room and private messaging, members can contact the research team and the Heart Foundation by clicking on the appropriate links at the top of the HeartNET page. One link takes them directly to the Heart Foundation's main webpage. From there they can navigate around the Heart Foundation's website.

Figure 4: Heart Foundation website (Heart Foundation, 2012)

One outcome from the HeartNET project is the use of members' heart stories on the Heart Foundation website. These stories are particularly useful for new heart patients who can access information and positive stories by reading about people who have been in similar situations. Another way members can get information is through referrals to other websites. Not surprisingly, members of HeartNET are often prolific users of the Internet and through their information searches they sometimes find sites which provide them with something they have been looking for or which they consider relevant. When this occurs they will often notify other members about the site via a posting on HeartNET. Roter and Hall, cited in Wright (2002), found that "informational support may help people experiencing health problems to feel more in control over their situation … [this] will help them make better decisions about coping with illness" (p. 197). This dynamic can certainly be observed on HeartNET.

HeartNET members have also provided practical information related to hospital admissions and what to expect after heart-related procedures. These are often matters that are omitted by health professionals. When Yvette was discussing her upcoming medical procedure she asked site members if there was anything she needed to know or do that would make this a more comfortable experience. Admitting fear of the unknown, she sought support and health information from other members. Rosemary responded, telling Yvette about her own experience and what she considered vital items to make a hospital stay more comfortable.

> Boxer Shorts if they go through the groin for anything, I forgot mine last time and had to where my partners joks for about a week, womens undies seem to sit right on the spot where the catherters go in.

> A good book or you could take a heap of blank chrissy cards and get them done whilst youre there. good luck youll be fine.

> Dont forget to pack in some positive attitude and lots of support from friends and family and I would also chuck in a couple of smiles. (Rosemary,⌨).

Information posted on HeartNET is available to all its members and due to the nature of the site there is a fundamental relationship between giver and recipient. Acknowledgement is usually reciprocated (Bergquist & Ljungberg, 2001). Providing information and support reduces feelings of social isolation and encourages

empowerment, which in turn provides what Green (2010) sees as the "development of reciprocal 'gifting', whereby members give each other time, regard, concern and support" (p. 157). It is not just heart health or emotional support that is freely available on HeartNET. The site provides users with many options including nutritional and dietary advice.

The following section provides examples of the gift economy in action on HeartNET where people share information about almost anything and through this sharing comes emotional support (Bergquist & Ljungberg, 2001). This information is provided by people who share similar interests and experiences (White & Dorman, 2001), while also allowing opportunities for them to feel supported.

5.2.1 Recipes

HeartNET plays many roles in the support of people affected by heart disease including access to heart healthy recipes and food information. There is evidence that support from others is useful, especially when someone is feeling vulnerable, while sharing successes and failures with others can help a person to maintain their healthy eating plan. Along the way they may even choose to share their experiences with others. In the *Diet, Nutrition and Weight Loss* forum members can discuss dietary, nutritional and weight loss regimes or share recipes.

Any new regime including diet, exercise and medication can be challenging. To have online assistance in the context of a community can be advantageous. Often the individual is given a diagnosis and some advice from the medical profession, dietician or practice nurse, but can then be left wondering where to go next. The reality is far different from what they anticipated. There are cooking clubs and recipes available online, but sometimes that is not enough. A diagnosis of heart disease is confronting and going shopping for the first time after being told to cut back on fats, sugar and salt; reduce cholesterol; and modify your tea, coffee and alcohol consumption can seem overwhelming. The Heart Foundation has a website that provides a healthy eating guide and also recipe books that can be purchased. However, it is often the information that is not in the recipe books that is required (Heart Foundation, 2012).

When HeartNET was first set up, recipes were shared frequently with many people showing how they had modified a recipe to suit their heart health needs. One

member living overseas found it difficult to read food labels as food packaging labels were less informative in the new country than they were in Australia:

> I live in [overseas] at the moment. In Australia, there are labels on all produce which permits you to check the contents. This is not available for most foods found in [country A]. Is there a site on the Internet that shows the calorie, carbohydrate, fat etc value for each food. Can anyone recommend a site where you can download such detail? I will be leaving [country b] shortly so cannot purchase a book from the Heart Foundation and have it sent in time. (Bernard,🖥)

Part of the HeartNET service includes the Heart Foundation dietician and cardiac rehabilitation nurses who respond to requests from the HeartNET moderator. Bernard's request for assistance was answered by the Heart Foundation dietician, who was able to recommend various online resources.

> Probably the most accessible, comprehensive and reliable source of nutrient composition would be Allan Borusheks Calorie and Fat Counter (available at newsagents, bookstores etc for $8 – $10). The web version of this can be found at www.dietclub.com.au under 'food data' where you can search for specific foods. While there are some international food items listed, you may not find the composition of some more specialised Asian foods if they are less available in Australia. Good luck! (Heart Foundation Dietician, 🖥)

Meanwhile, Bernard returned to Australia and posted that his daughter had purchased him a copy of the book and he was happy with its contents, and also with the prompt way in which the Heart Foundation had responded. While other well-known dietary plans and organisations are discussed frequently, the Heart Foundation advocates healthy eating and all online postings have similar responses from the dietician.

> The bottom line is that healthy eating is about eating in moderation (as if you haven't heard that before!). To help with weight loss you need also to reduce your kilojoule intake by choosing foods and drinks lower in kilojoules or by limiting the amount of food and drinks you consume. The other side of the equation is to increase your energy expenditure; that means build activity into your daily routine.
>
> Should you have any other dietary or heart health related concerns, while this is a good forum to address them, don't forget that the Heart Foundation's Heartline has nurses and dieticians available to answer your questions from 8.30 am to 5 pm – call [phone number

supplied] for the cost of a local call. (Heart Foundation Dietician, 🖥)

Much discussion ensued over a period of time about the need for fruit and vegetables, especially when someone has a chronic condition like heart disease. One HeartNET member wondered if the reason many people who have had heart disease since childhood struggle to eat fruit is because "I don't eat most fruits either more to do with loathing the smell and all the antibiotics u get put on as a kid with a heart condition are all fake fruit flavoured ...." (Harriet, 🖥). This in turn led to posts about various movies and television shows that were related to food.

In 2004, a movie was produced that discussed the fact that many fast food outlets would 'supersize' foods for a minimal additional cost and that this practice was unhealthy. *Supersize Me*, filmed and produced by Morgan Spurlock, demonstrated the impact of eating three meals a day from McDonalds over four weeks. During the filming of this documentary/film, if Spurlock was asked if he wanted to supersize his meal choice he had to say yes. Over time he found himself becoming increasingly unhealthy. He gained weight, had rising cholesterol levels and also suffered with excessive mood swings (Spurlock, 2004). This movie elicited significant discussion on HeartNET after one member had watched it and posted a response.

> I guess this post is a little old seeing the movie I'm talking about has been out for some time now but today I watched the movie "Super Size Me". This is the movie about the guy over in the US that lived on Maccas for a month. If you haven't seen this movie you should. It was very interesting and scary. To think that this fast food can be worse than drinking is so scary. I guess the good thing about this movie was the fact that it made them change their menus. It does make you think just where we are heading in this country. As I said if you haven't seen this movie you should see. It's a big eye opener for everyone. What does everyone think about it and have you seen this movie?? (Andrew, 🖥)

While a number of members had not seen the film, many of them were happy to comment on the fast food industry in general and how much was taken for granted when they were younger.

> Hi Andrew, I was shown the movie as part of my nursing curriculum last year. I have never been a "Macca's" fan & everything I saw only reinforced my opinions. I think it's a real pity so many people take their children to "Macca's" for their

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> Birthdays, special events etc. It's a shame as we are now seeing young children with type II diabetes, which was considered an adult onset form of diabetes until recently. When I was a child growing up, we never had the money for fast foods or take-aways. Sometimes fish & chips on a Friday (good Catholics) but more often it was eggs on toast. (Matthew, 💻)

> All take away food is rubbish, I saw the movie too, Matthew rented it so I could watch it. I have always known these chains for fast food were poison deelers, Yukk. Give me a home cooked hamburger any day over that rubbish. (Sarah, 💻)

This movie elicited many comments, including why anyone would actually want to inflict this sort of 'punishment' on their bodies. The main theme however, was about the unhealthy nature of the food available at fast food outlets. For most heart patients fast food is no longer an option, and there is clear evidence that eating fast food on a regular basis increases the risk of developing both heart disease and type II diabetes (Swinburn, et al., 2011).

5.2.2 Laughter online

Another aspect of the gift economy is the sharing of humour and laughter. Laughter is known to "lower blood pressure, reduce stress hormones, increase muscle flexibility and boost immune function" (Weinstein, 2009, p. 188). Laughter can be healthy and is often shared freely in social situations. Exponents of yoga promote several benefits of laughter including boosting the immune system, relieving pain and depression, improving one's social life and relationships, providing a mini exercise regime, and protecting the heart by lowering blood pressure and improving respiratory function (Mansfield, 2013). Weinstein's (2009) research found laughter therapeutic, with individuals using humour to share their thoughts and feelings, and to deal with unpleasant memories. Vilhauer found that women with breast cancer who joined an online support group "inspired hope and provided opportunities for shared humour" (Vilhauer, 2009, p. 399).

Members of HeartNET use humour for similar reasons. Several of the HeartNET members would meet every Thursday night in the chat room to discuss their week, heart health and any other interesting issues. One discussion that arose provided both the HeartNET members and me with a great deal of delight. Hannah was concerned that members were not utilising the chat room facility and posted the

following interaction over a period of 10 days. She would come onto the site and add to the 'medical crisis' that she could see occurring.

Hannah says BOO!

Wednesday
Hannah :: No response! hmmm...Has the chatroom flatlined??

Friday
Hannah :: --------------------------------- ---------------------------------- ---
Bianca :: ....back at you Hannah....lol

Saturday
Hannah :: the chatroom needs defibbing..its flatline atm..hahahaha!!
Hannah :: ^----^----^------^--------^ I plugged in the jumper leads...no defib machine here!!

Tuesday
Hannah :: Beeeeeeeeeeeeeeeeeeeeeeeeeeeeeeeeeee eeeeeeeeeeeeeeeeeeeeeeeeeeeeeeeeeee ep

Thursday
Bianca :: thats flatline
Bianca :: beep beep beep

Friday
Hannah :: we have a pulse Bianca???....lol
Bianca :: yep we have a pulse ..lol slow but it is there

Sunday
Hannah :: beep

Wednesday
Hannah :: beep

Friday
Hannah :: beep
Bianca :: beep

Saturday
Hannah :: beep
Hannah :: Hi Bianca u still here? beep beep beep!!

Tuesday
Hannah :: :o(
Bianca :: Beep

Wednesday
Bianca :: Hello!!!! any one around.

Saturday
Bianca :: Hello guest 1252 how are you?
Bianca :: maybe i am alone again

Wednesday
Hannah :: beep beep beep

Friday
Hannah grins

Saturday
Bianca :: one day....lol
Hannah sings...Somewhere over the rainbow.....lol

Bianca joined the discussion and both Hannah and Bianca spent many days continuing their story of the chat room that had flatlined. Flatlining is the term used by medical personnel to describe the absence of heart or brain activity and is often portrayed in movies or television by using a monitor which shows either a flat line or a line with '_^__^__^_' or an audible 'beep' (Veysman, 2010). As heart patients, both Hannah and Bianca were aware of the significance of flatlining and its associated medical implications. Bianca and Hannah continued their repartee for several days and finally conceded that keeping the chat room alive and functioning might be an issue. Hannah posted a final comment in the chat room "still no one in the room. Thought I would try again tonight, still empty room, can still smell the air freshener Hannah sprayed around" (HeartNET,⌨). This confirms Morreall's findings that sometimes "humor like game playing, is often engaged in for its own sake rather than to reach a specific goal" (cited in Shifman & Blondheim, 2010, p. 1365).

Another form of catharsis is the use of poetry and storytelling (Hockx, 2005). Poetry can provide emotional support for both the reader and the writer. The use of poetry may also aid in recovery and promote self-esteem. The sharing of poems on HeartNET appeared to be cathartic, but also provided some of the men with an outlet to share their emotional feelings.

5.2.3   Poetry online

> Poetry is one way to communicate existential issues which experience is generating. A poem gives shelter to and can contain what it evokes as strong emotions. The poem can be a place of safety (Erikson, 2004, p. 50).

Many of the men on HeartNET shared their feelings through poetry. This confirmed the findings of Høybye et al, (2004) that sharing poetry online reduces social isolation and helps provide emotional support when family and friends are no longer available. Poetry can also be a gift to others. This was apparent when several members shared poetry on the site. They were comfortable opening up to other members and through their poetry were able to acknowledge their fears, worries and the emotional impact heart disease had had on them. For these members, "being able to write about their feelings helped them to feel better" (Vilhauer, 2009, p. 397). Henry's poetry allowed him to discuss death and dying in a non-confrontational way that he could not openly articulate to his loved ones. For both Henry and William, posting their "poetry was a way of creating a 'public journal' which they were able to keep for 'personal reflection'" (Nardi, Schiano, Gumbrecht & Swartz, 2004, p. 45). Expressing poetry allows writers to utilise what Stepakoff (2009) sees as a contribution "to the desensitization of traumatic memories" (p. 105). Kahaner (2012) elaborates on Stepakoff's findings stating that "the act of writing poetry can often leave the client with a sense of relief, because the client is able to let out their feelings and raw emotions by way of organised language" (Kahaner, 2012, p. 15).

Many of the poems placed on HeartNET related to death, loss and grief. Bracegirdle analysed how writing poetry became a means of showing how "her feeling self-became visible as I wrote myself onto the page" (2011, p. 81). The poetry that was posted onto HeartNET demonstrated this self-awareness, and also showed how heart health events can be "embodied in the writer and may be transferred to the reader" (Hunt & Sampson, 2006, p. 149). William prefaced his publication of the poem featured below stating that he was "Not too proud of this one, it dwells too much on my hurts and frustrations, hey... but what can you do?" (William, 🖳).

> Something bothers,
> Me tonight.
> I cant sleep,
> Troubled thoughts.
>
> Woke me again,
> Pouring rain.
> Aching pains,
> Deliver me.

Manic depression,
Desperate visions.
Why don't they just,
Go away.

Family beckons,
Torn between,
Their love and my,
Insanity.

Add to that,
And I don't have,
A heart that copes,
Anymore.

Wordless phrases,
Endless pages,
Clean the slate,
And start again.

Another day,
Same again,
My own weakness,
Lets them win.

Throughout the years,
All its been,
Is love me or,
You hate us then.

Mask that with,
The Christian ethic,
You must be pure,
Or you are sin.

And give me God,
He lives above,
Beyond my pain,
And suffering.

To tide me through,
The naked brew,
Another shot,
Of burbon.

When do I find,
An end to this?
Rest my soul,
From yearning. (William,🖥)

Henry's poetry such as *A walk on the dark side* also evoked strong responses when posted on HeartNET, with some members contacting me to help make sure that Henry was not exhibiting suicidal intentions. When I contacted him he told me that "HeartNET allowed him to write his thoughts and feelings … an outlet he had never had before" (Rodan, Uridge & Green, 2012, p. 11).

A walk on the Dark Side
I took a walk on the dark side
and looked into the dark Abyss..
was a dark haunting ride..
thort of the loved ones I'd miss.

I took a walk on the dark side
saw the monsters and demons down there..
sat there frightened, eyes open wide..
heart filled with terror, dread an despair.

I took a walk on the dark side
shadowy figures reach out from their den..
always waiting, at the end of the slide..
and if not today..then when.

I took a walk on the dark side
felt the battle raging within..
tearing at my heart, destroying my pride..
this is a battle, they could so easily win.

I took a walk on the dark side
so people place your bet..
for the demons no not, of those allied..
they take on, not just I..
but friends from heatNet [sic]. (Henry, 🖥)

While members of HeartNET were concerned about the darkness of Henry's poetry, Bracegirdle (2011) believes that how other people interpret poetry is their own concern. She states that "whether [poetry] is well written or badly written is of no consequence. What matters is the process of containing in words/images the uncontainable" (Bracegirdle, 2011, p. 82).

These poems "were posted to the site in the early hours of the morning when people are known to be at their most vulnerable and do not wish to concern their families with their fears" (Rodan, Uridge, & Green, 2012, p. 15). This observation supports White and Dorman's (2001) research which found that carers logged on in late evening or early morning and patients often logged onto sites when professional

resources were not available. Writing poetry can be cathartic to the author and elicit responses both positive and negative from the reader. While Erikkson (2004, p. 50) asserts that "to be touched by a poem tells you that you are still alive".

When Henry was contacted about the use of his poetry his response was an emphatic yes. "Your request to publish my poem just blows me away. (It doesn't have copy writes...lol.. but appreciate you asking) :0)". He continued that he had been looking at some of his poetry after my request and had "read some of the poems I posted, and ones I didn't... and realised the pain I was feeling back then in [year] still linger very close to the surface to this day. (Rattled me badly reading them again)" (Henry, personal communication, 2010).

Humour and poetry are important on HeartNET as they provide the members with an outlet to share their creativity, but to also share their support and encouragement. For men especially it provided them with an outlet to share their inner most fears without the fear of embarrassment and provided them with space where "difficult and painful subjects could surface" (Høybye et al., 2005, p. 203).

Occasionally however this safe environment can be challenged by 'others'. Rumours would start on Facebook or in other support sites, stating that HeartNET was closing and members would need to seek support from elsewhere. The next section deals with one such incident and provides insight into the importance of the HeartNET site and its moderator.

5.2.4   *Rumours, innuendo and great research data*

Occasionally HeartNET members get stressed about the site and its continuation. As it is a research site they are aware that when I complete my PhD the funding ends and the likelihood of HeartNET continuing in its current moderated form is slight. While the active membership is currently small, the allegiance to the site is strong and researchers such as Zeng (2014) and Nielsen (2006) indicate that the number of lurkers often far outweighs active members. Any talk of member take-overs, closing down or other permanent change elicits strong feelings and provides an opportunity for members to use the forum for "rational, [and] critical debate" (Ferne et al., 2007). The members feel considerable ownership of the community and do not like to think there is any chance of the site being in jeopardy. Fred had heard

the site would probably close when I completed my research and was very concerned about what would happen when I left. He posted the following plea.

> I've been a member of HeartNet for just over 3 years & in that time there has been talk between disgruntled members of taking over HeartNet & think they can run it better. If you don't like the way HeartNet is run, please consider this, you can send your thoughts/complaints to the moderators, or you can cancel your membership. So STOP trying to take over & leave it alone. As it's impossible as we are a research program as well as a self-help group. Thank You. (Fred,⌨)

Within minutes he had responses. Some members had been oblivious to the behind the scenes complaints and were automatically concerned about what they would do if the site closed or changed 'hands'.

> Yes must agree with Fred LEAVE HEARNET ALONE. Thank You. (Bianca, ⌨)

> So true Fred, let those of us who are happy here alone or put ur complaints to the moderators but stop trying to take it over. I know many of us want to be able to come on here and feel we can find the support we need without getting caught up in all this, I for one need this support group to get me through so if you dont like it leave. (Veronica, ⌨)

> i agree with Fred and Bianca leave heartnet alone go and find something else to do. i live in the country and found out we dont have the support like the city folks have and told about this group and found it great to be able to get on and talk about anythin and everything and like Veronica i need this group also so if dont like leave also. (Judith, ⌨)

> Nobody is taking HeartNET over folks, they can't- we are a research site, based at ECU and supported by the Heart Foundation. If there are any changes to this- I will be the first to let you know. But rest assured while I am the Moderator HeartNET is not going anywhere. (Lynsey,⌨)

> thats great to hear Lynsey we do enjoy this site and we all friends here. (Judith, ⌨)

> What all this about? Where did you hear of this Fred ?. Oh my.. I nearly called out the swat team. No one better try to kidnap our site...Thanks for the clarification Lynsey xxx Hugz. (Sarah, ⌨)

> Please, please understand that NO ONE is taking over the site, no one is thinking of taking over the site and no one will take over the site. Promise!!! Relax and enjoy Christmas - but remember to come onto the site on Christmas Day and leave a hello message please!!! (Lynsey,⌨)

> As I opened this can of worms. Please rest assured HeartNET is &
> always will be in good hands. Thanks Lynsey & all those behind
> the scenes. (Fred,⌨)

It would seem that being the moderator of HeartNET is, in some members' eyes, an important component of the site and becomes an integral part of a site which needs protection and support. Fred has a tendency to post comments that he knows will provoke a response since, to his way of thinking, it will motivate people to post in return. When I questioned him about why he had posted the comment knowing that it would cause distress, his response was "because I felt like it" (Fred,☎).

While this time it had no long term ramifications, at other times inappropriate or inflammatory comments can have a significant impact. Inflammatory comments do occur on HeartNET, but are fortunately rare. When they do happen the problems arising are dealt with quickly and if possible, in private. As with any negative interaction between different parties such conflict can sometimes lead to bad feelings. Rheingold was one of the first to recognise that "words on screen can hurt people", going on to comment that "although online conversations might have the ephemeral and informal feeling of a telephone conversation, it has the reach and permanence of a publication" (Rheingold, 1993, p. 37). Fred, can be provocative but he appears well-meaning and he is a prolific and passionate member of the HeartNET site. His aim seems to be to contribute to the site's well-being and if that involves a degree of innocent 'stirring', then Fred is happy. Interestingly, anytime he does stir the site he usually phones me to tell me what he has done so that I can respond immediately.

HeartNET is still functioning and providing valuable data to add to the limited data available about the role of therapeutic websites in the gift economy. As part of this research non-HeartNET members were also recruited and their participation in the community as volunteers is the focus of the next section of this chapter. Often forgotten, volunteers play a key role as participants in the gift economy by sharing their skills and expertise without thought of payment, but, as in this project, a means of paying back the help and support they received when they were facing their changing health status.

5.3 Volunteering as a Non-HeartNET Member

This section describes the role volunteering plays in the life of the non HeartNET research participants. It highlights the importance and benefits of volunteering and how this activity has now become an integral and anticipated part of many participants' daily lives. This section will define volunteering, describe why people volunteer, the possible health benefits of being a volunteer and identify some of the roles participants undertake as volunteers in various organisations or in their neighbourhood. It will identify the impact that volunteering has on the non-HeartNET members who were interviewed.

All of the research participants who were interviewed volunteered in some capacity within the community. For some, volunteering becomes an integral part of their everyday life and volunteers are a necessary component of many organisations in terms of their capacity to function adequately. The Australian Bureau of Statistics (ABS) identified more women (36%) than men (32%) as volunteers in 2006 (ABS, 2007). Age groups differ and rise to 48% among women aged 35-44, as this age group represents more women with school-aged children. Support for family commitments such as sporting activities, is reflected in this age group (ABS, 2012).

Volunteering Australia defines volunteering as an "activity which takes place through not-for-profit organisations or projects and [which] is undertaken to be of benefit to the community and the volunteer; of the volunteer's free will and without coercion; and for no financial payment" (Boulet, Healey & Helton, 2008, p. 29). Volunteering can be categorised as either formal or informal. Formal volunteering involves working at specific tasks for organisations. For example, many of the participants in the current research volunteer to participate in a hospital-based support group, while others were involved in informal volunteering including helping family, friends and neighbours.

The Australian data is similar to findings from the Institute of Volunteering Research (IVR) in the United Kingdom (UK). The IVR estimated that around 41% of adults undertook some type of unpaid voluntary work with "62% volunteering informally giving unpaid help as an individual to someone who is not a relative" (Institute of Volunteering Research, 2012, para.1). The IVR writers also identified several benefits of volunteering including enjoyment, personal satisfaction and the

making of new friends. However, there were barriers identified to becoming involved including not having enough time, bureaucracy, personal liability or legal issues, and not knowing how to get involved (IVR, 2012).

There is evidence that volunteering enhances life satisfaction and the physical and mental wellbeing of the volunteers. It has also been linked to increased longevity among those who volunteer (Mutchler, Burr & Caro, 2003, p. 1269). According to Narushima (2005, p. 569), volunteering connects members of society with each other and their community, with many volunteers citing their involvement as "something you chose to do often as a way to learn about yourself or to gain some satisfaction". Alternatively there may be a "need to help a cause they believed in" (Narushima, 2005, p. 569). Clary and Snyder (1999) identify six functions associated with volunteering:

- values – belief that by volunteering they are helping others;

- social – affirming the norms of significant others;

- career – seeking ways to get promoted or advance along career path;

- enhancement – increasing or promoting ones sense of self-worth;

- protective – escaping negative feelings about oneself; and

- understanding – engaging in activities that promote learning (Clary & Snyder, 199, p. 157).

Many of the participants in this research found their volunteering fulfilled some, but not all of Clary and Snyder's functions. This may be due to the small size of the participant group, their age and their general retirement status.

5.3.1 *Why do people volunteer?*

There are long term benefits that result from volunteering. Lum and Lightfoot (2005) found people who volunteered more frequently had more positive health outcomes than those who did not. They determined that volunteer work "reduced the risk of disability and mortality" (Lum & Lightfoot, 2005, p. 54). While Luoh & Herzog (2002, p. 498) assert that remaining active and integrating volunteering into one's identity may be beneficial. People undergoing diagnosis and treatment for heart disease may feel vulnerable. Using volunteers in the health care services

provides them with the opportunity to "gift their time, skills and experiences without obligation or wish for return, in order to enhance […] the wellbeing of persons or groups, who are strangers to them" (McKinnon, 2002, p. 41). The use of volunteers in non-medical roles such as providing support, reassurance and information can improve quality of care, by providing "a warm human dimension during a difficult time for the patients and their families" (Handy & Srinivasan, 2004, p. 30).

There is clear evidence that helping others regardless of physical or health impairments can "promote socially productive identities" and improve overall wellbeing for the volunteer (Thomas, 2010, p. 356). Thomas emphasises that people who volunteer may be at risk if they "spread themselves too thin in providing support to other people" (Thomas, 2010, p. 356). This was certainly something that was emphasised by many of the volunteers interviewed for this project. They stated that over time, many of their initial co-volunteers were no longer available, either due to ill health or death, resulting in little likelihood that these people would or could be replaced.

> I've been doing it so long, it does get boring or on top of you. It's the same thing all the time. You want to help people but then you've got your own life to lead as well, and really once or twice a week and then the rest of your time doing things. So it's a, you get bored I suppose. As you see, what I'm getting at is if you've got a full day there, and then if you're going in, you've got another, by the time you've, you only do four hours in there, say, but by the time you've done that and then come home, that day's shot as well. So you know. Yeah well…it's a funny one. You get a bit…you know what committees are like. [laughs] That's, the thought, I've done it for a long time, and there's nobody there now on the committee who was there when I started. They haven't died, they've just, you know…Drop off. Retired. I mean I'm 74 so you know, you think well, am I going to keep going or should I stop or what? But then it's very interesting and I think it's very helpful. (Blair, ⟨image⟩)

All the participants discussed in this section were part of the control group and non-HeartNET members and many volunteered at a major metropolitan hospital. Some also volunteered at a local medical school as hospital patients as well. All found it very therapeutic and it appeared to be the highlight of their week.

The motivation required to undertake volunteering has been widely explored. What motivates people to volunteer on a regular basis has been rigorously studied

and Penner (2002, p. 448) defined "volunteering as long term planned pro-social behaviours that benefit strangers and occurs within an organisational setting". There is clear evidence that volunteering is very much a part of the gift economy whereby the very act of volunteerism meets or "satisfies a private (non-altruistic) motive" (Blanchard, 2006, p. 32). Volunteers fill gaps when paid staff are unavailable and it also "contributes to the happiness and comfort of patients, their families, and visitors" (Hotchkiss, Fottler and Unruh, 2009, p. 120).

A Canadian study identified several major reasons why people volunteer. These included a belief and personal interest in the organisation they volunteered for, to use their skills and experience, and to explore their own strengths (Hall, 2001). This has since been confirmed by both UK and US research. Results from the UK survey found that often people volunteer for altruistic reasons, but also because volunteering met their own needs. While many enjoyed volunteering, they felt a sense of satisfaction in themselves and were proud to be associated with the organisation for which they volunteered. They also met new people and felt a sense of personal achievement at being able to help other people (Institute for Volunteering Research, 2012). The US study had similar findings noting that individuals who volunteer feel a "sense of satisfaction and recognition, respect and appreciation" (Nyhof-Young, Friedman, Jones & Catton, 2003, p. 76). However, they also emphasise the need for volunteers to be screened so their objectivity can be reviewed to ensure those who are still dealing with their own illness experience are not put at risk.

Several of the non HeartNET participants belong to the successful Fremantle Heart Patients Support Group that is attached to a major Perth metropolitan hospital. This group provides ongoing support to residents of the South-West corridor of Western Australia, an area that includes the Cities of Cockburn, Melville, Fremantle and Rockingham, and the Towns of East Fremantle and Kwinana, with a population of over 465,000 people (South-West Corridor Workforce Development Plan, 2009). This Heart Patients Support Group was established in the late 1980s and involves around sixteen support personnel and upwards of fifty volunteers to cover the opening hours of key support services and procedures provided by the hospital for heart patients (Fremantle Heart Patients Support Group, 2012). Support is provided by peers who "share salient target population's similarities (e.g. age, ethnicity, health

concern or stressor)" while possessing "specific knowledge that is concrete, pragmatic, present-oriented, and derived from personal experience rather than formal training" (Dennis, 2003, p. 326). Three of the non HeartNET participants are inaugural members of this support group and they spent many years lobbying to get this facility up and running. During their interviews a number of participants referred to this Heart Patients Support Group and recounted its effectiveness in providing an outlet for people to share their anxiety and concerns.

> We make ourselves known. We've got a little pamphlet about why we're there and what we do. And then we, most days nurses are too busy to monitor whether the people have taken on board [their] food or their fluids, well we're able to do that and report to the head nurse that somebody, the odd time, refuses to take on board food, and also won't have any fluids, even the, with their wife beside them where I encourage her to have a cup of tea or something and they still won't do it. Our job in that sort of case would be to report to the head nurse that they are not taking on food or fluids, and the answer would be from the head nurse "Well they won't be going home until they do". You know, that's […] that's just very simple. You know the importance of it because I've been there,[…] and so it's a team job. (Blair, 📷)

Simon found it difficult to secure a job when he arrived in Australia. Simon's country of origin and Australia have had an arrangement in place since the 1920s that allows "citizens of both countries to enter each other's country to visit, live and work, without the need to apply for authority to enter the other country before travelling" (Department of Immigration and Border Protection, 2013, para. 2). Simon believes his problems with finding a job reflect his position as an older jobseeker with a history of heart disease. That diagnosis precluded him from many aspects of his former career, even though he was well qualified and experienced in his field. He did not like sitting at home doing nothing while searching for a new career path. Rather than remain idle, Simon decided to volunteer in his local community, both to improve his career choices and also to escape his growing feelings of inadequacy and distress at finding he was 'unemployable':

> I wanted to give something back […] So I wanted to do something to give back because I didn't have any jobs, couldn't get a job here, and so [wanted to] help in some other way, to help the community. (Simon, 📷)

Simon and Blair both commented on how patients waiting to undergo treatment or surgery would ask 'how would you know what I am going through?' They felt this gave them the opportunity to share their own heart health story and offer support which may provide a "form of experiential learning in which participants engage in an activity that serves an unmet need in the community" (Barclay, 2007, p. 12). Blair feels that his role extends beyond just helping the patient. He also sees it as providing additional support to the nursing staff and to family members.

> So you go in. I mean you – you've been in with me in the morning with the Cath [Catheter] Lab when they've done a procedure and you go in the morning, you go up into the Cath lab, they do the procedure, because you can't eat until you've had the procedure. And then – they've got a – a lass in there who works for the hospital and she – that's her normal job, but it's a good inroad for us and I'll say to the patient, you know, 'would you like something to eat and drink?' Yeah, 'what would you like?' 'Orange juice, tea, coffee?' and I'll make it. And then it gives me – there we are, enough [time] to say 'well I'm Blair from the Heart Support Group, an ex-patient the same as yourself and how are you progressing?' and then you can […]

> Just talk to them. So that's – that's basically what we do and the way we work with the patients. And the same applies even in CCU [Coronary Care Unit] where you've got patients who have come in overnight […] and had a heart attack and you'll talk to them as well. (Blair, 🎙)

This support group has a policy that only volunteers who have had the same treatment as the patient are allowed to speak to them. So even though both Simon and Blair belong to the same volunteer group and have both had major heart events, they cannot speak to the same patient because their clinical histories are different. This lessens the risk of confusion and wrong information being shared with the patient at a time when they are most vulnerable. In this way the health care provider assists patients by incorporating "peer lay individuals with experiential knowledge who extend natural (embedded) social networks and complement professional health services" (Dennis, 2003, p. 322). Several research participants volunteer as active peer supporters for people facing cardiac treatment and subsequent surgery. This volunteer role appears to offer patients many advantages over organised medical professionals' face-to-face support groups due mainly to "the non-hierarchical, reciprocal relationship that is created through the sharing of similar life experiences"

(Heisler, 2010, i24). Access to other people's personal experience meant that many of the non-HeartNET research participants could relate on a more personal level to the patients with whom they shared their knowledge.

While most of the participants volunteered for a hospital-based support group, one of them was unable to do this due to her ill health. However, she found a way to volunteer in her local neighbourhood by providing a community vegetable plot. Her aim was to gift vegetables and fruit to those who could not access the garden, actions which also helped her overall health status and well-being.

5.3.2 Neighbourhood volunteering

There is clear evidence that volunteering is good for your health, especially amongst older people. Grimm, Spring and Dietz (2007, p. 10) investigated the health benefits of volunteering among members of the Baby Boomer generation (people born between 1946 -1964), and found that "volunteering activities can strengthen the social ties that protect individuals from isolation during difficult times, while the experience of helping others leads to greater self-worth and trust" (Grimm et al., 2007, p. 4).

Miller (2000) identified neighbourly volunteering as a means of promoting community wellbeing, and that such volunteering is often associated with supporting people who are ill, marginalised or disabled. HeartNET member Caroline became more closely involved with her neighbourhood as the recipient of "a community grant to put up a raised garden bed here for the community here" (Caroline,☎) when she developed a community vegetable patch. Caroline seemed both enthusiastic and pleased with the project:

> Well, I can't get down to gardening anymore and I thought a raised garden would be lovely and then I looked at the cost and that's a no-no. So I applied for a community grant, and costed it all out, and got the grant, and I'm in the process of doing the purchasing and getting it set up. It's not huge; it's only a three metre long one, but we'll just grow some vegies, some herbs, got a few lettuce plants, you know, where you, sort of, pick your leaves. When you're living on your own you don't need a whole lettuce, you need half a dozen leaves, at most. (Caroline,☎)

Caroline had initially met with skepticism from the other residents in her local housing development, but once they saw the vegetable garden taking shape they

became involved. When I asked her how it was affecting the community she indicated that everyone would benefit from her initiative:

> There are 24 units, and, I don't know, six or seven of them would be able to get out to [do] it [gardening], but I'll put the offer out to them but, you know, the rest of them if they can't get out to it then give us a ring if they want something and, yeah, hopefully share it all around. (Caroline, ☎)

The garden initiative appeared to have provided Caroline with a role and with status, and this element of the gift economy may have had a positive impact on her energy and enthusiasm for life. Caroline expressed concern about exposure to undesirable elements in her community as the only space she could place her vegetable patch was in the back garden which overlooked a local reserve, but she decided this would not stop her from getting the garden established and felt that her neighbours would also keep an eye on the garden. She was hoping it would provide her with the chance of connecting with her immediate neighbours and sharing the produce. She said that "most of them will be able to access it on their wheelie walkers or in their motorised wheelchairs, the ones that can't walk out to it." Caroline went on to note that:

> They keep very much to themselves here. Most of them are in their 80s [or] 90s and they've been there, done that, you know, they used to do that sort of thing [have barbecues] when these [units] were first built 24 years ago. But they're all mostly past it now.

> They were quite surprised, actually. Yeah. I thought it best, before I actually put it out there, to get permission to put it out there. No, I wrote to head office and asked for permission, and, yeah, they were very surprised and quite pleased, and gave me permission to do it, so. (Caroline, ☎)

When I spoke to her the second time Caroline was still struggling with health issues, but was articulate, passionate and had become involved in her community. She appears to have been motivated by cheaper vegetables, organic produce and a touch of rebellion, because the management committee had initially refused to provide the facility which motivated her to seek a grant. Sourcing alternative funding, winning the grant and creating a better relationship with many of her neighbours had made a positive difference to her life. The power of her involvement in a self-help and gift economy was demonstrated by the fact that whilst she was

almost crippled with arthritis and struggled to get about, Caroline was prepared to deliver vegetables to neighbours who were less mobile.

5.4   Summary

The gift economy is a complex phenomenon and HeartNET provides an example of the gift economy in action. HeartNET allows its members to develop relationships and to share common interests and their heart stories without an expectation of something in return. A key finding in this chapter was that an online community like HeartNET shared support more than gifting it.

For a community to continue there must be relationships which lead to trust and collaboration between members. When this is missing it can affect the entire membership group. Much of the information available on community bulletin boards such as HeartNET was offered to the group as a whole, thus reciprocation can occur from anyone, not just the intended recipient. HeartNET members among other things shared recipes, poetry and humour, as described in this chapter.

Online interactions and responses can be immediate or delayed. Sometimes people will share online hoping for instant feedback, but due to the asynchronous nature of a site there may not be an immediate response. This 'silent treatment' can cause distress and may discourage people from continuing to make posts. HeartNET members were generally moderate to heavy Internet users and would often share other resources they thought might be relevant with the HeartNET community. There was also a tendency to share more intimate details about issues than one would in the real world, and moderators needed to be aware of such impulse posting.

Non-HeartNET users were also part of the gift economy. Almost all participants volunteered in their community in some way. Neighbourhood volunteering was important as it made a positive difference in the volunteers' live and to the wider community. Spending time with others made the majority of volunteers feel they were 'giving back'. Many of the non-HeartNET members volunteered within the health sector and provided support to others by sharing similar heart health experiences. Every participant who volunteered found their volunteering to be therapeutic.

CHAPTER SIX:
IDENTITY RECONSTRUCTION AFTER A HEART EVENT

6.1   Introduction

This chapter details the journeys that HeartNET research participants undertook in order to establish new versions of their self after experiencing a heart event. In some ways HeartNET has provided its members with opportunities to share their journey by creating a persistent record online. Erickson and Herring noted that "unlike face-to-face conversation, [online interaction] leaves a trace in the form of text on a computer screen, sound files etc. – that persist for varying amounts of time" (Erickson & Herring, 2005, p. 1). This digital text allows members to read, explore and use the journaling of others as a motivation to move from existing versions of their online persona to an alternative within the safety of an environment inhabited by fellow travellers. This persistent conversation can be renewed or reused later (Bregman & Haythornthwaite, 2003), especially by people who chose to lurk and read the "conversational threads" on the site rather than participating actively (Preece & Maloney-Krichmar, 2003, p. 35).

This chapter aims to explore the value of people with a chronic illness keeping an online journal through posting letters, blogs and online comments onto HeartNET. Such acitivity provides researchers with "uniquely detailed and extensive sources of data that reveal the structure and content of computer-mediated social interaction" (Welser, Gleave & Fisher, 2007, p. 6). This chapter also explores the participant's identity as a person with a chronic illness according to a model identified by Charmaz (1987) in Table 2 (p. 140), and the value of keeping an online journal is explored for people with heart disease.

6.2   Identity as a Heart Patient: The Online Journal

Lasnick (2007), a prolific blogger who is living with a chronic debilitating medical condition, posted the following letter on her blog. Her letter provides hope and humour for many people living with a chronic condition, which at times can be harsh and unpredictable: She prefaces the post with the comment "sometimes you

just have to laugh" (Lasnick, 2007, para. 1). The letter has since appeared on many different blogs and websites, including HeartNET:

6.2.1 A letter from the disease

To whom it may concern:

Congratulations! You have been selected to be the host for (any chronic condition — [heart disease]). You will begin to experience many or all of these symptoms — and may even deal with several of them at the same time.

–Pain can be anywhere you can imagine. We are equal opportunity destroyers; therefore we will choose many places for you to experience pain. We have even devised many different types of pain — it could be aching, stabbing, throbbing, tingling, burning, gripping, or cramping. We are continually improving our repertoire of pain categories, so updates are to be expected.

–Dizziness. This can be accompanied by nausea, mental confusion, ringing in the ears, vomiting, loss of coordination, and sensations of spinning, rocking, or shaking. We try to simulate the experience of riding a never-ending roller coaster to satisfy your adventurous spirit. No safety harnesses required, and you have no choice of when the coaster ride starts, ends, or how fast it goes.

–Extreme fatigue (Now remember, this is not just being "tired". We will suddenly "pull your plug", so to speak, and you will have NO energy at all. Even dressing or taking a shower will be too daunting of a task for you to complete. And because we like surprises, we will NOT give you any advance warning, so you could be in the middle of the grocery store, at work, playing with your kids, or trying to clean the house.)

–Poor balance, lack of coordination. Let's just say you may walk or talk like you are drunk — even if you haven't had any alcohol recently. And for those of you who have never indulged in alcohol, you are now going to understand what it is like to be drunk and to have a hangover.

–Forgetting, losing, dropping things. These are just a few of the perks of your condition. You will learn to expect them, but never to enjoy them.

In addition to the symptoms above, we also want to eliminate some things from your crowded lifestyle. Here are a few of the things which will be taken away from you now that you are chosen to have a chronic condition:

The ability to stand or walk for longer than 15 minutes without experiencing pain in your feet, ankles, knees, or legs.

The ability to sit for longer than 10 minutes without experiencing cramping in your legs and butt, or shooting pains in your back.

The ability to complete any task which requires more than 10 minutes of concentration, multi-step activities or long-term projects will take 2-3 times longer than average.

The ability to play and run with your children like you did before.

The ability to have a "normal" social life.

The ability to accumulate sick days at work/ school to earn the perfect attendance bonus.

As indicated previously, this condition is in constant flux and more symptoms will be added as we deem necessary. There is no warranty guarantee, technical support, or customer service available.

Sincerely,

Your chronic condition. (Lasnick, 2007)

Lasnick's letter was posted on the HeartNET site and provided members with the opportunity to discuss how they felt. Many argued that those who do not find themselves in the same situation do not understand how it feels. These experiences of living with a chronic illness will be discussed in more detail later in this chapter, where HeartNET members discuss their own reality of living with a chronic condition.

Research undertaken by Bury (1982, p. 169) describes "chronic illness as a major kind of disruptive illness." He conjectures that such illness is usually perceived as happening to others. While others may provide encouragement and emotional support, there has always been a degree of separation between what is happening in others' lives as opposed to one's own. Suddenly, illness or disease becomes real. "disrupting normal rules of reciprocity and support" (Bury, 1982, p. 169). While G. Williams (1984, p. 179) supports Bury's findings, he claims that "the individual's narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose." When this identity, which encompasses daily activities and interactions, is dislocated because of illness, Kelleher and Leavey, (2004, p.12) believe that the "meaning attached to these identities, such as being male, a mother, a teacher and so on are disrupted".

According to Corbin and Strauss (1987, p.247), readjustment to this new identity following a diagnosis "cannot help but separate the person of the present from the person of the past, and effect or even shatter any images of self held for the future." This is confirmed by Armstrong, Michie and Marteau (1998, p. 1658) who state that the identity of those with a chronic condition is "reconstructed in the past as well as in the future." For many people with a chronic condition their disease becomes an integral aspect of their lives. Corbin and Strauss (1987, p. 251) believe that subsequent lived experiences allow individuals to "incorporate into their lives the illness and the changes that it has brought". This idea will be discussed further in the next section of this chapter.

6.3 Identity Levels

The following section elaborates on what Charmaz (1987, pp. 287-289) identifies as the four health-related personas that chronically ill people explore and investigate as they deal with the challenges of constructing new identities following the onset of a chronic illness, in this case CVD. These reactive stages include the supernormal identity level, the restored self, the contingent personal identity and the salvaged self (see table 2 below).

Table 2: Identity Level

Identity Level	Assumed role following an illness
Supernormal Identity	Persons aiming for this identity level often may attempt to participate more intensely in conventional worlds than non-impaired others, despite the serious limitation their conditions may impose
Restored Self	The person aims to reconstruct a similar identity to the one they had prior to their illness
Contingent Personal Identity	Individuals define their identity as questionable, but possible, in the future.
The Salvaged Self	In this identity level, ill persons attempt to define self as positive and worthwhile, despite their reduced ability to function. They accept that due to their ill health they have become invalids.

(Source: Charmaz, 1987, p. 287)

Each of the identity levels identified in Table 2 will be discussed in relation to members of the HeartNET community who either fit the criteria above or appear to be striving to achieve one of these levels. For some HeartNET members their journey in search of a new identity has been successful, possibly due to the lesser

severity of their heart events. For others, it has been and continues to be, a constant struggle to function at a level close to their pre-heart event condition.

6.3.1 Supernormal identity

Charmaz (1987) describes people who fit the criterion of 'supernormality' as persons who aim to participate more intensely in conventional worlds than non-impaired others, despite a degree of limitation due to their chronic illness.

Following his heart event Sam was very depressed and found he was thinking that every twinge and ache or pain in his chest was the precursor to another heart event. He admitted to having severe panic attacks and needing long term medication and ongoing counseling to help him deal with these:

> Don't ever think that you're immune from depression when it comes to cardio vascular disease, even those of us that refer to ourselves as being superhuman are prone to bouts of depression. It is part and parcel of this disease we suffer – but the essence of humanity is our ability to rise, albeit eventually, above it… When it comes to depression and anxiety occurring from a medical event, the only fool is the fool who doesn't admit there is a problem and refuses to seek professional help. I have had many counselling sessions to help me understand myself better, why it is that I feel the way I do, and the fact that to feel any other way would probably be more of a concern than to feel a little depressed and a little anxious. At the time, the anxiety and the depression seem insurmountable, but they are anything but. The fact is that sometimes we cannot see the forest because of the trees and need some professional guidance to make sense of what we see as the insensible. It is with this professional guidance that we are able to negotiate the maze of emotions that naturally follow a serious medical event. We are human, we are not programmable machines that follow a logical algorithm to every stimulus –we are emotional beings… we are human with all the foibles that this involves. (Sam,⌨)

Sam has continued to document his heart story leaving a persistent record of his conversation with others on HeartNET so later members can read and respond. The following sections highlight how this persistent conversation functions much like an online journal, created by members of HeartNET as they assume new roles following their heart events.

Sam now trains for half-marathons and iron man events while continuing to post on how it felt when he was first diagnosed. These feelings had implications for his future and he continues to strive to return to his pre-heart attack activities, albeit

with perhaps a degree of urgency because of the uncertainty around his long term health. While acknowledging he still is and will always be a cardiac patient, Sam aims to remain healthy and to become medication free. He has become a self-appointed ambassador for healthy living and aims to prove that while cardiac disease cannot be conquered, health can be maintained. For Sam, the "maintenance of social identity and valued activities appear to outweigh exacerbations of pain and discomfort" (Ong, Jinks & Morden, 2011, p. 8).

Although Charmaz outlines four assumed roles, they are not fixed. It appears that Sam also exemplifies other identity levels, depending on his health at the time of his posts on the bulletin board. He admits to worrying still about every twinge and pain that he experiences and to "popping the odd blue pill", especially when he is experiencing panic attacks. Sam says, however, that he now "manages his heart health…[It is] not his heart health managing him" (Sam,⌨).

As Sam wrote in one of his posts, after visiting his cardiologist for an annual review:

> [Because I] do the amount of triathlon training that I do (6 days per week) the likelihood of my suffering a further cardiac event is no greater than the general population, if anything, it is lower. The cardiologist then qualified his statement, suggesting that I should continue with annual check-ups for no-other reason than my mental wellbeing, and the fact that as a cardiologist, it is pleasing to see a patient who does what is necessary to tackle heart disease head-on and defeat it.
>
> I was lucky, now it is up to me to ensure that my luck continues and I maintain and improve my health -"Luck is not something that occurs by chance. Luck is something that you make happen!" (Sam,⌨)

While Sam is one of the more extreme sportsmen on HeartNET, his latest post shows how far he has come in the years since his heart attack:

> I am now rapidly approaching my fifth anniversary of my cardiac event, and I have never been fitter, stronger or even healthier than I am today. The reason is simple – 'THIS MONGREL THING AIN'T GUNNA BEAT ME'. ... I have taken up Triathlons, fun-runs and half-marathons and therefore exercise and train daily as well as trying to eat right. I have conquered the magical 2:30:00 Olympic Distance Triathlon barrier completing the [local regional] Tri in 2:26:00 in 2010, the fasted that I have run 10 km to date has

been 40:50 min's, and the half-marathon in 1:35:00 in training. (Sam,🖳)

Sam is very proud of his achievements, having completed his first half marathon early in 2001 prior to his heart event. With Sam's continued posting to the HeartNET bulletin board about his sporting achievements, several other members also posted their training achievements on the site. At one point, the most active thread on HeartNET was three members posting their training programs, schedules and achievements. This caused other members some distress, especially those who felt unable to exercise because of their own heart health. Some commented behind the scenes about how wonderful it would be to be able to do what Sam, Colin and Peter were doing. Others chose to respond with humour, as can be seen in the following interaction between Peter and Bianca:

> Anyway toady [sic] I did another bike session as I am just coming back from injury, so am keeping it low key or at least sort of low key. I did another 24.26 km's today in 65 minutes at an average of 21.9 km/hr and a max speed of 31.4 km/hr into a cross head wind. (Peter,🖳)

> and you call that low key lol [laughing out loud] Peter? (Bianca,🖳).

Reading through the threads dedicated to the training schedules of the men involved in pursuing a supernormal heart patient identity, reveals snippets of humour from the other, less active members. I have included some of these comments here, which usually occurred after Sam, Peter and Colin had posted about various weather conditions or other minor issues that disturbed their exercise regimes. For example, after Colin experienced difficulties riding into head winds he made the following comment "At one stage there I was leaning the bike to the right just to go straight. Even with that wind I still managed to average 24 km/h so not too bad considering I have not really been riding seriously for that long". (Colin,🖳): Fred responded soon after saying "Don't you just hate head winds!" (Fred,🖳). Bianca continued the light hearted banter saying "Hi! Fred and Colin [I] do visit and read your posts but am usually puffed by the time I have read them … lol" (Bianca, 🖳).This banter continues through the 13 continuing threads now dominated by the members who are very physically active.

Sometimes comments viewed as positive by the 'supernormal' heart patient doing the posting may have negative consequences on fellow site members. Several months prior to my taking on the role as moderator, an incident had occurred following Sam's posting of a 'motivational' statement about his exercise regime. At the conclusion of this post he added:

> what's holding you back?-[t]he simple answer, youselves [sic] – you know what you can do and can't do, so get out there and do what you can do- don't make excuses, excuses are just a way of denying the possibilitilties [sic] tha[t] life has to offer." (Sam,💻)

This posting caused some distress to members who were struggling with their own health issues. These were the site members who found that "the [over] emphasis on 'healthy lifestyle' may have a negative effect in chronic illness, where symptoms can limit their adoption" (Bury, 1991, p. 464).

Toby responded:

> I must admit you made me cry, I wish I could do the stuff you do, I wish I had the energy and the strength to exercise, believe me it is not a mental thing, some of us just don't have the health to do what you do. You were lucky, your heart problem was healed with a stent, some of us have much more serious problems. Sorry if this offends some, but I felt very cheated and upset by your posting Sam. We all do try to live our lives to the fullest, we don't make excuses, some of us just can't physically do the stuff you do, or even the basic stuff. I would love to be able to have an operation and be able to do what you do, but I can't. No matter how hard I try, what you do is a dream, I just live my life to the best of my ability at the moment, and hopefully for a while yet, but please don't belittle me and others in my position, for not being able to do all that you do. My heart disease is terminal and it is very hard to come to terms with it sometimes. Being lectured does not help, it only makes me more aware of the differences in heart conditions, and the lack of options that I am facing. (Toby,💻)

Sam was distressed that his posts had caused anyone distress, responding:

> OMG, to upset you was the last thing on my mind. You are someone to whom I look to for inspiration. My God, all I had was an itsy bitsy little heart attack, that with the advances of modern medical science is as close to reversible as I think it will ever be – the fact that you are still able to live life to your fullest potential makes you more superhuman than my avatar. Do not for one moment ever think that because I can lift weights and run many km's, and win medals in ski events that somehow that makes me better than anyone else. If anything, the only thing it means is that I

was fortunate not to have had the misfortune of having a more serious medical condition. You are an absolute inspiration to me, and some if not in fact all of you emails to me have shown me just how special and strong a human you really are. Your the hero, not me. (Sam,⌨)

While this incident was resolved fairly easily by the moderators of HeartNET:

Sometimes...you just have to leave the ring to let 'em battle it out on their own. For all those concerned – it's reassuring to know that despite differences of opinion, miscommunication and even the odd heated discussion....it's good to know that you are not voting with your feet – that you are hear voicing your opinions. Virtual communication brings its challenges but I appreciate every perspective. The fact that we can continue on is reassuring...remembering that a community brings different perspectives, circumstances and abilities. (Moderator,⌨).

While supernormal behaviour may be appropriate for some heart patients such as Sam, there are others whose degree of disability allows them to only look on wistfully and perhaps embark on some wishful thinking.

After Sam wrote about being up early, feeling nervous about competing in a particular sporting event and generally wondering aloud why he was putting his body through this, Fred responded:

O'k Sam, you say that you pulled up sore after a 21.1 k run & don't know why. Well hello you've just ran 21.1 k. I sure hope you're not planning to run to the airport when you have a perfectly working car in the driveway. It was 4.30 am when you wrote your update, haven't you got sleeping pills or ABC tv to help you sleep at that time of morning. Goes to show running ruins your sleep.

O'k I've tried humour Sam, best advice I can give you is run on your feet not your toes it hurts like heck (Fred,⌨).

Sam also claims credit for motivating others to take up running. He believes that he motivated Colin and Peter to take the final step and challenge themselves to participate in training for marathons, as the following sequence of events shows. Sam and Colin competed in the same marathon. Sam posted his times and about how he felt (almost) immediately after the race:

Now I do not mind admitting that I teared [sic] up as I sprinted down the final 400 m's in the finish chute. Why? Because I HAVE BEATEN THIS MONGREL THING! Five and a half years ago I lay in the intensive coronary care unit wondering if it was the end for me – I vowed then that I would run a marathon one day. WELL

I %$#*& WELL HAVE AND I AM PROUD OF MYSELF FOR
DOING IT. (Sam,⌨)

Colin was more reticent in claiming his bragging rights. I had messaged both Sam and Colin to congratulate them a couple of days after the event and asked Sam how Colin had performed. Sam was more than happy to let me know privately how long it had taken them both to complete the course. He wrote that he deliberately did not want to brag on Colin's behalf, but would only stay quiet for a short while longer before claiming some of those bragging rights for himself:

> I have deliberately not posted anything about his achievement on the site because I believe that he has every right to brag about it. If he doesn't, then I will do the bragging for him because he deserves to be in the limelight, and I would like to claim some of the credit for his achievement. This is because he decided to take up running and cycling as a result of reading my posts and realizing that just because one has a heart event does not mean that life stops – on the contrary... Life has just begun. (Sam, private message⌨)

Sam's version of Colin's decision may be overstated, but there is certainly a competitive streak between these two men as they compare times, injuries and general comments on their training schedules. In fact, they now use the HeartNET threads to journal their progress and often refer back to how they felt prior to joining HeartNET and taking up their chosen physical activity.

Despite Sam's view of the situation, Colin's story differs slightly to Sam's. Colin is another supernormal heart patient, has been a member of HeartNET for less than a year, and initially posted about how frightened he was following his heart event two years previously. One of his first posts related to how hard it was to even contemplate a future following heart disease. Colin had experienced an episode of severe chest pain and within weeks had to "get my life in order – organise friends and family for support, catch up with people and tell them the news, get angry" (Colin, ⌨). He was facing what Ogilvie, McCloughen, Curtis and Foster (2012, p. 315) describe as a "chasm forming between what was known and safe in their lives to what is unknown in their future". Joining HeartNET some six months post heart surgery, Colin described how he felt after his operation - "going home was good, my own bed - my own space. I remember walking around the block (only about 300 metres) and it took me an agonising 12 minutes" (Colin,⌨). This joy of being home and walking round the block highlights the uncertainty that Colin faced when he had

to address "an uneasy balance between seeing the condition as an outside force and yet feeling its invasion of all aspects of life" (Bury, 1982, p. 173). As time progressed Colin was able to extend his walking time until he was successfully walking or riding his bike five to eight kilometres a day.

Colin began journaling his training schedule not long after joining HeartNET. His first posting about his exercise regime was exuberant and recounted how he had managed to ride his bike successfully in a challenging environment:

> Yesterday, for the first time, I used my mountain bike to do more than just pedal around the scenic bike paths in [my home town]. An experienced friend took me out to [the nearest mountain range] to ride some of the "easy" trails. For those who don't know – this place was the site of the World Championships last year. Wow! What scarey heart pumping fun! I would not have been able to do this a year ago before my bypass op – perhaps not even 5 years ago. Riding up to the top of this mountain – with a couple of short breaks – felt like such an amazing achievement for me. Those of you who have had a bypass will know what I mean. Going up was hard, coming down was scarey [sic] – but the best part for me was that I felt so full of energy after so long feeling lethargic. Will I do it again? For sure! (Colin, 💻)

At some point, Colin decided to set the goal to train for and participate in the same marathon as Sam. Thus, two years following his open heart surgery, Colin posted the following message to other HeartNETters about how he felt after participating in and completing the marathon:

> As Sam said – I made it!! It was the toughest thing I have ever done. So many times I kept asking myself why was I here? Then I recalled the weeks in hospital rehab after my bypass, and walking SLOWLY (and painfully) – and just how far I have come.

> Near the end I started to let a few tears loose (probably mistaken for sweat by the spectators!) when I knew that I was going to finish this marathon! Saw many people needing treatment along the course – collapsed with heat mainly, few pulled muscles or knees, and at the finish line the wheelchairs were whizzing around everywhere! So I took care all the way, monitored my heart rate, and told myself to slow down or drink extra if I felt ill.

> My goal was a sub-4 hours' time, and up until the 28 km point I was smack on track, but then my calf's [sic] and the back of my knees felt like lead weights and I just had to slow down. At least this helped my heart to also rest!

This was the complete opposite of 2 years ago when I was in hospital. Then – EVERYTHING felt impossible, I could not see much of a future, and as much as people tried to encourage me I felt worthless. Not a good time in my life. Now though I have done something that few "healthy" people will ever be able to do, and I've seen that with hard work and determination that many things are possible. The marathon has really restored my hope in unexpected possibilities. (Colin,⌨)

Both men were enthused about their accomplishment, even though one stated that they "must have been mad to even contemplate the biggest physical challenge of their lives" (Sam,⌨) and the other "I will not ever do it again!" (Colin,⌨). Behind the scenes several of the other less active members laid odds on how long it would take Sam to make the decision to participate in another marathon even though he was adamant he would "NEVER" put himself through the stress again. Sam took less than a week, while Colin took somewhat longer.

While these two men were discussing their exercise regime a newer member on HeartNET also started posting messages about training schedules and exercise plans. At 35, Peter was much younger than Sam and Colin and used their postings to motivate himself to return to his pre-heart event career. Now Peter is also exploring the possibility of entering a marathon when he is given the medical clearance to do so. After taking a break from HeartNET for around six months Peter came back to 'motivate' others to become more active physically. He wrote about undertaking his first triathlon and admitted he had to pull out, due to cold and adverse conditions. He did however leave a motivational comment for all the current users of HeartNET:

For those of you sitting there saying I could never do that I want to leave you with a little inspiration. If you get off the couch and walk 1 meter you have lapped someone that is still sitting on the couch. It does not matter what you do just take the first step on journey towards better health and do some thing. (Peter,⌨)

The current members greeted this comment with their usual equanimity and humour.

Good Luck with it all Peter but as Fred says dont over do it...remember the tortise?? (Polly,⌨).

If you treat housework as your warm up Session, then your run is o'k (Fred,⌨).

While these three heart recovery marathon runners are the exceptions to the norm, HeartNET members have been able to read their training journals online and see how they remain focused on their health. While Sam, Colin and Peter write enthusiastically about their times and other issues relevant to intense training schedules, they never lose sight of the fact that they are and always will be, heart patients. They challenge themselves and extend themselves beyond what most people including their cardiologists would perceive to be normal physical exercise, hence they fit within Charmaz's supernormal identity. Even so, for Sam and Colin their commitments have put them in the enviable position of being able to claim to be marathon runners.

> Now he [Colin] and I [Sam] can rightly claim to be MARATHONERS, part of the elite club that many aspire to but few actually go the distance to join. Membership is free and all it will really cost you is some of your time, a lot of sweat, a lot of pain, 42 kilometres 195 metres in distance... in one lump sum without a break lol." (Sam,⌨)

I was not surprised when the following post appeared on the HeartNET site less than six months after Colin competed in a marathon, "I have bit the bullet, and entered the 2012 [local] marathon. Now that I know what a marathon feels like I think I am looking forward to it!" (Colin,⌨). Colin has not posted his training schedule and personal times for the local marathon, but several months later posted his achievements from the Berlin and London marathons.

> Well – it's been a long time – but I made it to Berlin for the marathon. Trained really solidly – even getting up at 5am when it was minus 5 degrees in Canberra! The reward: a sub 4 hour time: 3:55:00, Really happy to finish and to feel comfortably tired. Next stop: London in April! (Colin,⌨)

Several months later Colin posted again about his success in the London marathon.

> Just back from running in the London Marathon – along with 38,000 other keen people. Fantastic experience: the support of the crowds, the general good feelings, the warm sun (only time in a week I saw sun). Managed to go under 4 hours again (3:56:51) so was very happy with that result. Can honestly say that this was the most amazing crowd support I have ever experienced.
>
> Caught up with the British Heart Foundation prior to the race at the Expo. So much fundraising for all sorts of charities – but my

support was for the Heart Foundation of course! They gave me a nice red t-shirt as well!

Glad to report that the heart held up well to the challenge. It is now (as of this week) 4 years since my quad-bypass surgery. One thing is for certain – I am not going to look back in 15-20 years and wish I had given something a go.... (Colin, 💻)

While these men may not be unusual in the non-heart event world, they are certainly rare in the post-heart event community. For many heart patients, contemplating any kind of vigorous physical activity would send them and their surgeons running for the glyceryl trinitrate (GTN) spray! Alternatively, their cardiologists might refer them for psychiatric treatment. However, it is apparent that these men fit Charmaz's (1987) category and aim for supernormality. They participate more intensely in conventional worlds than the majority of non-impaired others, despite a degree of limitation due to their chronic illnesses.

6.3.2   Restored self

While a few may aspire to achieve supernormal identity, more individuals aim to assume the identity of the restored self. Charmaz (1987, p. 287) identifies the restored self as the "identity level in which ill persons expect to return to their former lives, where the individual aims to reconstruct a similar identity to the one they had prior to their illness". Although many people who suffer a heart event wish to return to their former activities and hobbies, their families and friends may not understand the difficulties they face as they strive to achieve their pre-heart event identity. Even so, these aspirants reshape themselves (Yoshida, 1993) and ultimately begin an "on-going process of living their lives, managing disruptive events and maintaining an overall sense of wellbeing" (Reeve, Lloyd-Williams, Paine & Dowrick, 2009, p. 178).

Maria, who had been working part time in a veterinary clinic, experienced a heart attack while hiking in the wilds of Tasmania. Ignoring her symptoms she continued her holiday. On her return to Perth she was diagnosed with chronic cardiac disease. This was a surprise as it was the last thing she expected, having convinced herself it was a terrible bout of influenza and the antibiotics would cure everything. She has not worked full-time for some time and says she was:

absolutely shocked to the core, I thought no, they've made a mistake, it's not true. But I think probably if I was honest with myself, I'd have to say that my immediate reaction was a bit of fear but fear for not being here for my daughter. That, to play that, it took me a long time to come to terms with the diagnosis and I think I fought against it for the first six months of you know […], yeah so it was quite a shock you know, but I'm just a bit over it now. (Maria,🖳)

Maria felt overwhelmed and entered what Ogilvie (2012, p. 315) describes as a "time of chaos" where she had to come to terms with her diagnosis and deal with the confusion that comes with "making sense of bewildering symptoms, reconstructing order, and maintaining control over life" (Charmaz, 2000). Maria took several weeks off work while her condition stabilised, and returned to her job part time about three months after her heart attack. Although she had returned to work, she found that there were some changes in her attitude to both work and herself. She says she has learned to say 'no'.

I think I take time out for me; I do take time out for me where it was all the time about everybody else. Now I take the time to sit and read I don't feel guilty about sitting and reading. I don't feel guilty about wandering if I want to wander. You know I don't feel guilty about saying no if I don't want to go somewhere […] it just about you know and just making the most of your life, you know I mean life's too precious, you've just to go out and live it you know. (Maria,🖳)

Maria had always worked and found that to help her deal with her new health status, she had to make adjustments to her new life (Ogilvie et al., 2012). Alongside a change of attitude and by reconstructing the heart event as a trigger for a more self-aware lifestyle, Maria was able to make sense of it and reduce her feelings of helplessness. These adjustments reflect the identity of a restored self.

Allison had been working from home and experienced an episode of breathlessness and ultimately lost consciousness. The next thing she remembers is waking up in hospital and finding a cardiologist talking to her about her cardiac problems. I first interviewed Allison in the first six weeks after her heart event. She was very anxious and wouldn't venture further than ten to fifteen minutes from the doctor or hospital. When Alison first entered HeartNET, she posted that her family were becoming frustrated because she would not leave home for any length of time.

… the last couple of days have had chest pains etc. and as we are going away camping this weekend am scared as to how I am going to cope away from the security blanket of my doctor. As the cardiologist said everything heart wise was good think this is just from overdoing things and a bit of stress. Will let you know if I catch a big fish the weekend. (Allison, ⌨)

Allison admitted that her fear of another heart event upset her interactions with her family and friends and had led to everyone "organising family and occupational activities around it" (Pierret, 2003, p. 5). She had to deal with all three of the challenges highlighted by Lasker, Sogolow, and Sharim (2005). Firstly, how to create a new 'ill' self and to determine how this self will affect family, work and social relationships. Secondly, how to deal with any stigma associated with the illness and the limitations posed by it and thirdly, the "uncertainty regarding the future" (Lasker et al., 2005, para. 16). Using online support similar to sites like HeartNET and asking questions can help people understand their illness. Reducing feelings of isolation and seeing the attitudes of others and how they are coping can help the newly diagnosed person to develop strategies that may help (Drachler et al., 2009). Allison admitted to receiving great encouragement from the HeartNET members who all urged her to go away for the weekend. A couple of days later she responded to their support with the following post:

> Had a wonderful time – didn't catch any fish but kayacked about 2 hours each day on Saturday and Sunday. Weather was glorious and the scenery and serenity (with about 100 people there) was good for body and soul (Allison, ⌨).

Allison has since continued engaging in wilderness activities, catching fish and enjoying life. When I asked how her heart event had affected her socially she responded:

> The first few weeks I wasn't going anywhere at all. But now we go away for weekends. I go camping; we went on a houseboat the other weekend. We're going out on the boat this weekend, and I'm not going to let it [my heart problems] rule me. And I've just got to come to [the conclusion] okay, nothing is going to happen. They got it before anything happened. You are doing all the right things you are supposed to do. You know I've got my cardio, he is at the end of the phone, and the GP is at the end of the phone. It's not going to rule me. (Allison, 📷)

When I interviewed Allison the second time, she had returned to work, taken up volunteer work and was also working at a local school, and enjoying life again.

My husband owns his own company. We got four young blokes working for us. So I did a lot of the paperwork, sending the faxes, the mail, all that sort of stuff, including the paperwork, but I'm still doing it. It's wonderful. (Allison, 🔲)

Abby who I identify as having a restored self admits to believing, unrealistically, that once she recovered from her heart attack everything would be all right. This was not the case. She lost confidence in herself and found that people around her acted in a tentative way. She now accepts that this was their way of coping with her having had a heart attack. Abby had been very active, working full time shift work in a job she really enjoyed. Her boss suggested she move to better hours with no night duty after her event, so she gratefully accepted the offer.

After I had the heart attack my boss was really good and said did I want to go to days instead of doing shift work or did I want to reduce my hours so I took that opportunity to get rid of one of my night shifts so that I went down to working 11 shifts. Then one of the other girls wanted an extra shift for some reason so I gave another one away so I'm now down to half time. I don't know that reducing the other shifts is really because of my heart more just because I'm at the age where I don't actually have to work that much financially and it was more because I enjoyed my job so yeah I've reduced for that reason rather than the heart attack. (Abby, 🔲)

Abby continues to work and travel, but only to countries that have adequate medical facilities. She believes that she has not changed very much apart from appreciating her life more.

It made me reassess my life and appreciate what I've got and that I don't want to make changes in my life. I often hear people say when they have a health scare that they want to do this and they want to do that but I didn't feel like that I felt like I really do like my life and I want to continue with that so I guess I've got a deeper appreciation. I don't know that it is a hugely significant change it's just a slight shift in the way I look at things. I guess I look at things with a different perspective; it's hard to articulate that I guess its related back to living in the moment type of thing so you're more aware of what's going on around you. (Abby, 🔲)

Abby had to reassess her life, making adjustments that allowed her to still pursue her interests while recognising the limitations her heart condition created.

6.3.3   Contingent personal identity

The Contingent Personal identity is associated with individuals who see the future as questionable, but hope to achieve a viable way of living (Charmaz, 1987, p. 287). For some, this identity occurs because they are newly diagnosed and due to their health status, cannot see themselves returning to their pre-heart event roles. Heart event survivors may experience this as a transitional stage as they wait for their diagnosis and prognosis to be confirmed. In many cases family and friends do not see the patient as managing a disease and they struggle to give empathy. In some ways this period aligns with the experience described earlier in Lasnick's letter to her medical. Lasnick wrote the letter to help describe how she felt following a diagnosis of Lupus and placed it on her blog in 2007. Sharon whose heart story appears later in this chapter, placed it on HeartNET. Many of the HeartNET members identified with Lasnick's letter as it summed up their thoughts and feelings about their own heart event and how people responded to it.

Corrine had difficulties returning to work following her diagnosis and was struggling to cope. Her story exemplifies the contingent personal identity. She had found her employer helpful, but due to her health status, was not allowed to work on her own. There was always another person in the room with her.

> I was off work for about a year when this happened and then I only worked part time so I was only working part time when I went back so it was like I dropped a group. I was only working with 2 groups of children instead of 3 and so my hours, I went from 35 hours or something like that down to 24. So and I found, that I could cope with that […] So yeah so and then I then I just kept losing the grips and I'd had time off, on and off but yeah, they were very good at my work. (Corrine,☏)

Corrine was in the rare situation where she had first to deal with a diagnosis of heart disease and then had to re-identify with "a *new* identity, one that is added to or conflicts with an existing diagnosis" (Armstrong, Michie, & Marteau, 1998, p. 1657). In this case Corrine was put on the waiting list for a heart transplant. While waiting for a suitable donor her health deteriorated and she made the decision to leave work. She is now 12 months post-transplant and is still not back at her job, but planning to return with reduced hours in due course.

Natasha found it hard to come to terms with her changing health status. One minute she was on holiday and the next she was facing a diagnosis of heart disease:

> I am 57 and have recently been diagnosed with ischaemic heart disease it came as quite a shock as I am not overweight have a low blood pressure do not smoke and never had do not drink and follow a healthy diet I am not a meat eater and do not like fatty or spicy foods
>
> So when on holiday and developed breathlessness and chest tightness was very surprised when I returned to find out after a stress test that I indeed had a heart condition It has taken both me and my husband a time to come to terms with the changes in our lives and the fact that this is the future. (Natasha,⌨)

Facing a questionable future while "navigating unknown and uncharted territory" (Ogilvie et al., (2012) may encourage people to seek online support. Heart patients will "slowly rebuild their lives and search for new identities following the destruction caused by their chronic condition" (Dickson, Knussen & Flowers, 2008, p. 471). While the initial focus is on the disruptive aspects of their condition, over time these patients may learn to continue living their lives within the restrictions of their heart condition.

Fred exemplifies a contingent personal identity. He refused initially to go to hospital when he had his first heart attack. He jokes about how he had complained about heart pain and visited his GP. When he left the surgery he had chest pain, and while his wife wanted to take him to hospital, he wanted to go for coffee.

> Then [date of heart attack] our world turned upside down, as my spray never worked it's magic, […], (my wife) rushed me to [major metropolitan hospital] with me arguing it's just a mild pain which was a waste of time as my colour was not backing me up. Good thing she never listened as, had I waited another 1/2 hour, I would be dead. (Fred,⌨)

Since this time Fred has struggled to return to work, can no longer drive a car and has frequent admissions into hospital with heart related issues. He frequently posts to HeartNET about how he doesn't know what his future holds and he worries about how his family will cope.

Katrina was a new heart patient when she found and joined HeartNET. Katrina had frequent admissions to hospital due to her heart condition and was still dealing with the changes it has meant for her lifestyle. When she first joined HeartNET she was searching for answers and was frightened about her heart health issues. Katrina wrote her heart story biography on HeartNET.

Am trying to keep life together as I get well. It's very slow, I get so exhausted that I feel sick and just have to lay down. My mind races around telling me stupid things and I have to stop a sense of fear and panic.

Long winded story but I'm on the mend. It [my heart problem] has really affected every part of my life. My boyfriend is tired of me being sick and we have grown apart. I've been too unwell to consider a physical side to our relationship and he feels neglected after 2 months. So looks like I am going to lose him as a result. People have been okay, but expect me to be well. But I'm not well and any exertion makes me tired. I mask it and try to make people feel okay. Such a change. (Katrina, ⌨)

Over a period of three months Katrina updated her heart story. As time progressed Katrina still had to deal with hospital admissions, but she was sounding more positive.

Another month has passed and three more hospital stays. Can't seem to get the angina in control but I have a cardiac doc appointment this Thursday. Had a dreadful 4 hour angina attack last week which has put me back a couple of months in progress. Still can't drive but imagine how much I'm saving in fuel costs! (Katrina, ⌨)

Katrina is in the early stages of her heart journey and it would appear that she is in the contingent identity phase as identified by Charmaz (1987), negotiating her response to the challenge she faces as she confronts her heart disease. Katrina continued to journal her heart journey and shared her response to reading others' messages on HeartNET: "I didn't feel alone or that I was going crazy as many people said the same things that I've been feeling or thinking. I thought it was just me, so thanks for wonderful stories" (Katrina, ⌨). Katrina continued to post over several months about her continued stays in hospital, the adaptations she needed to make in her work and social life, and her family's concern about her.

Charlie also demonstrates the contingent personal identity phase. As a relatively new member of the HeartNET community, he posted just after joining and reading the Lasnick letter and its reply (later in this chapter). He found that it helped him to understand what was happening and the emotions he was feeling, as well as helping him come to terms with his diagnosis:

I am new to HeartNET but certainly not to heart disease. I like the reply letter – and in my case it reminds me of all the GOOD things

that have come out of having heart disease. Much better to look at the donut rather than the hole! (Charlie,⌨)

Ten months after joining the site and after a short absence from posting on HeartNET, Katrina also responded to Lasnicks letter and to Charlie's post.

> That's a terrific way of looking at this life that's been thrown at us, Charlie!!! I have stopped looking at the hole and have found the donut! I have found, only the last 2 weeks, a whole new positiveness coming over me as I realised I accepted my dicky heart as it was and am making life changes to suit the new 'me'. Once I stopped thinking 'I will get well and back to my old life', I became accepting that it wouldn't ever happen. It's been enlightening for me to give up the older life and accept the new. I decided my attitude had to be that I stop fighting the heart problem and instead accept the new life I have been shown I have to live. Perhaps even more, embrace it and if that meant pills, being quiet and careful and rehauling my diet and stress levels, then bingo, I've done it.
>
> Funny how we are conditioned to believe good health is a 'right' and that we are hard done by when it goes. Instead, I've chosen to see good health as being every day I'm alive!!! If I have no pain that day or have energy and can get things done, wow, what a bonus and a tremendous day! (Katrina,⌨)

Katrina has continued to live her new life and although she experiences constant admissions to hospital, she no longer strives to return to her pre-heart event self. Instead, she chooses to live within her pain levels. This has meant taking on a part time role at work and allowing her body time to recover from her heart event. Dorothy responded to Katrina's post in an encouraging way.

> I agree that looking at the donut and not the hole Charlie is a positive way of dealing with what is facing us and allows us to follow new pathways in life that we may not have done if we had stayed so 'heart healthy.'
>
> I am now 60 plus a few years and have to say that I have done some pretty remarkable things that I would not have done had I have not had that first heart attack 34 years ago. I think you are on the right track Katrina. (Dorothy,⌨)

Interestingly, for some HeartNET participants reconstructing their identities following their heart events has had a range of long term benefits. These life changing actions have resulted in healthier pathways and in a fresh awareness of the

potential in life. While they might still struggle with their heart health and identity, they are able to look to the possibility of an improved health outcome in the future

6.3.4 The salvaged self

After their heart events, many individuals initially see themselves as invalids and define themselves according to their reduced ability to function. Charmaz (1987) identifies them as a "salvaged self". There may be a need to modify lifestyle, especially if the individual is not capable of continuing in their present job, which in turn can lead to financial difficulties or a role reversal where the partner needs to become the main breadwinner. The current family structure changes and all family members may need to take on new roles and deal with "a future now unrealized" (Charmaz, 1990, p. 1170). .

Sharon, a younger HeartNET member with 3 children, struggles with the fact that ultimately her heart condition will kill her if she does not have a heart transplant. I met her a few times socially at HeartNET meetings and then interviewed her over coffee. She appears extroverted, but when you sit and get her to open up, you can see the depth of her thoughts and feelings. Sharon faces the thought every day, that when she waves her children off to school every morning she may not be there to greet them when they come home.

Accepting her medical condition is one of the main issues Sharon faces as she deals with her savaged self. She had been posting regularly on HeartNET and then took a break for a time due to her failing health. When discussing the support she had received from HeartNET, Sharon confided that she feels like an outsider due to her age, but she also feels comfortable and comforted by the other members of HeartNET because of their shared experience.

> Everyone else is kind of 10 steps ahead and already been through that process of acceptance and dealing with it and at the time that I came on the site, I was one of the very new, I was one of the few very new ones and so I was stuck in that rut of, there was nobody walking side by side with me. But at the same time I became close to Simone and Fred and Bianca and everyone and so I actually have now fitted in, but it's still confronting when you realise these people have serious illnesses and conditions and holy crap I am one.

> I can blend into society, and pretend I'm not until someone goes, why don't you work? Or why do you wear a MedicAlert bracelet?

Or why do you have this box jutting out of your chest? "well that's my defibrillator, that keeps me alive, it's okay.

You know but I can avoid it, inside I can avoid it all, but when you get together in a group you're like, I really do fit and as comforting as it is to fit with people it's confronting to know that you fit in the group. (Sharon,⌨)

During the course of the interview, Sharon shared that she had been 'the life of the party' prior to her heart attack, but now she couldn't stay out late at night. She needed to be in bed by 9 p.m. and had to take "afternoon nanna naps because otherwise I fall asleep somewhere inappropriate" (Sharon, ⌨). In the process of the conversation it became apparent that at some point early in her heart journey she had initially closed herself off from people, and had found her illness triggered an experience of social isolation (Dickson, Knussen & Flowers, 2008). She now accepts help more readily. When I asked Sharon "what would you do differently?", without hesitation she replied:

I probably wouldn't seclude myself as much as I have done. It's been a real hard journey back into society. Because it was such a shock and such a rapid change, because I got really sick when I was first diagnosed, I had a massive coronary. (Sharon,⌨)

Sharon has spent a great deal of time on HeartNET and has been supported and encouraged by several of the older members of the site. They encouraged her to ask questions and she found that no question was too difficult as someone always had an answer or a helpful response. It may not have been the one she wanted, but she still felt affirmed. The rapport Sharon experienced allowed her to:

lean on people like Fred and Simone or someone [and say] I don't get this, I've got these problems, why is the medical [profession doing this], you know they're bombarding me with so much, what should you be concentrating on? And when I finally did get the courage to ask Fred, he was so good about it, he was like, no, no you don't really get over it. [Sharon was discussing here the fact that she would not take all the medication prescribed for her]…and just take the pills, and make them happy would you, they don't affect you, just take those damn pills. If you stop any other pill, take those pills cause they don't make you sick. And having them, not being so rebellious to the support you get as well. You know like having people say, have you taken your pills? And not go, I can do what I damn well like; I'm [only young]. Going, yeah, I should really go and swallow those pills. (Sharon,📷)

At one point, Sharon disappeared, did not respond to emails, text messages or to Facebook queries. No one could find her. This caused grave concern given her unstable heart disease and at one point everyone feared the worst. When Sharon reappeared on HeartNET, she explained that she had removed herself from society to work on her heart health:

> I have made friends [on HeartNET]. I still catch up with Bianca, quite regularly on MSN and stuff. Simone and Fred I caught up with a few times before I just disappeared again and I just, the combination of having a condition and [sick children] as well, I think it just got too much and I went over [another city in Australia] and I found it really hard to interact with everyone. Yeah, now Sam calls every now and then to check on. Sam took me under his wing within moments of [my] getting on the site ... I didn't go on the site; I really didn't want even participating in society. I have had four months out of the world. I haven't seen friends. I haven't done many things at all. (Sharon, 🔲)

We discussed other issues and then I asked Sharon what adaptations she had made to her lifestyle since her heart event. She laughed and I could see she was probably thinking "after all I have already said, you are now asking me this question." However, she replied very honestly that she was now taking time to concentrate on herself and her family. She had several times prior to the interview told me how she felt saying goodbye to her children every day. Before her heart attack, she would wave good bye "and not bat an eyelid" and then continue with her normal activities. This had changed significantly.

> Now I bring them back for, I say goodbye and they go outside and wait for the bus, but I always make sure they come back in for a second hug […] because I know too well that I may not see them again before they come home. There's every chance I could have another heart attack. So I want my children to see that I love them before anything happened […] it more clear to me now that there is always a chance that something could happen to someone. (Sharon, 🔲)

Throughout the whole interviewing process I spoke to people who were so willing to share their innermost thoughts and fears. I acknowledge that it must have been hard for them, but it was also extremely confronting for me, as I could feel my heart breaking in response to their stories. I could not fix their heart problems but hoped, while I listened, that they understood that I had a great deal of empathy and praise for how well they were dealing with a very difficult and debilitating illness.

For some, like Sharon, there was no guarantee of a happy ending. Sharon shared how she could no longer work, and that her prospects of returning to any type of work without a heart transplant were slim. She had been making changes and modifications to her own and her children's lifestyles.

> My whole life has changed, there isn't a single thing now that I do, that I did the same when I was [35]. I don't even have the same friends because a lot of my friends don't understand, I have one friend from when I was [35] to now because they do understand. When you say I can't go out today because I have a cough or please don't come over if you have a cough […] but you know I visit numerous doctors now add cardiologists, […] so I see a nephrologist and then I see a GP and then I see a registered nurse on a regular basis and you see a physiotherapist to keep your cardiac function cause I can't exercise like everyone else […] and then your tablets have an effect on neurological functions so you're followed by a neurologist for a review because a part of my condition is the vasospasm [that] also happens in your brain and that can cause haemorrhaging and clot formation and all those lovely things as well. But with every year you're on warfarin (blood thinner) your chance of a stroke goes up by two percent. So for somebody that's 80 that's great, they're going to die in 20 years' time anyway, but in 20 years' time, that's a 40% chance I'll have a stroke. (Sharon, 🎥)

Sharon spent many hours on the Internet looking for information about her complicated heart condition and in the course of her searching, found the Lasnick letter. It had an impact on her so she felt the need to share it with others in similar situations. She posted it for the other HeartNET members to read and comment upon. It became clear as Sharon and I talked that she was trying to define herself as positive and worthwhile even though she was no longer functioning at her pre-heart ability. These are key elements of the salvaged self. She and the other participants accepted that at the time of interview that they were likely to struggle to return to work or their pre-heart event lifestyle.

Penny, another HeartNET member who could be identified as a salvaged self, found initially that she had assumed a new role as an invalid, but over time this has improved. During her interview she was chatty, bubbly and laughing as she related much of her story. When asked about the impact her heart event has had on her life, she tearfully recounted the following story. Penny had found herself alone, her partner had gone to work and her children to school, and she was sitting in a dust filled room. She had been told that doing any kind of physical activity would

exacerbate her health problem and could even kill her. "The doctor, he said 'just go home and sit and rest. Don't make yourself a coffee'. And I said 'can I make myself a cup of tea?' 'No'!" (Penny, 📷). She laughed and reflectively asked "what was I supposed to do?"

> You were virtually left to your own devices. And I remembered the first time I decided to do something, we had, we were in a rental and we had lino on the floor and we sat there this morning and watched the rolls of dust rolling along the floor and I remember I just sat there and howled and I thought I've had enough of this so I got up, and I got the mop out the cupboard and I walked around the house with the mop because I was scared stiff to do anything else, so I actually walked with the mop and managed to get rid of the dust and then I got told off that night because my husband then came in and said oh who's done the floors?! (Penny, 📷)

Penny has had several more health scares since her initial heart event, but she now sees herself as functioning to the best of her potential.

For Denise, it was a different story. Denise had been feeling unwell for some time, but put it down to family issues, children and a busy lifestyle which included work and full time study. As she said, she was too busy to get sick. Denise had seen her doctor because she was getting progressively more breathless, and following some tests she was asked to return to the medical practice with her partner so they could discuss her test results. She initially ignored this request, but when she did attend the surgery a few days later, Denise had a panic attack and ended up in hospital undergoing major tests for CVD. The results of this ultimately led to her being placed on the transplant list. Overnight she had gone from a busy active mother to a woman who could not walk from her car to her place of employment without experiencing palpitations and or severe breathlessness. Denise was still very vulnerable when interviewed and her fear of what was going to happen next, one of the characteristics of the salvaged self, was evident. Several times during the interview I offered her the opportunity to stop, but Denise felt it was important to discuss her feelings.

> My career got stopped from that day, basically the day that I found out that was it. That was the last time I worked. I did go back a couple of times and I tried a real gentle thing but I ended up in hospital each time afterwards not during, because I tend to push it a bit hard. I think I'm being gentle but it was just not gentle enough for what my body needed, and that was just doing yoga and tai chi

and stuff which I thought would be all right. I suffered a lot of depression from that, that's how I identified myself for a very long time. (Denise, ⌨)

Denise continued with her story, explaining how she had found it hard to accept what her doctor was telling her. She had been through a number of previous medical crises and had always bounced back, but this time she felt it was different. She had previously seen herself:

As a competent go getter who motivated other people to be energetic, and greet each day with zest and pizzazz, to live life. And I'd had benign tumours and I've had all my reproductive system taken out and everything, all since 2004 … DVTs, a whole heap of things. I've been told this is it; gather your family before then, from the DVT, because they thought I'd had a stroke when I'd had the Warfarin as well. So we've been through some scary times. But I'm not sure if that had used up all my supply of coping, or if this was, I don't know, I had nothing left this time. I had nothing in reserve to deal with it and be strong and be fearless and be bouncing back the next day. I think the doctor telling me 'you could drop dead', that was too big a fright for me to be able to get over easily. (Denise, ⌨)

Denise recovered from her heart event, but realised that she would probably never get back to work full time. She nonetheless decided to continue with her studies at the local university. Even so, she found at times that she had to adjust her study life as well.

I was too sick to go anywhere, or too dizzy to drive because I'm not meant to drive if I'm having ectopics and I've had my keys taken off me from here many times by the medical staff. They're like you're not going anywhere. I used to take note of what number car bay I was and try and park in the same area so my husband would know where to find the car and stuff. (Denise, ⌨)

Interestingly, Denise found HeartNET online about 6 months after diagnosis and says that finding that support was exactly what she needed in those initial stages. She had been getting most of her support from family and friends, but found a new connection when she started communicating with others who were in similar circumstances. During her interview I asked Denise how she had found support and this led to a discussion about HeartNET.

HeartNET was the first thing and that was June/July this year. I didn't have a support group. ... But HeartNET was there. There are other people out there who are making cakes and who were having

hard days and who were meeting up for coffees and who were turning down meeting up for coffees because they were too sick and who were exercising. That was the biggest thing that hooked me at first, was seeing somebody who had had a heart attack riding a bike, and he was a heart patient and he liked exercise too. (Denise, ▣)

It appears that exposure to others on the site perhaps offered Denise an opportunity to move between Charmaz's identity levels. Her experience of HeartNET members who had assumed the supernormal identity gave Denise the chance to believe that perhaps she too, could one day move on from an identity as a 'salvaged self'.

Denise commented that she had found it encouraging that some members of HeartNET were riding bikes and training to compete in half marathons. She, however, was finding it difficult to move beyond feeling like the salvaged self. She had found HeartNET very supportive and encouraging, but ultimately she perceived this support as overwhelming and chose to remove herself from the site, as it was difficult to cope with the positivity. Denise was not the only one to feel this way. She had what I would describe as an 'ah-ha' moment when she found support and other people in similar circumstances who were able to help her in her current situation. Over time however, this intensity of connection turned to an 'oh – oh' moment when she realised that she had shared many personal and intimate details with people and now felt uncomfortable that they knew things about her and her relationships that Denise wished she had not discussed.

Although people in her circle accepted Denise's disease, for other people the legitimacy of their illness can be called into question by their loved ones, especially when it is invisible such as heart disease (Dickson, Knussen & Flowers, 2008). This can lead to added stress, particularly when the "disbelief of a significant other can leave [an individual] bereft of support, frustrated and fearful" (Drachler et al., 2009, p. 10). Denise initially had shared details about her family situation with other HeartNETters. She had described relying on her partner for support and found that members of her family and friends could not understand why she had not returned to her normal bubbly self. While HeartNET gave her encouragement, Denise ultimately found it was the support of her husband and children that provided her with the impetus to improve her health and well-being. Denise said that at times she:

wanted to die really and I was so depressed I just wanted it to hurry up and take me, so I didn't have to put up with it anymore. I just got past the horrible feeling to [be glad that I was] still be alive. (Denise, ▣)

There was an almost visceral fear in Denise's talk about her illness and I began to react to it as well. At some point I wondered whether I would have to undertake cardio-pulmonary resuscitation (CPR) on her, as when she got excited or emotional there appeared to be a cardiac reaction. At times I was unsure as to who was reassuring whom. I also related to her on a personal level as her young children were of a similar age to my own and I could identify with her feelings of despair. In fact, asking the participants if their heart events had had an impact on them elicited some fairly strong reactions. For many, like Denise, the heart event challenged their whole relationship to mortality. While HeartNET allows members the opportunity to share their thoughts and feelings, for many this is not enough. Denise did not find HeartNET a useful tool and in fact it was the thought of her children growing up without a mother that instigated a change in her behaviour

Alistair found himself in a similar situation to Denise. After feeling unwell for several months, he was shocked to learn that he had to have emergency surgery for heart blockages. He then struggled to return to his pre-heart event self. Alistair was surprised to find that he had heart problems, even though he had been having escalating symptoms for many months prior to seeking medical attention. At first Alistair attributed his symptoms to the stress of holding down two very demanding jobs. It was not until one of his colleagues told him to go and get a medical check-up that he found he had "blockages basically in all of my arteries of varying degrees but they were all quite serious" (Alistair, ☏). After immediate surgical intervention, Alistair found his health did not improve as quickly as he had hoped. He expressed his disappointment at finding that his experience was not the same as some of the other members of his cardiac rehabilitation group:

> Because after about 12 weeks they put me through rehab and everyone else there, there was a lot of them were 20 years older than me, were saying that after the angiopathy they hadn't felt that good for 20 years or something, whereas I felt the complete opposite. I've got the worst I had in most of my life. I couldn't understand why everyone else felt better and I didn't. (Alistair, ▣)

After three further surgical procedures, Alistair returned to work, but found himself unable to cope. The pressures of his employment, the inability to walk from the car park to his place of work and finding that he was having repeated exacerbations of his original heart problems, eventually led Alistair to re-evaluate his career options. Alistair identifies with Charmaz's salvaged self. He is currently unemployed and due to his heart health is unable to return to any form of physical activity or paid work.

Alistair became quite angry during the interview concerning some comments made by doctors, friends and colleagues in relation to his heart and general health, and demonstrated the finding that people who talk about their illnesses "commonly include references to their encounters with health care professionals, especially their doctors" (Reeve et al, 2010, p. 358). Several times he commented on the fact that the medical profession put his declining health down to the fact that he smoked and was overweight. The cardiologist he saw after his first stent was inserted told him: "well you just need to lose weight and exercise" and several months later this was repeated by his general practitioner (GP) "Oh yeah, you just have sciatica, you just need to lose some weight. What she said offended me so much, I just got so angry" (Alistair, 🔲). Leaving the doctor's surgery was a turning point in Alistair's life. He remembers returning home and searching on the Internet for answers, laughingly stating: "I just said, 'oh, hell', and I walked out of there and I ended up ordering three books on cardiology from Amazon.com". He believes this was the turning point in his recovery.

Alistair has found that his heart event means that he cannot return to work of any kind. He has resigned himself to being an invalid for the rest of his life. He sounds very angry and is often depressed, Alistair feels that not only has his work place given up on him, but so have his colleagues, family and friends. When I was interviewing him Alistair automatically started a monologue about his medication regime. In fact, I didn't even get a chance to ask him an initial question. Each time I asked him a question, Alistair would relate it back to medication issues. When he agreed finally to tell me his story, he spoke about feeling unwell for a few days and when he found that he was also slowing up and getting stressed over minor issues, his partner encouraged him to seek medical attention. This he did, and like many other participants, he found himself suddenly in hospital undergoing immediate

treatment. It is the abruptness of the change from appearing to be healthy to being a heart patient that has caused the most concern for many participants in this research. Issues such as coping with functional restrictions, the interference their heart condition places on their daily activities, an uncertain prognosis, treatment requirements, ongoing management of rehabilitation and factors around dealing with family, all take their toll (Livneh & Antonak, 2005). These heart patients must incorporate the constraints of being a salvaged self into their lifestyle.

Time and again the participants I interviewed discussed the fact that they had developed or were still dealing with depression. This often occurred on or just after diagnosis and it affected their subsequent heart health journey. Several of the participants interviewed were very forthcoming about their anxiety levels, state of mind and how they dealt with these by either seeking medical help or writing on HeartNET about how they felt. Some shared their feelings in their posts on the bulletin board while others wrote poetry and songs. Research indicates that the proportion of heart patients who develop major depressive symptoms is high. Around 15-20% of people develop major depressive symptoms while a further 27% of heart patients develop mild depressive symptoms (Kemp, Malhotra, Franco, Tesar & Bronson, 2003). This aspect of the recovery from a heart event is beyond the scope of this research, but appears to be a major issue with people who have had heart disease.

Sandra found that "it was just so nice to be able to vent [on HeartNET] and just learning about other people too, because someone might say something and you think 'oh yeah, I can do that too'. Everybody has got their own little ways of coping" (Sandra,☎). Following her heart event, Sandra returned home and tried to retain a semblance of normality. She discovered, however, that even the most minor levels of activity left her breathless and feeling generally weak and lethargic. Sandra was referred to HeartNET by the Heart Foundation and at one point was one of the more prolific users of the site. When asked about the impact her heart event had on her life, Sandra shared some of the highs and lows of her journey. Her story demonstrated the characteristics of the salvaged self and that she accepts her current abilities.

> Huge impact, far more than I ever imagined it would because I
> know people who have had heart attacks and gone on with their life

and been pretty good. I get breathless a lot. I've got no strength, no upper body strength, vacuuming is guaranteed to bring chest pain on, pegging washing out. ... Yes, I have this really low clothes line [laughter], yes you just adapt to things. Psychologically I just lost total faith in my body, myself. I'm not scared any more about it, I'm pretty fatalistic. A big thing for me was reaching 62 because I just had it in my head that I was going to die at the same age as dad, so him and I are the only ones alike. My mother had five children and I'm the only one like him and so that, I firmly had it in my head, so that was a huge relief to reach 62. I mean logically and realistically that doesn't happen with the medical expertise they've got now. I mean they would have been able to keep him alive possibly. ... Okay now, the early days like I tried to get back into [my hobby], but I just couldn't do it. They were good; they let me have a chair and all the rest of it, but just the heat and the waiting and waiting, not to mention the [activity needed to maintain my hobby] that has to go with it. I just didn't have the energy, I tried to do the walking but my ankles would blow up like balloons and I'd get leg cramps.(Sandra,☎)

Sandra has continued to struggle with her inability to return to normal life and had to give up her hobby. This caused her a great deal of distress, as she was unable to salvage her previous identity. Following the interviews, Sandra has moved to another state and reduced her involvement on HeartNET. The last contact I had with her was when she invited me to take up farming on Facebook.

Many HeartNET members identified with confronting a health threshold (Reeve, 2010) which they either faced or moved beyond as they recreated themselves within the restrictions their heart disease placed upon them. People with chronic illnesses often have to "slowly rebuild their lives and search for new identities following the destruction caused by their chronic condition" (Dickson, Knussen & Flowers, 2008, p. 471). To make changes to one's self following a diagnosis of heart disease as demonstrated by the HeartNETters posts may involve "adjustments in self-evaluation and attitudes" (Drachler, et al., 2009, p. 11).

The focus of this chapter has been on the reconstruction of the self-online following a major heart event, with members of HeartNET developing or attempting to develop new versions of their selves according to the levels as identified by Charmaz (1987). Lasnick's letter (2007) from her disease started this chapter and the members of HeartNET responded with their own stories. Often, when one receives a medical diagnosis there is initial shock and grief. For some, there may be further exacerbations of their disease. When reading the letter one can sense Lasnick's

projection of an almost gleeful response on the part of the illness. This chapter discussed the fact that people who shared their innermost thoughts, feelings and fears are now living in a new, harsh and unpredictable reality. Each person in turn must negotiate their own response as they challenge the limitations imposed by their heart disease. Lasnick has the last word however, and provides a conclusion for this chapter with her response to her chronic condition.

> Dear My chronic condition: I would like to clarify that, while you may wreak havoc on my body, and maybe even confuse my mind — you cannot have my heart or my soul. You cannot have my faith, my hope, or my love. There are some good things that you have given me, things I never could have experienced had you not come to possess my body. You have given me: – strengthened prayer life and increased dependence on God's grace and strength, rather than my own – renewed friendship with strong, close, true friends – appreciation for every precious moment I am given. A gift that is sometimes lost on the "healthy" – growth in character, perseverance, and hope – inspiration for to help others – more compassion for others who are suffering – better knowledge of my own body & health – a reason to eat more nutritiously and take care of myself – reasons to rest when I need it. You see, you will not find me an agreeable host. I will fight you, I will not give up. On bad days, I will take care of myself. On the good days, I will take advantage of every precious moment. You have thrown some obstacles in my life's journey, but I will go over them or around them, no matter what it takes. In fact, while I am overcoming them, I will stop for a moment to reflect upon the mountain I am climbing, plant a few seeds and then continue on. I will learn and grow from this experience and help others.
>
> Sincerely. (Lasnick, 2007)

6.4   Summary

This chapter explored the journey of several HeartNET members as they dealt with a diagnosis of heart disease. For some people HeartNET provided an outlet to journal their journey as they dealt with a chronic illness. This activity was of benefit to both the authors and readers.

This chapter began with a creatively imagined letter written by a 'chronic disease' to its 'host body' and ended with a response from the host body to the disease. The posting of these documents provided an opportunity for HeartNET members to journal and share their thoughts and feelings about living with a heart condition.

A medical diagnosis can be disruptive and readjustments are likely to be needed. This chapter outlined four identity levels that people with a chronic illness may seek to achieve and elaborated on them in some detail with respect to HeartNET members. These identities were the supernormal identity, the restored self, the contingent personal identity and the salvaged self. As I interviewed participants and analysed the posts on HeartNET, it became clear that most of the participants in this research appeared to be in or striving to achieve one of these levels. For some members positive adjustments have occurred, while others were still on the journey.

The next chapter of this thesis investigates how heart disease in the print and television media has been reported on HeartNET. It highlights how HeartNET members focus on creating obituaries for high profile people who have passed away due to a heart condition. This chapter also identifies how the media influences people's health care decisions and explores the Hollywood myth that surrounds the signs and symptoms of a heart attack.

CHAPTER SEVEN:
MEDIA ON HeartNET

7.1   Introduction

The media, especially newspapers, are seen by many researchers and health care providers as an important source of information for both lay people and health researchers (Bartlett, Sterne & Egger, 2002). When I took on the role of HeartNET moderator from the previous incumbent, one of the aims to be investigated was how the media portrayed people with CVD and the impact of the media on a new patient's sense of identity. Initially it was anticipated that HeartNET members would post about media issues as and when they arose. This worked to a degree. It soon became apparent however, that most HeartNET members were more interested in high profile individuals who had passed away due to heart disease rather than more general media messages.

This chapter has two sections. Firstly, it investigates how the media, both television and print, portray CVD. Secondly, it examines the participants' postings on HeartNET regarding heart related issues in the print media and on television, and subsequent discussions on the HeartNET bulletin board. HeartNET members sometimes comment on news items they have read or seen, and they use the site to discuss the impact of these stories.

7.2   Health Reporting

Mass media have the potential to reach a large and diverse audience and have an impact on how the public views major health issues such as CVD (Guyatt, et al., 1999). The reporting of health stories in the media can potentially influence the way people gather health information and make decisions about their health. Medical reports influence decision-making about seeking health care. How a story is reported has the potential to raise people's hopes about possible cures or alternately cause distress or alarm (Leask & Chapman, 2002). Health reporting can influence "individual health behaviour, health care utilisation, health care practices [and] health policy" (Larsson et al., 2003, p. 324).

A relevant health story may face many obstacles even before it appears in print. These obstacles include issues such as editorial space and deadlines, relevance to the media audience, and the authenticity and validity of the research. Schwitzer (2005, p. 576) believes "journalists have a special responsibility in covering health and medical news…readers and viewers make important health care decisions based on the information provided in our stories" . As with any reporting it is important that sensationalist, misleading, misinformed, incomplete or biased information is not reported. Mudur (2005) believes the context of all health reports is crucial, especially when advances in health care are being promoted.

It is therefore important to know what the public believes constitutes legitimate medical information since journalists need to identify, process and then report these stories. One common definition for a valid health report is that it can be "anything that interests a large part of the community and was never bought to its attention before" (Johnson, 1998, p. 89). This approach has inherent problems as journalists, like many others, have deadlines to meet and competition from other journalists and newspapers. Readers, on the other hand, want to be informed of medical breakthroughs as and when they happen, and even before there has been extensive verification. This may mean that an advance is reported early, but erroneously. The quality of such reports is an issue and Robotham asserts that "preliminary findings by researchers are just that preliminary … like life, news is a work in progress, a rolling tide of updates, each modifying the last" (2006, p. 479).

7.3   Obituaries on HeartNET

It was assumed that HeartNET members would comment about media stories on HeartNET, thus providing me with an opportunity to analyse these posts about the media and how heart disease is portrayed. While some reality shows and lifestyle related issues were discussed, the majority of posts were obituaries about heart-related deaths among high profile individuals. HeartNET members acknowledged the achievements of these people. Comments were written about Davy Jones, the lead singer of the Monkees, a musician and actor who appeared from 1966 to 1971, as a member of the made-for-television pop-rock group the Monkees (Hinckley, 2012).

> Davey Jones lead singer of the Monkees sadly passed away
> yesterday from a heart attack. Thanks for the great songs Dave.
> (Fred, 🖥)

> What a shock – wonder if he knew he had CAD? like most of us,
> he probably didn't (Fred, 🖥)

> I always loved the tv show and the music, fond memories of a
> simpler, funnier time. (Sam,🖥)

Sir David Frost, an English journalist and broadcaster, well known for his interviews with prominent American politicians including Richard Nixon, died from a heart attack (BBC News & Entertainment, 2012).

> Sir David Frost, The English reporter famous for the tv show the
> Frost Report in the 60's Has passed away on the 31/8/13 From a
> Heart Attack. He will always be remembered for his interviews.
> RIP David & thanks for the memories (Fred, 🖥).

Tony Grieg a former English cricketer and Channel Nine (Australia) sports commentator who was diagnosed with cancer passed away from a heart attack (Saltou & Lallo, 2012).

> R.I.P. Tony Greig.:

> Thanks Tony for all you've done to promote the game of Cricket.
> To battle cancer for many years too be stumped by a heart attack
> on 66. R.I.P. (Fred, 🖥)

> Yes a big Man in more ways than stature. sympathy to his family
> (Bianca, 🖥)

Sharing obituaries online potentially informs a larger number of people more quickly than traditional media outlets (Magnani, Montessi & Rossi, 2013). Previously media events have been managed by media consortiums. Now social media allows a much greater and faster dissemination of news, thus generating vast amounts of Internet traffic (Rossi, Magnani & Ladarola, 2011).

Death and grief are no longer private. The advent of visual and communication technologies allows people's lives and deaths to be open to public scrutiny (Gibson, 2007, p. 418) and identifies that for some "celebrity deaths do resonate in the lives of individuals". This may be due to "the private lives of celebrities [being] intertwined in the relationships and conversations of ordinary people" (Gibson, 2007, p. 420). For HeartNET members there is an additional effect. When a public figure dies from

a condition similar to their own it may "render fragile their own sense of mortality" (Gibson, 2007, p. 421).

In hindsight, creating a forum from the outset for media messages would have been valuable. However, HeartNET members did create some threads about media issues and these will be discussed further throughout this chapter.

7.4   Television and the Reporting of Health Stories

The use of the media, especially television broadcasts of a specific global event, allows viewers to remove themselves from the "reality of everyday life and enter an alternate reality by giving them an opportunity to enter a 'liminal period' one during which social life is characterized by the suspension of usual norms and structures" (Turner, cited in Dayan and Katz, 1987, p. 192). Television is a media which can involve publicly audiences in a shared spectacle, while still providing a separation from reality. Whereas in the past people would congregate in a public arena to view an event, now they meet in "small groups around a television set, concentrating on the symbolic centre, keenly aware that myriads of other groups are doing likewise in similar manner, and at the same time (Dayan & Katz, 1987, p. 194). Viewing television "can extend the boundaries of home beyond the front door" (Silverstone, 1994, p. 29), and for many, "television today is an integral part of the family household- almost another member of the family" (Gunter & Svennevig cited in Silverstone 1994, p. 32). Television today is used for different purposes such as immersing yourself in cult dramas (Creeber, 2001) or seeking health information and education.

Schwitzer (2005) argues that many people get their health news and information from television, although most of these stories are no longer than forty-five seconds. Television is an important avenue for health dissemination. There are various issues that determine where health news is placed in the television news bulletin. Breakthroughs in health outcomes will usually get good coverage, however there is often little reporting on health policy, and minimal follow-up on news items after their first reporting (Wang & Gantz 2007).

7.4.1   Marcus Welby syndrome

People do not necessarily see their doctor on a regular basis. This may mean that the media is the primary place for regular health information and subsequent health decisions may be based on such media messages. For a proportion of viewers, health knowledge comes from watching American medical dramas on television such as *ER, Chicago Hope, Grey's Anatomy, House* and for Australian viewers, *G.P., A Country Practice* and *All Saints*. In these programs the medical profession is portrayed as "all powerful and all-good" or in Neuendorf's terms (1990, p, 327), benefiting from "the Marcus-Welby syndrome". In this Marcus Welby scenario health issues are resolved in less than 60 minutes with often miraculous results (Daniel, 1969-1976). In reality, months or years of long term care and treatment are required, and it is not always possible to return to everyday life.

Watching television allows viewers to enter worlds to which they may never have access. Add the impact reality television shows have that allows viewers to experience authentic medical dramas, emergencies and procedures in the safety of their home environment such as *One Born Every Minute UK, Embarrassing Bodies* and *RPA*. Ibrahim (2007) suggests that television in these cases can be seen as "a myth space where reality and fantasy occupy a liminal world" (p. 41).

7.4.2   The Biggest Loser

One television show that has elicited a great deal of comment on HeartNET is *The Biggest Loser,* a syndicated reality television show where overweight and obese contestants lose large amounts of weight over a very short time period, with the winner ultimately receiving a financial reward (Stevenson, 2012). While some HeartNET members enjoyed watching the show, others were quite disparaging. Shona argued that the show is purely for entertainment "with as much trickery as *Bewitched*. Who remembers this oldie?" (Shona,🖥). She continued that she felt many of the contestants would require cosmetic and other surgery once they had left *The Biggest Loser*. "I heard the winner of the previous BL [*The Biggest Loser*] say he had multiple cosmetic surgery ops since the show to remove deal [with] all his excess skin – a result of too-fast weight loss" (Shona, 🖥). Monica agreed: "I can see Damien and Kimberlie lining up for that kind of surgery after BL...so far I reckon the other gals look OK although there are a few sets of man-boobs that look odd" (Monica, 🖥). After further discussion about various aspects of the *Biggest Loser,*

and the 1964 television show Bewitched depicting "a witch married to an ordinary man who cannot resist using her magic powers to solve the problems her family faces" (Arnold, Froug & Asher, 1964-1972; 2012), Lorraine posted about a fellow gym member and her unrealistic obsession with *The Biggest Loser*.

> I go to the gym and there is a girl there that is obsessed with THE BIGGEST LOOSER. She seems to think that she should be doing 4 hours of exercise a day as well. She doesn't realise that they don't have kids to run around after, work to attend, housework etc. and that they get to rest throughout the day. I loved Bewitched when I was younger. (Lorraine,⌨)

Kerry responded almost immediately writing passionately about her feelings for reality shows that put people's health into the spotlight.

> I personally don't like shows like the *Biggest Loser* or *Teen Fat Camp*. Like Monica said, its good that you can take note of some of the exercises/diet that they use to lose weight quickly, but shouldn't it be possible to have tv shows that focus mainly on the principles of losing weight as opposed to exploiting these overweight people and their personal struggles by sticking a camera in their face so the rest of Australia can watch them cry and talk about it over their coffee breaks? They're like makeover shows with their before and after pictures, when the person's family/friends gather around before to say how little confidence she has and how she's always wanted bigger boobs/nose job etc. Programs like these work to create an illusion that these people are very very different from the rest of us; so we kick back and watch them 'achieve the almost impossible' in a weight loss utopia while forming unrealistic expectations of ourselves to be able to achieve the same. (Kerry,⌨)

Continuing Kerry then discussed how this would relate to HeartNET members, who for continued heart health needed to lose and then maintain their weight loss.

> Its great that people on HeartNET know the right principles of weight loss, but what about the average misguided consumer (like the girl Lorraine was talking about) who can't see the difference between TV and reality? I reckon screw the reality programs and bring back good tv drama or comedy. Or at least, stick to talent quests or Survivor style shows that don't put the spotlight on weight loss competitions and quick-fix cosmetic surgeries. A person's health is so precious and individual that [it] should be valued as an essential part of your being, not as a tool to win money by. (Kerry,⌨)

7.4.3 *What's good for you?*

Terry felt that there were other shows that were more useful for long term health information such as Channel Nine's Australian health and lifestyle program *What's Good For You.* This show investigates myths about health and wellbeing by using a team of doctors and reporters who "act as detectives-turned-human guinea pigs to investigate some of the common experiences that impact everyday lives" (Rochford, 2012, ¶1).

> Well you can always watch shows like Whats Good for You, but no one gets evicted every week and no one cries or has tanties, [tantrums] so they aren't as popular. But they have the information that we are all talking about. Good diet tips, exercise etc. So sort out the rubbish shows from the good ones. Sure watch the biggest loser shows for the entertainment, if you call it that, and something else a bit more informative and less spectacular for actual advise on lifestyle choices. (Terry,⌨).

Fred responded that he had been watching one episode of this show that was exploring sleep apnoea in an episode entitled "The Facts of Sleep Disorders" and learned that "Sleep loss costs the Australian economy an estimated \$3 billion in productivity losses each year" (Rochford, 2010, para. 1). Fred's wife's response indicated the value of Terry's post:

> Well said Terry, I have to agree with you that Whats Good for you is worth watching. They did a segment on sleep apnea & my wife wants me to go & see someone about it so she can have a good nights sleep from my bouts of not breathing while snoring. (Fred,⌨)

In response to watching this episode and his 'wife's nagging' Fred underwent sleep studies and is now using a CPAP (continuous positive airway pressure) machine and mask to treat his sleep apnoea (ResMed, 2012). Sleep apnoea is a condition that could have caused major long term health issues if Fred had not been watching the television program or using the HeartNET site.

According to Rodan (2010, p. 5) makeover shows such as *The Biggest Loser* are about "the ordinary person on television". It is often only the winners of these reality shows however, who can maintain their weight loss away from the competitive atmosphere during the production of the series. For many of the HeartNET members, extended weight loss or prolonged periods of time in the gym are beyond their physical and health capabilities. For many viewers it is easy to

forget that these shows are "highly edited, casting is an important element [and …] that contestant's personalities are constructed through the editing process" (Rodan, 2010, p. 7). However, people continue to watch shows such as the *Biggest Loser* for its entertainment value.

7.5   Health Information

Investigations into the health information conveyed by the mass media have raised several areas of concern. These include the brevity of health information found in both television and print media. Television health reports are usually less than a minute and printed items in the press are often less than 500 words per article. Many stations and newspapers do not employ full time health journalists and may rely on sensationalism and hyperbole to add impact to the information reported. There is also a risk of commercialism, where many reports originate from private companies or their public relations firms. This is especially true of pharmaceutical corporations (Schwitzer, 2004). Other issues relevant to health reporting include the fact that a story is more likely to be shown if it has a "quirky or feel good element" or portrays a "cute child" in need of treatment as opposed to items on health policy (Picard, 2005). There is also likely to be emphasis on local research, because people are interested in health advances occurring in their own home environment. Wang and Gantz (2007) note that tragedies and medical scares are often covered as news.

HeartNET members will occasionally email me in my role as the moderator with issues that have been highlighted in the local newspaper and ask me to clarify the position the Heart Foundation might take on that issue. One such incident occurred when Fred read the following small article in the *Sunday Times*. The study reported in the article involved the introduction of folate into bread, and an argument that this could lead to an increased risk of heart patients developing cancer. This research was published after the Australian Federal government had passed "laws forcing bakers to add folic acid, a vitamin found in leafy vegetables. Only organic bread is exempt" (Bread Cancer Fear, 2009, para.3). Fred emailed me and then phoned to ask if I knew anything about this, and if not, where on the HeartNET site he should post his concerns. Fred also wanted to know how the Heart Foundation felt about this and then Fred asked "Why weren't we informed of this risk to our health?" (Fred,⌨). Fred's post reflects his alarm.

Cancer increase for Heart Patients in Australia.

A law was passed in Australia last month to add Folic Acid to all Bread. According to the Sunday Times, This was done to decrease the risk of Spina Bifida in pregnant women, but as Folic Acid is derived from green vegetables it will increase the risk of cancer in heart patients by 21% according to the Research by the American Medical Association. Only Organic bread is exempt. Was the Heart Foundation aware of this law when it was a bill & why weren't we informed of this risk to our health? (Fred, 🖳)

This posting elicited several responses from other HeartNET members. Fred even rang the Western Australian Health Department and was told to contact other agencies which he did (continuing the thread):

I rang the W.A. Health dept to get further info, but got told to ring the Cancer council who told me to ask my G.P. I'm waiting for the reporter who placed the story to get back to me along with the Minister of Health. Meanwhile as Folic Acid is derived from Green vegetables, it will effect your I.N.R. if your taking Warfarin. ?"(Fred, 🖳)

Discussion continued on the HeartNET site. Fred's concern was that while folic acid was appropriate for pregnant women, as folate reduces the incidence of neural tube defects, it was an issue for him due to the warfarin-based medication he was taking. Fred searched the Internet for the research this newspaper report was based on and found a paper by Ebbing, et al., (2009). The article argues that the "experimental evidence suggests that folate deficiency may promote initial stages of carcinogenesis whereas high doses of folic acid may enhance growth of cancer cells" (p. 2119). Ebbing's study, undertaken in Norway, found that among the 6837 participants 9.2% had developed cancer during or post the study, with more of these cancer patients in the group consuming folate. Ebbing et al., expressed caution about the findings, stating that further research was needed, but recommended in the meantime for safety monitoring following the "wide-spread consumption of folic acid from dietary supplements and fortified foods" (Ebbing et al., 2009, p. 2125). While many countries had already implemented the addition of folate into grains and flour, Australia did not introduce this until late 2009.

Adding to the interest in this topic, folic acid had been prescribed to some of the HeartNET members by their cardiologists to see if it was an effective medication in treating heart disease. Folate is also used as a treatment in Crohn's disease. For

some, folate appears to be an effective treatment, while for others it can trigger a drug interaction.

> I take one folic acid tablet every day, as instructed by my cardiologist. There is an article in the papers every other day about some product which causes cancer. Why does it effect heart patients more than the general public? How much folic acid is to much? Are you going to stop eating green vegetables? What type of cancer? What is the baseline for the 21% figure? For example if the general public risk is 1% and the heart patient is another 21% on top of that, it puts the risk at 1.21%. Folic acid is very important. The benefits outweigh the risks. (Matthew, ⌨)

> I agree with you scoop that folic acid is good for us if we're pregnant, & it can be found in many foods. When added as a supplement that's when it effects those of us that are not allowed supplements in our diet because of the risks. (Fred, ⌨)

> I take Three Folic acid tabs per day, part of my treatment for my Crohns.. :o. (Sarah, ⌨)

As this article caused concern among the HeartNET members, I emailed a Heart Foundation colleague for advice and also to determine the Heart Foundation's stand on this issue. This person referred my query to one of the dieticians, who responded with the following:

> Thanks for this. I'm not aware of the study that the query is referring to, but I do know that FSANZ [Food Standards Australia New Zealand] comprehensively assessed the potential health benefits and risks from increasing folic acid consumption across the population. And based on all available scientific evidence, adding folic acid to bread making flour in Australia is safe for the whole population. (Heart Foundation Dietician, personal communication, November 25, 2009)

Following the Heart Foundation's response, discussion abated and Bianca's comment summed up the feelings of many of the HeartNET members.

> Thanks Lynsey, we have to be careful we don't believe all we read on the net about things so to have it from the Heart Foundation is reassuring. (Bianca, ⌨)

Fred had also contacted his GP and was reassured that folate was relatively safe for other people, but Fred had to avoid its use due to his ongoing medical conditions.

7.5.1   Covering health issues

Concerns raised by commentators such as Sweet (2005) and Swan (2005) regarding the media coverage of health issues include the lack of some journalists' capacity to critically appraise health and medical claims. Sweet contends that targeting journalists is only one component of this issue and argues that commercial interests from industry and drug companies also form part of the media culture (2005, p. 194). Swan confirms this, believing that the Australian media "falls below the standards that might allow the community to make rational decisions about their health and medical care" (Swan, 2005, p. 194). This perception is reflected in the research undertaken by Smith, Wilson and Henry (2005) which highlights a recent incident where women in Australia were alarmed about the prolonged use of hormone replacement treatment (HRT) and the adverse effects this treatment might have on their long term health. Studies undertaken in the United States of America (USA) in 2002 found that women who took "combined HRT were at greater risk of stroke, breast cancer and blood clots in the lungs". After the publication and subsequent reporting of this research, "sales of HRT drugs plunged by 40% in Australia and worldwide" (Cresswell, 2009, p. 4). The impact of this was far reaching, with continued anxiety and concern from many women about the long term benefits and health costs of HRT.

Clarke, van Amerom and Binns (2007) undertook a longitudinal study of all English language magazines available in Canada and North America and found that seventy-five articles published from 1991 to 2001 mentioned heart disease, CVD, heart attack and heart-related terms. This print media was selected for the research as "magazines tend to be more permanent than television or radio reports, inexpensive, read and re-read, and in broad circulation" (p. 20). When reviewing the magazine articles, the researchers found that CVD in men was described in stereotypically masculine terms using "metaphors of aggression" (p. 23), with researchers concluding that heart disease is "taken as an element of, or even a badge of manhood" (Clarke et al, 2007, p. 23). Alternatively, women were portrayed as caretakers, uninformed or in some cases the "causes [of their] heart attack were not attributed to job pressures or stress, but to the women's lack of [the choice of] a healthy lifestyle, women were also portrayed as emotional in the face of heart disease" (p. 26). Clarke et al., also found that while men were happy to publicly

share their heart history and health, women were more hesitant to acknowledge their heart stories. This is contrary to the experience on HeartNET, where women share their heart stories freely, while the male members of HeartNET currently tend to talk more about their sporting achievements and exploits (HeartNET, 2012)

Clarke (1991) believes the media often positions articles according to either the Medical Model or the Lifestyle Model. While the Medical Model reports on issues such as advances in treatment, medication usage and prevention, it often criticises non-medical or holistic treatment as a risky alternative. Lifestyle perspectives see "diseases and death as the result of faulty lifestyle choices made by individuals" (Clarke, 1991, p, 291). This dichotomy will be elaborated on later in this chapter, as this is an issue upon which many of the research participants commented.

Media such as newspapers, television, radio, movies and magazines contribute to the construction of social reality (Soffer & Aizenstadt, 2010; Clarke, 2004). According to Mosca, Ferris, Fabunmi and Robertson (2000), 43% of the population gain heart health information from popular magazines, 24% from television and 18% look to their health professionals for heart health information. So for many readers, becoming immersed in the media is an integral part of daily life.

7.6   Hollywood Myth

The influence of the media was underlined by Hope (2008), whose UK Heart Foundation research determined that 38% of people experiencing a heart event believe the Hollywood myth and think the signs of a heart attack will always be crippling chest pain (Hope, 2008). As a researcher, I found this alarming and discussed these findings with several of the cardiac rehabilitation nurses at the Heart Foundation in Perth, only to discover that many of them faced this sort of comment on an almost daily basis.

Hope elaborates on the research stating that many Hollywood movies perpetuate this stereotype. In movies such as *Oceans 13* and *Something's Gotta Give*, the main stars suffered heart attacks where they "fell over clutching their chests" (Hope, 2008, para. 4). Television also perpetuates this myth with characters from British and Australian television shows such *EastEnders*, *Coronation Street* and

Neighbours having heart attacks, while Homer Simpson has not one, but three, heart attacks!

Recognising this fact, Sam posted the following on HeartNET:

> It's still portrayed in a Hollywood style the big [clutch the] chest and you keel over the bed, when it is portrayed the media does not portray it in a real life world, in a real world situation. Heart disease is insidious. It is not in your face. It is that little chest pain that doesn't go away that people don't take notice of and that message is not advertised enough. (Sam, aged 41)

It would appear the Hollywood perception remains. The symptom of a debilitating heart attack is still believed to be a sudden clutch-your-chest and die scenario whereas in reality, many people experience obscure symptoms which are insidious in nature. For example, Bianca reported feeling unwell all day:

> I had a pressure pain in the centre of my chest, but then I would burp. So I thought "oh I've got indigestion. But why have I got indigestion at this hour of the morning when I haven't eaten?" This just constantly, pain, burp, pain, burp, it was just as constant as that. Burp, burp. (Bianca, 🖼)

Bianca continued with her daily activities until late evening when she thought something serious was wrong. She phoned a local emergency help line for advice and they offered to ring for an ambulance. She refused and chose to call her neighbour to take her to the local hospital. In hindsight she admits this was foolish, especially since she had private hospital cover that would pay the ambulance bill. In the midst of this emergency she was worried about the expense, and thought:

> I can't ring 000 and get an ambulance. I'm on a pension, I can't afford to get an ambulance." So I called my neighbour, who took me to hospital, not thinking I had private cover anyway so I was covered for ambulance. (Bianca, 🖼)

Kate reported similar findings, although she left it several days before attending the hospital. To her the symptoms were uncomfortable, but manageable. She was shocked when she was told she had had a heart attack.

> I said my gall bladder is playing up, which is [the pain] I thought was the gall bladder and when I got there, [local hospital] they took me straight in and as I am walking towards the bed they said "you know she's having a heart attack" and I said "no I'm not don't be so stupid". You're having a heart attack and I said "no I'm not, it's my gall bladder", I am burping like crazy and everything like that,

they said you are having a heart attack so the next minute I know they have thrown me on the bed and the next minute I am getting jabbed and stuck and I am thinking oh wow! (Kate,🔲)

Abby and Ingrid experienced symptoms more like those reported in the media and similar to the Hollywood myth. Ingrid experienced pains over several days and had a previous admission to hospital with chest pains. Eventually she experienced pain that would not go away even with medication.

I didn't think of ringing an ambulance because even though the pain was bad it would go away but I wasn't sweating or vomiting or anything and so I just left it and then about seven o'clock the pain changed and it was like an elephant on my chest. And I thought oh god this is no good so I just kept taking the spray. (Ingrid,🔲)

Abby also spoke of waking with chest pain that mimicked classic heart attack symptoms.

Oh the pain, when I got the chest pain it was just overwhelming, it was the worst pain I've ever had in my life, worse than child birth. It was very intense, very sharp but not a stabbing sharp just very acute I guess and overwhelming, very overwhelming. […] In the centre of my chest, yeah I mean classic heart. If I hadn't had that I probably wouldn't have recognised I was having a heart attack at all. (Abby,🔲)

To counteract some of the power of the Hollywood Myth, the Office of Women's Health, US Department of Health and Human Services has created a webpage to provide advice on how to *Make the Call, don't miss a beat*. This site is an attempt to educate people especially women to know what a heart attack looks like.

- The victim stops what they're doing.
- Their eyes open wide.
- They clutch their chest, make some funny noises, and then they collapse to the floor. Right?

Wrong. Don't believe everything you see on TV (OWH, 2014, para 1).

The main concern raised by the Hollywood Myth are that most people do not know the symptoms of a heart attack, and because of this, many people die. Nearly 40% of people who have a heart attack die before they reach a hospital. Another

concern is the fact that most people wait several hours before seeking medical help, because "they don't recognize the true warning signs" (Heart Health, 2013).

7.7   Use of the Media

The following section highlights how both HeartNET and non-HeartNET members use the media, and their perceptions of how the media portrays heart disease to those who have not had a heart event.

When I interviewed Alf, a non-HeartNET member, discussion ensued about how he had both the *West Australian* and *The Australian* newspapers delivered daily. After reading them he would go online to clarify issues via other news sources. He said he only used his email for keeping in contact with others, but for the main part his use of the Internet was a way of "assessing vital sources of news" (Alf,📷). When I asked how accurate he found the stories about people with heart problems and the reported advances in technology and treatment, he was quite scathing in his response.

> When they say there's a major breakthrough and this, that and the other, I sort of have to treat it with a little bit of salt, because a lot of it is sensationalist, and if you start asking a professional who's in that area, they say "oh yeah, that's true, we got that report, but you know it's still in the experimental stage, blah, blah, blah, and if it does pan out it might be 10 years from now". I once talked to my heart specialist, and I said "looks what's changed in the last 10 years?" And he said, "Everything". He said "we used to run a butcher shop here, now it's not" and that was his opinion of it. (Alf,📷)

Alf a non-HeartNET user is an articulate man who at times would comment provocatively on issues, pausing to see what my reaction was to his sometimes outrageous comments. Initially I would respond without thinking it through, until I realised this was what he wanted. I discovered that waiting for him to continue led to him revealing a depth of understanding about the research topic, unlike some of the other participants. Whether this was due to Alf's level of education or his interest in research, I am not sure. He was insightful, however, as the following comment demonstrates:

> I feel sorry for the person who's I can't say semi-literate, but say a half bit literate, you know reads the paper, gets a couple of papers

delivered every day or whatever, and they believe what they read in the paper, cos [because] that's all they have. (Alf,📷)

Laughing, he continued:

you'd be driven crazy, I mean coffee's good for you one day, the following day it's bad for your heart. Or its lousy for your kidneys or whatever. I drink six cups of coffee a day, and I don't think I'm going to crock [croak] from it [laughing]. If I did, I'd be dead already. (Alf,📷)

While Alf was discussing this during an in-depth interview, the issue of coffee consumption was covered at length on the HeartNET site. Sabrina had posted a link to a British Broadcasting Corporation report (BBC News, 2008) indicating that "daily caffeine might not be so bad after all – it protects the brain", continuing "thank goodness for that!" (Sabrina,💻). There was an immediate response with many of the members aware that even though coffee is not 'good' for heart patients they were still drinking it, sometimes in significant quantities. "Where would I be without it, hate to think" (Sabrina,💻). Raewyn, Sam and Donna all continued the thread stating how they loved their coffee.

Well at least something I drink is good for me ....allejua (wrong spelling I know but I guess you know what I mean)...I love my coffee! (Raewyn,💻)

There are many things that we must as cardiac patients give up for the betterment of our health. BUT I REFUSE TO GIVE UP MY MORNING COFFEE [obviously I haven't had my first cup yet, otherwise I WOULDN'T BE YELLING ARGGGHHHHHHHH] lol. I figure with all the drugs they give us to control our hearts rhythm's etc., a little DOSING up can't be that bad. Hail oh Cup of Coffee for thou art great! (Sam,💻)

I treasure my morning coffee. I only allow myself one cup a day so bought myself the biggest mug I could. Yea, I know, only fooling myself, cos it really holds the equivalent of two mugs. Better than the five or six strong ones I used to drink (Donna,💻).

I was fascinated by Alf's insights and thoughts about the media. He was obviously a well-educated man and believed that progress had advanced heart treatment considerably. He recalled his father having major heart bypass surgery which necessitated a 3-4 week hospital stay. Alf stated that his heart surgery only took an hour and he was home the next day. This discussion came about when he suggested there should be a quarterly newspaper that focuses upon the latest

advances in heart disease treatment. He immediately followed this by stating "not that most people would be interested in reading it, because a lot of people are shit scared about the whole thing" (Alf, 🎦). Alf tended to contradict himself at times, speaking rapidly and then elaborating on issues he thought important while disregarding some questions posed to him. He felt that while newspapers were important, when someone was faced with major health issues the newspapers they read are:

> Not what people remember, it's not what they read in the paper, or what they see in a production, or even the information they get from their doctor. They remember the trauma their brother went through or their uncle or somebody, and they think it's going to happen to them and that's what makes them scared. (Alf, 🎦)

Personal stories and knowing the individual in the story are both features of the HeartNET community. Roberta, another non-HeartNET participant, confirmed what Alf had said about being driven crazy by all the news about drinking coffee or eating chocolate. Members on HeartNET had also posted about chocolate consumption, and how it was no longer considered healthy. Others argued that there is now evidence that a small amount of dark chocolate daily does minimal harm to one's health due to the antioxidants and flavonoids dark chocolate contains (Collins, 2005). Roberta was upset because she perceived that she no longer had choices when it came to shopping.

> Yeah, and they're taking a lot of choices away, that's what I'm getting angry with, cause one year they tell you coffee does this, gives you cancer. And the next year its sugar. You can drink as much coffee, then its chocolate. You'll get fat. And then they tell you, you can have chocolate. And it goes on and on and you go to the supermarket and all these health things they say you shouldn't take, they're all lined up. Where's the health inspector saying "No you can't put that on the shelves?" But you've got no choice. There taking every choice away and I know I hate shopping now! (Roberta, 🎦)

During the research, the Heart Foundation issued a statement in *The West Australian* to say that drinking red wine or coffee and eating chocolate does not help lower the risk of heart disease. They stated there is more evidence that eating fresh fruit and vegetables and drinking green tea or black tea is more beneficial. While red wine, coffee and chocolate do not need to be avoided, they should be eaten in moderation (Pownell, 2010). A follow up media report outlined a review by the

Heart Foundation on the antioxidant effects of drinking red wine or eating dark chocolate, reiterating that there was no benefit to consuming chocolate. This article reported that the best way to get antioxidants was through a healthy diet containing fruit and vegetables. There was some evidence that tea did lower heart attack risk, but adding milk negated some of its effects (Rose, 2010). The Heart Foundation recommends nutritious food, exercise and sleep as necessary for optimal health, and overall moderation is recommended. Goldsmith (2010, para. 3) contradicted this finding, stating that eating modest amounts of chocolate may lower cholesterol in some people, and there was some evidence that "eating moderate amounts of cocoa could be a 'worthwhile dietary approach' for preventing high cholesterol in certain groups of people". However Goldsmith also found that there needed to be more research undertaken.

7.7   Lifestyle Issues or Plain Bad Luck?

On several occasions the issue of how the media portrays heart disease invoked some intense feelings, especially among participants who were not overweight, healthy, non-smokers and (in one case) a non-drinker with no family history of heart disease. Simone became quite emotional when discussing this issue. Very young, fit and healthy pre-heart event, she felt the media tended to focus on specific aspects of heart disease with which she couldn't associate personally.

> I find that what's in the media is probably saying that if you don't do things right, then this'll happen, but if you do it…it implies that if you do everything right that it couldn't possibly happen, so it…yeah. […] Yeah. Yeah. I actually, and sometimes I feel annoyed by it because I feel like I'm being judged because I have a heart issue, as though, well maybe I deserved it, because I didn't do what I…which is a bit of a cut and dried way of saying it, but that's how I feel sometimes. I feel like I'm being, "Oh well you can't have looked after yourself the, you must have smoked or did you drink then? Did you have a bad diet? Didn't you exercise?" And I did all the right things. (Simone, ☷)

This sense of being judged distresses Simone. Later in the interview she returned to the issue of how the media portrays heart disease and the effect it had on family members.

> Well I think they see it, they portray it as something that happens if you don't do the right things. Yeah. I think lifestyle choice, I

definitely don't think they show the whole picture, they only show one part of it. And perhaps the statistics of people who suffer heart disease are greater in that area, but yeah. […]. I'm not saying that what they show is not real, it's just I don't think they show a complete picture, and a complete picture can really change the way people think about something, I feel. I don't have a victim mentality, but I feel like I'm a victim to something beyond my control and it's no different to, well it is very different, you know, people who get hit by a car or suffer some kind of ailment…There's just so many things wrong in the world, I don't know how to say it without it sounding like I want people to feel sorry for me. I don't. But I just don't want to be judged as having done something wrong. That's all. (Simone, 📷)

This perspective was also voiced by several of the other women I interviewed. Abby, quietly sitting sipping a coffee looked straight at me and said:

The impression I have is that it is your own fault if you have a heart attack because it's a lifestyle issue […] but my attitude certainly went more to that way, that most heart disease could be prevented, and I don't think that's true actually. (Abby, 📷)

Even though Abby dismissed the issue as a lack of public understanding, it obviously caused her some distress.

It is not just the women who feel the media portray heart disease as a lifestyle issue. Jeremy felt that:

they [the media] portrayed it as the human condition under a lot of living conditions. You know it's all preventable but we'd have to change our lifestyles. You know it's the processed foods, the lack of exercise. You know we all work too much you know in sedentary jobs and things like that. Different to the way we should behave being as humans. Working with our hands out in the open from dawn to dusk and then eating [a] healthy meal of an evening or something. I just think it's our lifestyle, I think that's what we do with our hands, the excesses. (Jeremy, 📷)

Jeremy was one of the few participants who agreed that lifestyle, for him especially, was a major factor in his heart disease. The two women Simone and Abby felt that although they had lived a healthy lifestyle, it was automatically assumed by both friends and health professionals their heart disease was self-inflicted. Jeremy was in a difficult position. While he was aware that lifestyle was a factor for him, and admitted to knowing that diet and lifestyle were important post-heart event, when I questioned him further, the conversation took a humorous turn. We had just been discussing the use of statins [cholesterol medication] as a

preventative measure post heart event, an issue that Jeremy was passionate about. He disliked intensely having to take them. He was discussing the possible side effects this medication could have.

> Jeremy: Most doctors overuse it [medication] because it has severe side effects on other parts of your body, your liver and your kidneys
>
> Lynsey: Its frightening isn't it?
>
> Jeremy: It is yeah. So I've sort of been in the back of my mind thinking what I've got to do to try to keep my cholesterol down, you know through natural means, eating, my diet basically
>
> Lynsey: Yeah and your fruit and veges and stuff
>
> Jeremy: Animal fats and trans fats and things like that try to eat things, porridge and all the stuff that's good for you
>
> Lynsey: And is it working
>
> Jeremy: Haven't started it yet!
>
> Lynsey: So it sounds good in theory
>
> Jeremy: Yeah that's my theory (Jeremy & Lynsey, ☎)

My response was something like "oh I love it" and "let me know how it works". While Jeremy knew that lifestyle changes were necessary for optimal health, he had not put this into practice.

Balnaves and O'Regan (2010) contend that "audiences are sensitive about how they are represented and about how information about them is used" (p. 462). Market research studies indicate that Australians do not necessarily trust the media, with many people believing the "media often get their facts wrong and invade people's privacy unnecessarily" (RMR, 2004, p. 10). One thousand nine hundred and sixty three Australians aged fourteen and over participated in the *Media Credibility Study* (RMR, 2004) and were asked what they thought about the media? The key findings include that newspaper journalists are held in low esteem especially when compared to doctors or police. Participants also felt that accuracy of the facts reported by journalists was an issue, and many believe that when mistakes are made, there is often no effort to rectify the issue. This was confirmed by journalists who stated that mistakes were often not clarified (PMR, 2004). So, while the media can be a useful

tool to help people to investigate the world "outside their own experiences" (Kosicki, McLeod & McLeod, 2011, p 543), and to "form impressions of the relative importance of various topics, make judgements ... about issues and form opinions about the issues of the day" (Kosicki, et al., 2011, p 548), it is still the case that many viewers and readers are sceptical about the accuracy and credibility of material published.

7.8   Summary

The media is an important channel for the dissemination of information to the general population. Australia has little diversity in ownership of the major Australian newspaper press. There are few alternative voices. This chapter outlined the influence the media has on people's behaviour and on their subsequent health care. There is evidence that the quality and accuracy of information in the media is sometimes suspect.

Initially it was thought that HeartNET members would discuss media issues on the site, but in reality they would discuss celebrities and sports stars that were diagnosed with heart disease, or provide obituaries for high profile individuals.

Television allows people to immerse themselves into another representation of reality, with many people getting their health information from watching popular medical dramas. There is significant evidence that people are unaware of the actual symptoms of heart disease and chose to believe television portrayals of symptoms instead. Makeover and reality shows allow a small number of average people to become celebrities, and the media often uses these 'stars' to promote health information.

The media also emphasises issues such as lifestyle as a cause for heart disease. While HeartNET members agreed that lifestyle was a key factor, they also felt too much emphasis was placed on this, and other equally important issues were often neglected.

The following chapter investigates and codes the heart-health-related articles published in two Australian newspapers over a four month period from March 1 to June 31st 2010. It explores how the print media specifically portrays heart health information to its readers and how the impact (or not) on discussions on HeartNET.

CHAPTER EIGHT:
MEDIA ANALYSIS

8.1   Introduction

> News is no longer a series of monolithic reports each entirely true
> and complete. Like life, news is a work in progress – a rolling tide
> of updates each modifying the last (Robotham, 2006, p. 480)

This section explores the role news media plays in providing medical information to the public. Diseases and medical conditions are frequently discussed in mainstream media, with most newspapers having a dedicated 'health' section. *The West Australian*, a Perth-based daily newspaper, has a regular weekly health section which provides up-to-date coverage of medical issues and treatments. *The Australian* is a national newspaper which also has a dedicated health section and health editor. There is some indication that lay people read the reports found in newspapers and then use this information to make decisions about their own health. Anecdotal evidence suggests that "members of the public often base their opinions on what they have read or heard in the press and, subsequently, press cuttings are presented to doctors and become the basis of discussions about treatment decisions" (*Media+Doctor*, 2013, para 2). However, Jones found "newsworthy topics may not necessarily correspond with established health care priorities or even emphasize key concepts of the disease in question" (cited in Donelle, Hoffman-Goetz & Clarke, 2005, p. 187).

Two print media newspapers *The Australian* and *The West Australian* were surveyed for articles that related to or mentioned CVD, heart disease, heart attacks or the Heart Foundation over a four month period in 2010. The articles were sourced through the online database *Factiva* and articles were excluded if they did not meet the heart disease-related criteria. In total, 108 articles met these criteria and "these stories form the prompts judged available to members of the HeartNET online community" (Uridge, Green, Rodan & Cullen, 2014) which are elaborated on later in this chapter.

This chapter explores whether HeartNET members identify and then discuss media stories related to heart disease on the site. It investigates the lived experience

of HeartNET members and their response to the mass media's portrayal of heart disease.

8.2   Media Literature on Health Reporting

The Australian Press Council "advocates a conservative careful approach to health and medical reports" (cited by Wilson, et al., 2009, p. 4831). Public relations consultants/agencies are often retained by major pharmaceutical companies who "use active media strategies but these are designed to promote specific products rather than inform the public about health" (Wilson et al., 2009, p. 4831). These public relations consultants can be "behind the scenes providers of information and access to important sources of medical news production" (Furlan, 2012, p. 102). This is especially true when pharmaceutical companies are involved in the research and provide pre-packaged public relations information to reporters.

According to the Australian website *Media and Doctor* "the coverage of medical treatment in the lay press is regarded as poor and is prone to exaggeration in order to create unnecessary sensationalism" (Media+Doctor Australia, 2013, para 3). Companies using public relations organisations tend to highlight the benefits of their products while under-emphasising any negatives. When released to the media the "press releases often form the basis for stories in the lay press [they] are sometimes used directly without attribution" (Media+Doctor Australia, 2013, para 3). This was apparent when analysing the articles featured in *The West Australian* and *The Australian*. Readers were not always made aware of the commercial motivations underlying the 'news' coverage.

Smith, Wilson and Henry (2005) also reported concern about levels of honesty in media coverage of medical breakthroughs. They found that media releases about new medications were often prepared by public relations companies, lacked full disclosure of information and that any links to pharmaceutical companies were often omitted from newspaper articles. Of the 108 articles analysed, only one acknowledged that the research cited was linked to a pharmaceutical company.

The mainstream media often discusses medical conditions or diseases such as heart disease and cancer. The importance of this coverage is reflected in the fact that *The West Australian* has a regular weekly health section and health reporters, while

The Australian has a dedicated health section and a specialist health editor. While this commitment to informed coverage should allow for up to date, relevant and realistic treatment of health issues in these papers, this is not always evident. Bubela and Caulfield (2004) identify a range of issues that occur in the mass media. One problem is inaccurate media reports, including the rehashing of incomplete press releases in which benefits and risks are not clearly identified or where these are underplayed. Another concern centres on medication breakthrough announcements which may be incomplete or fail to elaborate on risks, benefits or costs. There is also evidence that scientific breakthroughs often receive significant media attention, even though the importance of their findings may not have been validated by the scientific community via expert peer review. People reading about these breakthroughs may be either skeptical or worried, resulting in doctors' waiting rooms becoming filled with "the 'worried well', resulting in part from 'scare stories' and unfounded claims" (Brown, 2004, p. 1).

Alternatively, medical sources may differ from media sources in what they judge to be newsworthy. Frost, Frank and Maibach (1997, pp. 842, 844) believe the "amount of copy space is an important indicator of perceived newsworthiness," with news reporting often driven by "rarity, novelty, commercial viability and drama more than concerns about relative risk" (Felton, 1997, p. 507).

Such a variety of advice and the diversity of sources can make assessing and interpreting news stories difficult, especially when trying to determine the value of the information available. The challenge of identifying quality commentary was confirmed by the US-based Association of Health Care Journalists, cited by Van der Weyden and Armstrong (2005, p.188), who argue that "journalists have a special responsibility in covering health and medical news, [including] professional standards of truth, accuracy and context in every report". These principles are discussed by Van der Weyden and Armstrong (2005), who maintain that journalists need to remain vigilant when sourcing material; have an understanding of the medical process; avoid writing sensational or vague reports; and include both positive and negative research outcomes. In contrast to an emphasis on the journalist's duty to report accurately, Donelle, Hoffman-Goetz and Clarke (2005, p. 187) suggest that the media has an entrepreneurial obligation to "publish information that promotes circulation rates and increases profits." They state that "newsworthy

topics may not necessarily correspond with established health care priorities or even emphasize key concepts of the disease in question" (Donelle, Hoffman-Goetz & Clarke, 2005, p. 187).

Corrigan et al., (2005) suggest that an analysis of media stories should be undertaken on a regular basis to determine how various health issues are portrayed. The following section analyses news stories published in two Australian broadsheet newspapers over a four month period in 2010 and identifies the relevance of this coverage is to the daily experience of people living with heart disease.

8.3   Thematic Analysis of News Articles

Two print media newspapers, *The Australian* and *The West Australian,* were surveyed for any articles that related to heart disease, heart attack, cardiovascular disease or the Heart Foundation over a four month period between March 1st and June 30th 2010. These articles were sourced from the online database *Factiva*. One hundred and ninety (190) relevant newspaper articles were initially identified. Articles were excluded if they did not meet the eligibility criteria or if they did not actually discuss the topic of heart disease. Often the title would mention heart disease issues, but the content would not. In all, 108 articles met the criteria and were included in this study, with 67 articles sourced from *The West Australian* and 41 articles from *The Australian.* The media articles reviewed were assessed for content, accuracy, worth and value (Bubela & Caulfield, 2004). The postings on HeartNET about media articles were also examined. A key finding was that the focus of the HeartNET community mainly related to lifestyle issues and high profile individuals who self-identified as having heart disease.

According to Wilson et al., (2010), the majority of articles appearing in Australian newspapers are written by generalist reporters. *The Australian* and *The West Australian* however, have dedicated medical reporters and health editors. Wilson et al., (2010, p. 2) also believe that the "stories written by specialist medical reporters [are] superior to those written by other groups". The research undertaken by Wilson et al. (2010) identified five key sources (see Table 3) for news stories appearing in the Australian broadsheet media. These included (i) no byline, (ii) general journalist, (iii) overseas media, (iv) news organisations and (v) specialist health journalists. The articles identified for the current research have been

categorised according to these attribution definitions, and appear in Table 3 below. In the dataset in Table 3, the majority of articles had no byline, while the rest were either written by a general journalist or a specialist health journalist.

Table 3: Category and Definition of Media Journalists

Category*	Definition	Number of articles
No byline:	All articles that did not identify authors	56
General journalist:	A Google search on the author's name revealed no reporting speciality	39
Overseas media:	Story imported from an overseas media outlet (e.g. *New York Times*	1
News organisations:	Story bought from a news syndicate, such as Associated Press or Reuters	0
Specialist health journalists:	A Google search identified the author as being a 'health,' 'medical,' or 'science' reporter	12
Total		**108**

(Source: Wilson, Robertson, McElduff, Jones & Henry, 2010, p. 3).

Reporters currently face issues related to the material to which they are given ready access. Media outlets are often inundated with material from multiple sources including individuals, researchers, government agencies and businesses. The reporter must determine the quality of the material and "interpret often impenetrable statistics and health jargon" (Wilson, Bonevski, Jones & Henry, 2009, p. 1), before submitting the article to the editor of the day for final approval and publishing. Broadsheet newspapers such as *The Australian* and *The West Australian* may have to source and purchase stories from foreign media outlets or other news organisations which can in turn affect the quality of the story. Knowing the source of information provided to the newspaper is an important indicator of quality for journalists and readers (Kovic, Lulic & Brumini, 2008), especially given the ready access to online health information and medical blogs, which may have content that is not credible or reliable.

8.4 Framing

Framing refers to a concept which aids in understanding the focus, limits and information included in a story carried in the media. Entman (cited in Harding, 2010) states that the framing of articles is important. He identifies major elements of framing, selection and saliency as particular priorities. He describes "selection as deciding what elements of reality to include while saliency involves making those aspects more important in the audience's mind" (Entman, cited in Harding, 2010, p. 20). A focus on saliency is particularly important as there is an emotional connection between a reader and the content of the article. Hallahan (1999, p. 206) asserts that "framing is conceptually connected to the underlying psychological processes that people use to examine information to make judgements and to draw inferences about the world around them". Framing is an effective public relations tool and many press releases are sent to reporters with a suggested frame already identified. Framing is accordingly "a critical activity in the construction of social reality, because it helps shape the perspectives through which people see the world" (Hallahan, 1999, p. 207). How an article is framed can have a major impact on the effectiveness of the message and reader response may "depend on several factors, such as the receiver's degree of attention, interests, beliefs, experiences, desires and attitudes … [the framing providing] an invitation or incentive to read a news story in a particular way" (Van Gorp, 2007, p. 63). These subtle practices influence the public's "interpretation of the media" (Davis, 2010, p. 122).

Donelle, Hoffman-Goetz and Clarke (2005) identify the importance of framing to reader response, and believe that current mass media use three major frames when discussing health and disease. These are lifestyle, political/economic, and medical. While lifestyle perspectives tend to present "diseases and death as the result of faulty lifestyle choices made by individuals" (Clarke, 1991, p, 291), the political perspective focuses on how disease can be a result of inequities such as socio-economic status and ethnicity. It has been well-established that these population characteristics affect morbidity and mortality rates among people with heart disease (Clarke, 1991). The medical model reports on issues such as advances in treatment, medication usage and disease prevention, and often criticises non-medical or holistic treatments as risky alternatives to conventional approaches.

The articles that appeared in *The West Australian* and *The Australian* between March 1 and June 30, 2010 will be explored using (i) lifestyle, (ii) political/economic and (iii) medical frames. These sections will be followed by a discussion of the major organising cues used by HeartNET members to frame their comments in the research. These predominantly refer to (iv) gender (in Heart Foundation advertisements), (v) recognition of symptoms (again, in Heart Foundation advertisements) and (vi) celebrities who self-identify as having heart disease.

8.4.1   Framing – lifestyle

Lifestyle is a major focus of the media, especially in stories related to heart disease and other 'preventable' medical conditions. Of the 108 articles identified in this research, however, only two discussed the lifestyle issues of heart patients. The first article discussed Alzheimer's disease, with Saunders (2010) reporting on the link between lifestyle, heart disease and Alzheimer's. Closer investigation reveals that this article outlines the need for increased funding into Alzheimer's due to the ageing of the Australian population, rather than a clear focus on heart disease. The second article discusses the implications for men's health of growing prostate cancer rates. Francombe (2010) highlighted that men are dying five years earlier than women and are more susceptible to heart disease and cancer. While no one interviewed during this research made a connection between prostate cancer and heart disease, one member posted on HeartNET that her partner had risk factors for a potential heart event, but refused to see his doctor. Several of the male members stated that they saw their GP annually for a cholesterol check and their GP routinely did a prostate exam at the same time. As Jason reported: "and they do the manual prostate test as well, doesn't hurt, well just the ego maybe! had that last year. No worries, passed both!" (Jason,⌨).

Lifestyle changes are regularly addressed on HeartNET, with many of the members discussing how they have had to make changes to their daily activities.

> I have returned to living life to the fullest. After my diagnosis, I found myself searching for answers and trying to cope with a wide range of emotions and issues that suddenly surfaced. Admittedly, I felt quite sad at first due to the lifestyle changes I had to make. I did not have a lot of control over how they changed. For my health's sake I try to think of coping with heart disease as a door being opened, not closed. I have tried to approach this new chapter in my life as a challenge, not as a defeat. One thing I think we all

have in common here is the disorientation we feel while doctors
are trying to make the right diagnosis. (Clara,🖵)

8.4.2   *Framing – political/economic*

Health funding is an important part of the Australian health care system and according to the Australian Institute of Health and Welfare, it is "a shared responsibility of all levels of the government of Australia" (Australian Institute of Health & Welfare, 2013, para 3). Australian States and Territories are responsible for providing many of the health services and programs, while the federal government has traditionally been the key financial provider (van Gool, 2007, para 9). In an article appearing in *The Australian,* political reporter Fiona Armstrong investigated financial aid for health reform under the Gillard government. She states that the "federal government said it would lighten the load by increasing its share to 60 per cent of the funding for hospitals, partly assisted by its appropriation of 30 per cent of the states' GST revenue" (Armstrong, 2010, para, 10). Even at that time, the reality appeared uncertain, while the Abbott administration has recently used their first budget to argue for a huge return of funding liabilities for health and education to the States and Territories (Armstrong, 2010).

The historical uncertainty can be seen in an article that appeared in *The West Australian* in March 2010. It started by discussing the Barnett government's (Western Australian state government of the day) "proposal to slash funding for library books by up to 40%" (The West Australian, 2010). Towards the end of the article there is an abrupt change in focus with the slash in library funding suddenly relating to resources for suicide prevention. The article then discusses the Western Australian Government's provision of much needed funding to *Lifeline* which "provides all Australians experiencing a personal crisis with access to online, phone and face-to-face crisis support and suicide prevention services" (Lifeline Services, 2013). The article also refers to the Australian Network Ten newsreader Charmaine Dragun, who committed suicide in 2007. It concludes by stating that "suicide causes more deaths among Australians aged up to 44 every year than cancer and heart disease combined" (The West Australian, 2010, para.8). So with only a brief mention of heart disease, an article which could be about resources for suicide prevention and the promotion of mental health is framed as a cut to library funding.

On HeartNET Veronica identified government funding cuts as a big personal issue. She posted that the media had highlighted the importance of cardiac rehabilitation, but reported that "our hospital is no longer going to fund cardiac rehab. I couldn't believe it, the support in a small community is limited anyway and then they take away the one good thing about having heart disease. Government and funding?????" (Veronica, 🖥). This post caused grave concern amongst HeartNET members as the majority were aware that "cardiac rehabilitation increases physical fitness, lessens coronary risk factors and improves psychological health and quality of life: [and] it also improves prognosis" (Bethell, Lewin & Dalal, 2008, p. 677). Staff at Veronica's local hospital had been volunteering their expertise to run the rehabilitation clinic, but due to increased work pressures they were no longer able to commit to the role.

HeartNET members posted messages of support and over several days members were informed about how the campaign to maintain the clinic was progressing. All agreed with Bethell et al (2008) about the importance of cardiac rehabilitation, with Denise stating that after a heart event it:

> would be a great shame for it to close as there is evidence of better outcomes for patients who go through cardiac rehab and also a great confidence building thing to have someone tell you how to exercise and monitor you so you feel safe rather than being left on your own and not feeling certain you're doing it right. (Denise,🖥)

Finally Veronica posted a positive outcome to her story:

> back in the paper today. Looks like some of our nurses are going to give up holidays to get through the back log of people needing rehab […] today's headlines, Cardiac Rehab will stay. Nothing like a lot of negative press to get things moving. (Veronica,🖥)

Funding priorities were a major issue for many HeartNET members, with some members highlighting issues they identified as State rather than Federal, responsibilities.

> Our health system is probably one of the best in the world, its just a pity that the politicians have to play around with it like a football…They just need to finance the various health systems in each state appropriately rather than spending money in coverup advertising campaigns to try to convince the masses that they're doing such a wonderful job. (Sam,🖥)

Polly's perspective is that:

> the health system seems to be struggling all over Australia, especially when u listen to the plight/fight of some of our members here on HeartNET..BUT there does seem to be some states that are doing it better than others for what ever reason! I personally think it sucks that the calibre of health help seems to depend on location LOCATION! (sounds like a real estate ad!) Existing Funding and Infrastructure or the lack thereof! Be interesting to see how things pan out with the current financial crisis, some hospitals fudging targets to keep the govt funding they currently have and to earn the govt financial bonuses (offered as incentives to meet targets)just to stay afloat!!! Sounds like a vicious circle doesnt it?! (Polly,⌨)

While these issues are especially relevant for heart patients, much of the media coverage during this time period highlighted issues with funding for mental health. Vasek (2010) reported that there "needs to be more government leadership on this ... Mental health is just as important as breast cancer awareness and heart disease". This was reiterated by Cresswell (2010), who reported that the online political pressure group *GetUp* were arguing that more funding was required for a "health problem that accounts for 14 per cent of Australia's health demand, and only 6 per cent of its funding, while being the leading cause of death among Australians under 45 -- larger than the road toll, cancer and heart disease – [this sector] needs an overhaul".

While it is beyond the scope of this research to discuss the political implications of health care funding, it is important to know that this remains a very relevant issue for people affected by heart disease, including the members of HeartNET, and was one of the 'trigger points' prompting discussion on the bulletin board.

8.4.3   Framing – medical

The medical and economic implications of heart disease are a major issue for people aged fifty-five and over. On May 19, 2010, a feature article in the *West Australian* titled *Five-year heart warnings for over 55s* (2010, para 1) highlighted recent findings that half of all Australians over fifty-five were at risk of having a heart attack or stroke over the next five years. This age cohort was described as a "generation risk," with those most at risk being the physically inactive, the overweight or obese, and those with high blood pressure and high cholesterol. Further, a number of people in this age group including some HeartNET members, choose not to take their prescribed medication which is supposed to protect them

from some key risk factors. One cautionary factor recognised in the article relates to the fact the study underpinning this report was commissioned by a drug company. In this circumstance, it is possibly unsurprising that one 'take home message' is to encourage the use of "medications for conditions such as high blood pressure (HBP) [which] can reduce an individual's risk of heart attack or stroke, but are grossly under-utilised in the long term" (The West Australian, 2010, para 3). There was evidence in this study that some people ceased taking medication for high blood pressure less than a month after prescription. The article also states that the "over 55s now represent one quarter of the Australian population and, with population ageing, this [proportion] will only increase, bringing with it a dramatic rise in the level of cardiovascular disease" (The West Australian, 2010, para 10).

While consideration of this factor is beyond the scope of this thesis, the article in the *West Australian* and the one by Adam Cresswell, *The Australian's* health editor, both mentioned the involvement of pharmaceutical companies. Cresswell noted that more than 1.1 million Australians aged fifty-five or over are at risk of heart diseases or stroke. He claims that almost "50% of Australians in the over 55 bracket [were] facing at least 15% [risk] of cancer or cardiovascular attack in the next five years" (Cresswell, 2010). Quantifying the 15% risk somewhat mitigates the more sweeping impression provided by the *West Australian's* focus on 'half' of over fifty-fives being 'at risk'. The *Australian's* (Cresswell, 2010) article highlighted the need to continue taking prescribed medication. However, Cresswell did comment on "warnings to treat the report with caution as it was commissioned and financially supported by the German drug giant Boehringer Ingelheim". He also highlighted the fact that "1 in 5 people stop medication after 1 month [and] 80% stop taking these medications after 30 months" (Cresswell, 2010, para 7). Included in this article was a comment by a University of Adelaide spokesperson who stated that "past experience has been that when drug companies support press releases, they do not always provide balanced information" (Cresswell, 2010, para. 9).

The media and the Internet continue to provide information which often causes more distress than assistance. Clarke and van Amerom (2008, p. 98) state that the media often relies on reductionism to portray the "body as a function of its individual parts". The following news article about cholesterol-lowering medication, an intervention prescribed to many members of HeartNET, uses an analogy drawn from

the Hollywood movie *The good, the bad, the ugly* (Leonie & Grimaldi, 1966). It discusses the effectiveness of cholesterol-reducing statin medication.

> Think of it as a remake of a Hollywood movie starring a cast of familiar characters: the good cholesterol (HDL), the bad (LDL) and the ugly (heart disease). The heroes are diet, exercise and a class of drugs called statins that cut cholesterol levels sharply by blocking a liver enzyme involved in cholesterol production. (Smith cited in Clarke & Van Amerom 2008, p. 98)

HeartNET members often use the site to comment about their struggles with taking anti-cholesterol medication. The following interactions occurred on the site and while both women involved in the discussion ultimately chose not to continue with their cholesterol-lowering medication, this was done with medical approval.

> well i can't take any form of col. [cholesterol] lowering drugs, they crash my liver. didn't have col before the heart event and don't have it now, so could see no point in being prescribed it. a Dr in [my home town] i see said should be no need for it. good rittens to bad rubbish as far as i'm concerned (my opinion only). i'm a believer that too many people are prescribed col. lowering drugs when they don't need them. (Jemima, 🖥)

> I agree, and it is only my opinion too. I am now off [cholesterol medication] and am determined that I will never touch a col lowering drug again. I will control it with diet. My normal cholesterol is good, it is my triglycerides that is high, so that is a goodie to control by weight management and diet. I also have no problems with my arteries, so never again. They really kicked me around. I am having a blood test today to find out how much damage was done. (Annabelle, 🖥)

> The sad thing is that sometimes some websites/sources give too much importance to a rare side effect and scare people away. (Louise, 🖥).

> I don't know what to think about statins these days, there's so much controversy about them. I read about it in the media and on the 'net but just can't work out the truth of it all. I think the best we can say is that the science on heart treatment is still a work in progress.(Susan, 🖥)

The debate around cholesterol medication remains an ongoing discussion on HeartNET.

8.4.4   Framing – gender representations

Most articles that portray heart disease in the media show middle-aged white males as the potential or actual victims. This was particularly evident during 2010 with the regular screening of a television advertisement released by the Australian Heart Foundation, I *wish I could have my heart attack again,*. The TV commercial highlighted the risks of ignoring heart attack symptoms (Heart Foundation Australia, 2009). This forty-five second advertisement explained the symptoms of heart disease and how the person experiencing these symptoms should seek immediate medical attention. The final scene shows the heart attack victim – a man lying on a slab in the morgue who having taken no action, has died.

When interviewed, two members of HeartNET commented on the fact that heart disease clearly affected women as much as men, but all the advertisements they had seen were related to middle-aged men, despite clear evidence that heart disease and stroke are the leading causes of death among women (Mosca et al., 2004). According to Armstrong, Carpenter and Hojnacki (2006), focusing on specific population groups as a means of identifying a disease cohort is not new. They identify the effects of politics and social movements by activists and researchers in health areas such as HIV/AIDS and breast cancer. This awareness of stereotyping has resulted in improved social support and access to drug therapies and treatment regimens. While "the numbers of organisations with a primary interest in heart disease is large and has grown, this community had not experienced the degree of expansion that occurred amongst AIDS organisations during the same period" (Armstrong, Carpenter & Hojnacki, 2006, p. 20). Although many more people in Australia are affected by CVD than by HIV/AIDS, this is not reflected in the research and other attention paid to heart disease.

Similarly, while heart disease remains the leading cause of death worldwide among women, it is "breast cancer that attracts much more organised interest, group attention and activity than doe's heart disease" in the media (Armstrong, Carpenter & Hojnacki, 2006, p. 35). This is confirmed by Clarke (2008) who found that breast cancer research received significantly higher funding than heart disease, when researching the representation of heart disease and cancer in the Canadian media,. She states that "*The Star* (a high circulation daily newspaper in Canada) was found to run three times the number of stories on breast cancer as heart disease" (Clarke,

2008, p. 19). This disproportionate coverage persists, even though more people, especially women, die of heart disease each year (Armstrong, Carpenter & Hojnacki, 2006).

8.4.5   Framing – symptom recognition

The National Heart Foundation of Australia posted the following request on the HeartNET website:

> The Heart Foundation is eager to hear from people aged between 30 – 64 years of age who acted quickly to the warning signs of heart attack so we can use their story in the media to reinforce our 'Will you recognise your heart attack?' campaign messages and motivate people to learn/know the warning signs of a heart attack and what to do. The campaign is being launched in early September. (HeartNET posting,⌨)

This post was in conjunction with the television advertisement *I wish I could have my heart attack again*. Although the HeartNET members were quick to respond, many posted how they had ignored their symptoms, reiterating the British Heart Foundation's findings that heart patients were often ignorant about relevant symptoms and doubted them instead of seeking medical treatment. In fact, many chose to ignore their symptoms (Hope, 2008). It was this kind of research which underpinned the *wish I could have my heart attack again* campaign.

Bianca, for example, had not identified the symptoms of her heart disease stating that: "I did not know I was having a heart attack. The symptoms were not what I had always thought: crushing pressure in the chest and this sort of thing" (Bianca, 👓). This perspective on expected symptomatology was also confirmed by Diana who, when asked what sort of health information she would like to see, responded:

> women's heart problems, you don't hear about women, you hear about men. At the moment there's an ad on TV and they rang 000, and it's a man. He's all like grey, and he's got tubes coming out his neck […] and he's lying on a morgue bed and that. And he's dead and it's him talking and he goes everything that happened to him. He goes, Tuesday I had a pain in my jaw here, and shows where he was in the house, and in the kitchen my shoulder started to hurt, I should have rung an ambulance then. And it's all the symptoms of having a heart attack and him saying, I should have rung for help then, I should have rung for help. And it's like you call first. Like it's trying to encourage people to call an ambulance if they need to. It doesn't matter, and after that it's got a doctor saying, it doesn't

matter if it's a false alarm, and that's the thing you want to have. The operator will help assist whether you need an ambulance, you've got to ring one to get one. It's like that sort of ad. (Diana,☎)

She continued that she would like to see this advertisement related to women as well, although as she was speaking her tone of voice changed. Diana became almost apologetic, explaining that she wasn't being a feminist or trying to be difficult, she wanted some information relevant to herself:

It's a man, I'd like there to be a woman ad too. I'm not sexist or a feminist or anything like that but so many women have things go. They're the ones who don't ring because they're busy going with their families and they've taken the check all the time and they're normal, until they have a heart attack and they're dead. That sort of, and you don't hear about what sort of research they actually are doing. (Diana,☎)

Most HeartNET participants have shared their stories with the Heart Foundation in the hope that it will inform media coverage and the outcome might "save people from their own complacency" (Sam,🖥) or "tell people the symptoms that i had and did not think were a Heart attack. Hopefully it can warn others to go to hospital. And have it checked out" (Bianca,🖥). Simon hoped that his story would encourage people who "don't feel right [to] make a fuss and go to hospital. As they say better to not need help than leave it to late and be beyond the need for treatment" (Simon, 🖥). A common theme throughout this thread was the fact that the majority of the general population do not understand the symptoms heart disease and that this was also true of HeartNETters prior to their initial heart event.

While these members are active participants in sharing their heart story with others and in the media, they have discovered there are still issues with the public's perception about what heart disease actually is.

I am finding it interesting that the more people I speak to in the media, the more I discover that most people in the community completely misunderstand heart disease. Everyone seems to have this "Hollywood" image of heart attacks etc., which is not what really happens. Equally, they seem amazed that it is actually possible to not only recover from a heart attack but actually thrive after it. (Sam,🖥)

Jamie agreed:

> I have had so many people ask how I can do what I am doing since my heart attack. Most of my friends are trying to tell me I can't do or at least shouldn't be doing what I am. My thing to them is my heart attack was not the end of life; it was the start of a new life for me. (Jamie,⌨)

Fred's post confirmed this misunderstanding. He had several heart events prior to joining HeartNET and had been admitted to hospital on several occasions with severe unexplained chest pain. Even Fred admitted that "out of the 5 heart attacks I've had I recognised 1. & that was the last one. The first was like heart burn & the others turned out to be Angina. The only thing they had in common? Chest pain." (Fred,⌨).

8.4.6   Framing – celebrity status sells stories

There is evidence that the use of celebrities assists the media by "giving a name, a face and a story" to the disease or medical discussion (Clarke & van Ameron, 2008, p. 100). Celebrities, according to Corbett and Mori (1999, p. 245), provide "a boost for both sustained media and medical attention." Nowadays celebrities come from all walks of life, however "a celebrity suffering from a disease may provide health professionals a boost in research funding, media publicity, and public awareness" (Corbett & Mori, 1999, p. 245). Celebrities or 'famous faces' are often introduced as people with a specific disease or as having a loved one with a disease, which promotes an emotional connection between them and the general public by "putting a face to the disorder" (Zhang et al., 2011, p. 41). Eventually, a few celebrities may become the public face for a specific condition. For example, the actor Christopher Reeve became a spokesperson for spinal cord injury and stem cell research, while Michael J. Fox speaks about his personal experience with Parkinson's disease (Zhang et al, 2011).

There is also evidence that a "celebrity cancer diagnosis can significantly influence public health behaviour, including the uptake of prevention programs" (Metcalfe, Price & Powell, 2011, p. 80). This project demonstrated that when a public figure was diagnosed, there was a subsequent increase in health screening. According to Chapman, McLeod, Wakefield and Holding (2005, p. 247), a celebrity's illness "can increase news coverage of health topics to levels that would ordinarily require campaign budgets". This was evident when Kylie Minogue was

diagnosed with breast cancer in May 2005. The general public appeared shocked and her diagnosis caused a media reporting frenzy. Chapman et al. (2005, p. 247) researched the media coverage of breast cancer prior to Minogue's diagnosis and compared this with the subsequent coverage. They found that "television coverage increased 20-fold" when the 'before' and 'after' periods were compared. There was also a "40% increase in average weekly [breast cancer] screening bookings made in the 2 weeks of publicity [… with] the increase most evident in females being screened for the first time" (Chapman et al., 2005, p. 248). What is now known as the "Kylie effect" had a positive outcome in terms of population health by increasing breast screening among younger women "and it might be expected that the 'Kylie effect' […] may further reduce cancer deaths" (Chapman et al., 2005, p. 249). However, a study by Metcalfe et al., showed that "news articles frequently neglect health promotion messages when reporting details of celebrity illness" (2010, p. 83).

More relevant for HeartNET, Lisa Curry-Kenny a former Olympic and Commonwealth Games gold medalist, experienced a heart event that necessitated the insertion of a defibrillator to regulate her heart function. Bronwyn, a HeartNET member who also has a defibrillating pacemaker fitted, posted about Curry-Kenny and while wishing her good health, also stated "It will be interesting to see how much more awareness is raised on heart conditions, defibs etc with such a high profile personality having problems" (Bronwyn, 💻). While there is no evidence that Curry-Kenny's heart disease has had anything like the same impact as Kylie Minogue's breast cancer diagnosis, it was felt by HeartNET members that Curry-Kenny's procedure would highlight the profile of heart disease. This can be seen in media reports following her diagnosis and surgery. All the articles examined stated that Curry-Kenny had a heart problem somewhere in the news story, even if the main topic was unrelated to her health or sporting prowess. For example, Caton's report in the *Tweed Daily News* comments that "the former sporting superstars turned high-flying property developers Lisa Curry Kenny and Grant Kenny may soon call the Tweed home. The celebrity couple's company is behind plans approved by Tweed Shire Council last week for two multi-million-dollar homes on the beachfront at Salt" (Caton, 2009, para. 1). The article then highlights that Curry-Kenny "had surgery to correct an irregular heartbeat. The three-time Olympian and winner of

seven Commonwealth Games gold medals had a special type of defibrillator implanted to correct an erratic heart rhythm" (Caton, 2009, para, 7-8).

While this sort of media coverage appears to be common and highlights the incidence of heart disease which can affect even elite sportswomen, it concerned some members of HeartNET. Those who had had pacemakers fitted could identify with Curry-Kenny's predicament and all felt having a positive attitude was vital to the recovery process. Having the media tracking her recovery would present an additional unwanted pressure, but HeartNET members also felt that it would highlight heart disease and raise awareness of the issues they faced.

> Now imagine going through all you went through in the beginning [of your diagniosis and] having the media swamp and be watching your every move, your every reaction and your every emotion? Thats a pressure no one needs! But the high media attention will highlight and make people more aware of how vulnerable life can be if we ignore the warning signs! I wish Lisa the very best for her recovery and hope the media will give her a little privacy too. (Lorraine,⌨)

All the HeartNET members felt concern for Lisa, but could also relate her distress to their own stories with Fred stating that "when Lisa cried "why me" there's 719 people here [on HeartNET at that time] who asked that same question. I do wish her a speedy recovery though" (Fred,⌨).

8.5   Summary

The media plays an integral part in people's lives. This chapter identified the key frames used in *The West Australian* and *The Australian* over a four month period in 2010. These frames were identified as (i) lifestyle, (ii) political/economic and (iii) medical. Examples of these frameworks have been identified and discussed. Three other frames were also identified via the conversations on HeartNET following this period of media coverage. They are (iv) gender (in Heart Foundation advertisements), (v) recognition of symptoms (again, in Heart Foundation advertisements) and (vi) celebrities identified as having heart disease.

Political/economic issues were promoted throughout the media, often through the use of celebrity or a key political figure, and the 'personality' provided a focus for the story. Celebrity 'hype', however, overshadowed the main themes or content of the coverage, leading to a lack of interest or desensitisation of the public

readership. Lifestyle factors play important roles in people's lives. Diet and exercise were accepted as integral components of healthy living. However, sometimes these factors were beyond the control of individuals due to income constraints, personal circumstances, educational opportunity, locality of residence and/or other environmental issues.

While medical issues have been elaborated, one key component that helped sell stories and facilitated health promotion was celebrity involvement in media stories. There was clear evidence that celebrity stories involving medical issues boosted circulation, increased sales and promoted an emotional connection with the public.

CHAPTER NINE:
CONCLUSION

9.1 Introduction

HeartNET was created in 2005 so its design is not as interactive as some of the newer support sites. There are around 900 members registered on the HeartNET database, but only a small core group access the site regularly and post about their heart health. Coronary Heart Disease remains Australia's largest killer with studies indicating that a large majority of heart patients do not follow the recommendations of their health practitioners. Instead they tend to deny the implications of their disease and delay seeking treatment.

9.2 Objectives

The original objectives of the project were to:

- evaluate the role of interactions on HeartNET by individuals in the early stages of assuming an identity as a cardiovascular patient;

- apply the theory of the gift economy to HeartNET participants;

- assess the influence of HeartNET in negotiating a positive self-concept; and

- identify whether media representations or health messages about cardiovascular disease influence interactions with others on HeartNET.

Whilst the objectives have been addressed throughout this thesis, a brief summary of the findings is provided below.

9.2.1 Evaluate the role of interactions on HeartNET by individuals in the early stages of assuming an identity as a cardiovascular patient

Over time, interactions on HeartNET indicate a change in participants' attitudes toward their heart disease. The gift of time, information and support were commodities that HeartNET members shared freely with each other. Newer members would often access the site at night time or in the early hours of the morning, usually when they felt at their most vulnerable, but did not want to disturb friends and family. Newly diagnosed heart patients would often enter the site, share their feelings, then leave and return later in the day to see if there had been a

response. Over time, there was a shift in focus from being 'needy' themselves to being supportive and encouraging to other newer members. With this support and encouragement it became clear that HeartNET members were willing to engage in the gift economy, sharing with, and assisting, other members in their recovery.

Access to HeartNET was cyclical. Use of the site would diminish over public holidays and at one point access by some of the more prolific users decreased markedly. After some investigation it transpired that many users were actively participating in gaming sites and using Facebook as a means of support. This led to them having less time available to access the HeartNET site. It is to be expected that people who enjoy online interaction would also enjoy social network sites and online social games.

Honesty and trust are key issues for the HeartNET members. Most of the time interactions are positive and supportive. There were incidences of perceived deception however, which led to aggression online and threats to take the issue further offline. At other times members felt they were getting too much support and felt they were not given enough opportunity to be honest and 'be miserable or sad'. An opportunity was created on the site for people to share their unhappy thoughts, but it was soon 'hijacked' by the more positive members and words of encouragement were shared. In cases where people are unhappy or disgruntled with the site, they will either leave or trigger dissent among other members. Ultimately a moderator may be required to step in and resolve these issues.

9.2.2 *Apply the theory of the gift economy to HeartNET participants*

A key finding is that HeartNET members share their time, support and encouragement, thus ensuring that the community continues to function. A common bond unites them and over time members can develop strong relationships. The dynamics of online communities mean that participants are not restricted by 'time', 'body' or 'space'. They are however, prepared to share with and encourage people they may have never met and whose identity may be dubious or fabricated.

HeartNET provides asynchronous access to its members. While the site is moderated some of the time, access is available twenty four hours a day, allowing members to post freely. This causes some issues. At times, responses to posts were immediate. At other times there may be a delay of several days or weeks. While I

could and did respond to response-less posts, it transpired that members generally want to interact with each other rather than with me as moderator.

Another significant finding to emerge from this research was a better understanding of differences between moderated lay communities and social network sites like Facebook. HeartNET provides asynchronous contact to users and if members wish to speak to each other in real time other than by accident, they must first organise a chat time and then meet each other. Connections on Facebook are public and linked to an individual's profile, with people likely to provide identifying information which is freely available to other Facebook users. In contrast the HeartNET terms of service recommend the use of avatars and pseudonyms. Facebook provides access to social gaming sites and this appears to be one of the reasons that the active membership on HeartNET waxes and wanes a little as members share their enthusiasm with other HeartNETters.

Information is freely shared on HeartNET, and this can range from advice on the most comfortable bra to wear to fit over a pacemaker, to how to modify recipes to be heart healthy or providing emergency information which allows members to feel more in control of their treatment and recovery. Some of the male members expressed their creative selves by sharing poetry and humour that may be suppressed in other environments.

Another key finding, among the non-HeartNET members participating in this research, was the importance of volunteering and how much it had become an integral and enjoyable aspect of many recovering heart patients' lives. All the participants volunteering at a local metropolitan hospital became peer supporters for people facing imminent heart treatment. Using heart patients in this volunteering role seems to support the extension of social networks and complements professional health services.

9.2.3 *Assess the influence of HeartNET in negotiating a positive self-concept*

Recreating oneself after a heart event is emotionally draining on the patient, their families, friends, and in the workplace. Initial stages of grief are often experienced and for some this may lead to chronic depression. The heart patient has to cope with an unknown and disrupted future which may be complicated by a lack of understanding from their significant other and extended network. As family

understanding wanes, accessing sites such as HeartNET can provide additional and beneficial support.

HeartNET allows members to document their heart story. Members can share their initial thoughts, emotions, fears and uncertainties. Sometimes and understandably, members would lack confidence in determining whether the pain they were experiencing post diagnosis was minor, or a precursor to another heart event. Initial posts would describe symptoms, visits to medical centres and significant anxiety. Over time, these posts would change in focus, with members expressing more confidence and independence, and they would begin to report on increased social interactions outside the home. For some, journaling their story provided them with an opportunity to see these improvements written down. They could chart the ways in which, over time, they had shifted from being vulnerable to becoming empowered and better able to deal with their heart health outcome.

While HeartNET members provide support online within the community, non-HeartNET members were often productive volunteers and provided information and support face-to-face in hospital settings. They freely gave their time to support people who were experiencing health issues similar to their own. One stipulation placed upon them when volunteering in one particular metropolitan hospital, was they were only able to support people who had the same condition. This meant there would be less confusion about information regarding treatment, procedures and recovery. It would not be reliable to deduce that all heart patients are moved to volunteer, just that non-HeartNETters who volunteered for this study were also likely to volunteer in other contexts.

9.2.4 *Identify whether media representations or health messages about cardiovascular disease influence interactions with others on HeartNET*

The research discovered that members rarely used HeartNET to discuss the media's coverage of heart disease. Instead members tended to write obituaries for celebrities or reserve their comments for when celebrities or famous people were diagnosed with a heart condition. Occasionally they would write about health issues in the media, but this was not a regular occurrence and was far less common than the media prompts might have indicated it would be.

Two daily newspapers were analysed for content about heart disease over a four month period. This media generally reported on health stories that were quirky

or had a feel good component. The papers predominantly highlighted lifestyle issues in relation to heart disease and this caused some distress to the HeartNET membership who felt that more emphasis should be placed on genetic and environmental factors

A content analysis of the four months of news articles indicates that the use of the Heart Foundation brand name or a passing mention of heart disease, was often used to raise the salience of the newspaper article, particularly in terms of its heading. It was difficult to ascertain the relevance of the link in some articles. A firmer finding would require the assessment of more articles over a prolonged period of time.

9.3   Limitations of the Research

There are limitations to this research. First, it only analyses messages from a single online support group of people affected by heart disease, which means it may be "difficult to determine if the observed pattern of social support is generalizable to other support groups" (Coulson et al., 2007, p. 14). However, the use of in-depth interviews and online interactions provides rich and detailed information from a section of the population that is often overlooked. The use of heart patients in this research provides a depth of understanding that can only come from the lived experience of having heart disease. The sample also lacked ethnic diversity which may not be representative of the West Australian population, although participants had differing educational, religious, employment and family backgrounds (Dare, 2009).

Second, the emphasis of this research was on activities on HeartNET as elements of a gift economy. While there was clear evidence that social support was an integral component of the HeartNET community, further research is required to determine whether the gift economy works in similar ways across multiple online support sites and to help establish generalisability.

Thirdly, while it is not an accepted role of HeartNET to provide medical advice, its nature as a health promotional tool for health practitioners is an area and function of HeartNET that could be explored further. It was also beyond the scope of this PhD to address all the issues identified during the in-depth interviews and when

analysing the posts to the HeartNET website. I hope that some of these issues might be the subject of forthcoming publications.

Finally, only two newspapers *The West Australian* and *The Australian* were examined in the media content analysis and online news reports were not considered. Thus the results cannot be seen as representative of all Australian newspapers or general mass media coverage. It is also likely that there is an overlap in the reading audiences of both *The West Australian* and *The Australian*. It is possible some HeartNET members read both of these papers and that they encountered the same stories repackaged by different media outlets and told in different ways.

9.4 Recommendations for Future Research

During the course of this research several areas have been identified that could lead to further investigation:

- The HeartNET site needs to be updated and restructured to make it more interactive and user friendly. The membership database also needs to be updated and members should be encouraged to return to HeartNET to update their heart health status. A new moderator will also need to be sourced as currently I am working as the moderator, but now my research is completed I will no longer be able to continue in the role.

- While, the focus of this research was on people affected by heart disease and some mention is made throughout this thesis about family and spousal relationships, it would be valuable to investigate how the spouse or family members perceive living with someone affected by heart disease.

- While HeartNET members and moderators are not permitted to give medical advice on HeartNET; future research could investigate the potential of HeartNET as a health promotion tool for health practitioners.

- There is a requirement for research into heart health from the patients' perspective. Investigation into why people delay seeking treatment, where and how patients access their heart health information, and gender stereotyping of illness in the media would all benefit from further research with a communication and community based perspective.

- There is clear evidence that people do not continue with their medication regime once they start to 'feel better', and this is clearly a major health issue and something that could be investigated in future research. However, due to the nature of the condition someone with medical knowledge would need to be involved.

9.5　Summary

In summary, HeartNET has proved to be a valuable tool for people affected by heart disease, as they recreated their self-identity following a heart event. HeartNET offered asynchronous support for people with heart disease. It was particularly valuable to members as a twenty-four hour resource in the early days of recovery. The nature of online support and of some heart disease, allowed members to seek support when they needed it, even though there may be days, weeks or even years between visits to the site. When there was a reoccurrence of their heart disease however, online sites like HeartNET was an important 'home' for members.

The media is one of the main providers of health information, so it is important that journalists develop a more nuanced understanding of heart disease rather than solely reporting it as a lifestyle issue.

Online therapeutic sites like HeartNET constitute important health communication tools for people affected by heart disease, and also for their families, friends and for health care professionals.

REFERENCES

Abelson, H., Lessig, L., Covell, P., Gordon, S., Hochberger, A., Kovacs, J., et al. (1998). Digital identity in cyberspace. *White paper submitted for 6.805/Law of Cyberspace: Social Protocols.*

The Advertiser (2012, June 8). *How Facebook killed the holiday postcard*. Retrieved from http://www.news.com.au/travel/travel-updates/iphone-killed-the-holiday-postcard/story-e6frfq80-1226388883092

Aldiabat, K., & Le Navenec, C.L. (2011). Clarification of the blurred boundaries between Grounded Theory and Ethnography: Differences and similarities. *Online Submission*, *2*(3), 1-13.

Adler, P.A., & Adler, P. (1987). *Membership roles in field research.* Newbury Park, CA: Sage Publications.

The Advertiser (2012, June 8). *How Facebook killed the holiday postcard*. Retrieved

from http://www.news.com.au/travel/travel-updates/iphone-killed-the-holiday-

postcard/story-e6frfq80-1226388883092

Allen, M.W. (Ed.). (2011). *Michael Allen's 2012 e-learning annual* (Vol. 54). San Francisco: John Wiley & Sons.

Altheide, D. L. (2000). Identity and the definition of the situation in a mass-mediated context. *Symbolic Interaction, 23*(1), 1-27.

American Heart Association (2014, March 3). *New report calls for more research on gender differences – American Heart Association urges FDA to adopt recommendations*. Retrieved from http://newsroom.heart.org/news/

Andrews, D., Preece, J. & Turoff, M. (2001). *A conceptual framework for demographic groups resistant to online community interaction*. Retrieved from http://www.ifsm.umbc.edu/~preece/Papers/Framework_Dorine_HICSS01.pdf

AppMeter (2014a). *Tracking Facebook apps usage metrics. Farmville by Zynga*. Retrieved from http://www.appmtr.com/facebook/app/102452128776-farmville/

Appmeter. (2014b). *Tracking Facebook apps usage metrics. Fish World by Big Viking Games.* Retrieved from http://www.appmtr.com/facebook/app/100354007223-fish-world/

Armstrong, D., Michie, S. & Marteau, T. (1998). Revealed identity: A study of the process of genetic counselling. *Social Science & Medicine*, *47*(11), 1653-1658.

Armstrong, E.A., Carpenter, DP. & Hojnacki, M. (2006). Whose deaths matter? Mortality, advocacy, and attention to disease in the mass media. *Journal of Health Politics, Policy and Law, 31*(4), 729-772.

Armstrong, F. (2010, May 8). Good climate for proper reforms: Health reforms. *The Australian.* Retrieved from http://www.theaustralian.com.au/news/health4

Arnold, D., Froug, W. & Asher, W. (Producer). (1964-1972). *Bewitched* [Television series]. United States: Screen Gems Ashmont Productions.

Asselin, M.E. (2003). Insider research - issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Staff Development, 19*(2), 99-103.

Australian Bureau of Statistics. (2006a). *Cardiovascular disease in Australia: A snapshot 2004-2005* (Cat. No. 4821.0.55.001). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2006b). *Household use of information technology, Australia, 2005-2006* (Cat. No. 8146.0). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2007). *Voluntary work, Australia, 2006.* (Cat. No. 4441.0). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2009). *Household use of information technology, Australia, 2008-09* (Cat. No. 8146.0). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2010). *Internet activity, Australia, Jun 2010* (Cat. No. 8153.0). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2012). *Gender indicators, Australia, Jan 2012* (Cat. No. 4125.0). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2013a). *Causes of death, Australia, 2011* (Cat . No. 3303.0). Retrieved from http://www.abs.gov

Australian Bureau of Statistics. (2013b). *Disability, ageing and carers, Australia: Summary of Findings, 2012* (Cat. No. 4430.0). Retrieved from http://www.abs.gov.au

Australian Bureau of Statistics. (2014). *Household use of information technology, Australia 2012-2013*. (Cat. No. 8146). Retrieved from http://www.abs.gov.au

Australian Communication and Media Authority. (2009). *Use of digital media and communications by senior Australians.* Canberra: Commonwealth of Australia

Australian Institute of Health and Welfare. (2013). *Public health expenditure*. Retrieved from http://www.aihw.gov.au/public-health-expenditure/

Australian Institute of Health and Welfare (AIHW). (2009). *Impact of falling cardiovascular disease death rates: deaths delayed and years of life extended*. (Bulletin No. 70. Cat. No. AUS 113). Canberra: Australian Institute of Health and Welfare.

Australian Press Council. (2006). *State of the news print media in Australia.* Sydney: Australian Press Council.

Bakardjieva, M. & Smith, R. (2001). The Internet in everyday life: Computer networking from the standpoint of the domestic user. *New Media Society, 3*(1), 67-83.

Balnaves, M. & O'Regan, T. (2010). The politics and practice of television ratings conventions: Australian and American approaches to broadcast ratings. *Continuum: Journal of Media & Cultural Studies*, *24*(3), 461-474.

Balnaves, M., Willson, M. & Leaver, T. (2012). Entering Farmville: Finding value in social games. In C. Anyanwu, K. Green & J. Sykes (Eds) *Communicating change and changing communication in the 21st century, Australian and New Zealand Communication Association Conference,* (pp. 1-12). Adelaide, Australia: Australian and New Zealand Communication Association.

Barak, A., Boniel-Nissim, M. & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, *24*(5), 1867-1883.

Barbrook, R. (1998). The hi-tech gift economy. *First Monday*, *3*(12). Retrieved from http://www.firstmonday.dk/issues/issues3-12/barbrook/index.html

Barclay, H. (2007). *Participation in a community service programme has a positive effect on high school volunteers' empathy*. Doctoral thesis, University of the Witwatersrand, Johannesburg, South Africa. Retrieved from http://wiredspace.wits.ac.za/handle/10539/4940

Bar-Lev, S. (2010). 'Do you feel sorry for him?': Gift relations in an HIV/AIDS online support forum. *Health*, *14*(2), 147-161.

Barrette, J., & Becker, B. (2007). Joining the social circle. *Medical Marketing and Media, 42*(4), 59-61.

Barrera, M., Glasgow, R.E., McKay, H.G., Boles, S.M. & Feil, E.G. (2002). Do Internet-based support interventions change perceptions of social support? An experimental trial of approaches for supporting diabetes self-management. *American Journal of Community Psychology, 30*(5), 637-654.

Barringham, R. (2009). *How to quit smoking: Without giving up cigarettes*. Brisbane, Queensland: Cheriton House Publishing.

Bartl, M., Hück, S., & Ruppert. (2009). Netnography research. Community insight in the cosmetic industry. In *Conference Proceedings ESOMAR Consumer Insights.*

Bartlett, C., Sterne, J. & Egger, M. (2002). What is newsworthy? Longitudinal study of reporting of medical research in two British newspapers. *British Medical Journal, 325*(4), 81-84.

Basdekis, I., Klironomos, I., Antona, M. & Stephanidis, C. (2006). Online communities for all: The role of design for all in the formation and support of inclusive online communities. *Proceedings of the International Design for All Conference*, Rovaniemi, Finland.

Baym, N.K. (1995). The performance of humor in computer-mediated communication. *Journal of Computer Mediated Communication, 1*(2).

Bays, H. & Mowbray, M. (1999). Cookies, gift giving, and the Internet. *First Monday, 4*(11).

BBC News. (2008, April 2). *Daily caffeine 'protects brain'*. Retrieved from http://news.bbc.co.uk/2/hi/7326839.stm

BBC News & Entertainment. (2013, September 1). *Sir David Frost, broadcaster and writer, dies at 74*. Retrieved from http://www.bbc.com/news/entertainment-arts-23920336

Beckmann, S. & Langer, R. (2005). Netnography: Rich insights from online research. *Insights@ CBS*, *14*(6), 63-66.

Belk, R. (2007). Why not share rather than own? *The Annals of the American Academy of Political and Social Science, 611*, 126-140.

Bergquist, M. & Ljungberg, J. (2001). The power of gifts: Organizing social relationships in open source communities. *Information Systems Journal*, *11*(4), 305-320.

Berkman, L.F., Glass, T., Brissette, I. & Seeman, T.E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*(6), 843-857.

Bethell, H., Lewin, R. & Dalal, H. (2009). Cardiac rehabilitation in the United Kingdom. *Heart*, *95*(4), 271-275.

Blanchard, J.A. (2006). Hospital volunteers: A qualitative study of motivation. *The International Journal of Volunteer Administration, XXIV*(2), 31- 40.

Blanchot (1983). *La communaute inavouable [The unavowable community]*. (P. Joris, Trans). Barrytown NY: Station Hill Press.

Bogost, I. (2010). *Cow Clicker: The making of obsession*. Retrieved from http://www.bogost.com/blog/cow_clicker_1.shtml

Bollier, D. (2003). The rediscovery of the commons. *Open Knowledge*, 10.

Bonevski, B., Wilson, A. & Henry, D.A. (2008). An analysis of news media coverage of complementary and alternative medicine. *PLoS One, 3*(6), e2406.

Bonniface, L.N., Green, L.R. & Swanson, M. (2005). Affect and an effective online therapeutic community. *M/C: A Journal of Media and Communication, 8*(6).

Bonniface, L.N., Green, L.R. & Swanson, M.G. (2006). Communication on a health-related website offering therapeutic support: Phase 1 of the HeartNET website. *Australian Journal of Communication*, *33*(2,3), 89-107.

Boulet, J., Healey, L. & Helton, R. (2008). Gift relationships and their political-economy: Of volunteering, community involvement and creating (a) civil society. *New Community Quarterly*, *6*(2), 28-41.

Bowler, G.M. (2010). Netnography: A method specifically designed to study cultures and communities online. *The Qualitative Report, 15*(5), 1270-1275.

Bowling, A. (2009). *Research methods in health. Investigating health and health services*. (3rd ed.). New York: Open University Press.

Boyd, D.M. *& Ellison, N.B. (*2007*).* Social network sites: Definition, history and scholarship. *Journal of Computer-Mediated Communication, 13*(1).

Bracegirdle. C. (2011). Writing poetry: Recovery and growth following trauma. *Journal of Poetry Therapy: The Interdisciplinary Journal of Practice, Theory, Research and Education, 24*(2), 79-91.

Braithwaite, D., Waldron, V.R. & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication, 11*(2), 123-151.

Bregman, A. & Haythornthwaite, C. (2003). Radicals of presentation: Visibility, relation, and co-presence in persistent conversation. *New Media & Society*, *5*(1), 117-140.

Brown, J.S. & Duguid, P. (2002). *The social life of information*. Boston, Massachusetts: Harvard Business School Press.

Brown, T. (2004). *Peer review and the acceptance of new scientific ideas*. London: Sense About Science. Retrieved from http://www.senseaboutscience.org/data/files/resources/17/peerReview.pdf

Bryman, A. (2012). *Social research methods*. London: Oxford University Press.

Bubela, TM. & Caulfield, TA. (2004). Do the print media "hype" genetic research? A comparison of newspaper stories and peer-reviewed research papers. *Canadian Medical Association Journal, 170*(9), 1399-1407.

Burnett, G. *(2000).* Information exchange in virtual communities: A typology. *Information Research: An International Electronic Journal, 5(4).*

Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness*, *13*(4), 451-468.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*(2), 167-182.

Butler, B., Sproull, L., Kiesler, S. & Kraut, R. (2002). Community effort in online groups: Who does the work and why? *Human Computer Interaction Institute, 11*. Retrieved from http://repository.cmu.edu

Caplow, T. (1982). Christmas gifts and kin networks. *American Sociological Review, 47*(June), 383-392.

Carey, S. A., & Gray, J. R. (2012). Women and heart disease: A diagnostic challenge. *The Journal for Nurse Practitioners*, *8*(6), 458-463.

Caspermeyer, J., Sylvester, E., Drazkowski, J., Watson, G. & Servin, J. (2006). Evaluation of stigmatizing language and medical errors in neurology coverage by 9 US newspapers. *Mayo Clinic Proceedings, 81*(3), 300-306.

Caton, P. (2009, February 23). Power couple pick salt. *Tweed Daily News*. Retrieved from http://www.tweeddailynews.com.au/news/power-couple-pick-salt/173727/

Chandler, D.L. (2000, October 20). Who 'created' the Internet? It's a tangled web. *The Boston Globe*.

Chapman, S., McLeod, K., Wakefield, M. & Holding, S. (2005). Impact of news celebrity illness on breast cancer screening: Kylie Minogue's breast cancer diagnosis. *Medical Journal of Australia, 183*(5), 247- 250.

Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. In J. A. Roth & P. Conrad (Eds.), *Research in the sociology of health care; The experience and management of chronic illness* (pp. 283-319). Greenwich, Connecticut: Jai Press Inc.

Charmaz, K. (1990). 'Discovering' chronic illness: using grounded theory. *Social Science & Medicine*, *30*(11), 1161-1172.

Charmaz, K. (1995). The body, identity and self: Adapting to impairment. *The Sociological Quarter, 36*(4), 657-680.

Charmaz, K. (2000) Experiencing chronic illness. In Albrecht, G.L., Fitzpatrick, R. & Scrimshaw, S.C. (Eds), The *Handbook of Social Studies in Health and Medicine* (pp. 277-292). London: Sage Publications.

Charmaz, K. (2002). Stories and silences: Disclosures and self in chronic illness. *Qualitative Inquiry, 8*(3), 302-328.

Clary, E.G. & Snyder, M. (1999). The motivations to volunteer: Theoretical and practical considerations. *Current Directions in Psychological Science,* 8, 156-159.

Clarke, J.N. (1991). Media portrayal of disease from the medical, political economy, and life-style perspectives. *Qualitative Health Research, 1*, 287-308.

Clarke, J. N. (1999). Prostate cancer's hegemonic masculinity in select print mass media depictions (1974-1995). *Health Communication, 11*(1), 59-74.

Clarke, J.N. (2004). A comparison of breast, testicular and prostate cancer in mass print media (1996-2001). *Social Science & Medicine, 59*, 541-551.

Clarke, J.N, (2008). Heart disease and gender in mass print media. *Menopause International, 14*(8), 18-20.

Clarke, J.N. & van Amerom, G., (2008). Mass print media depictions of cancer and heart disease: Community versus individualistic perspectives? *Health and Social Care in the Community, 16*(1), 96-103.

Clarke, J.N., van Amerom, G. & Binns, J. (2007). Gender and heart disease in mass print media: 1991, 1996, 2001. *Women & Health, 45*(1), 17-35.

Coffey, A. (1999). *The ethnographic self: Representation and the representation of identity*. Thousand Oaks, CA: Sage.

Coghlan, D. (2007). Insider action research doctorates: Generating actionable knowledge. *Higher Education*, *54*(2), 293-306.

Collins, K. (2005, April 15). Is chocolate good for you? Flavanoids in cocoa may protect the heart, but don't overdo it. *NBC News*. Retrieved from http://www.nbcnews.com/id/7339594/ns/health-diet_and_nutrition/t/chocolate-good-you/#.UxxpoLlWEqQ

Corbett, J.B. & Mori, M. (1999). Medicine, media, and celebrities: News coverage of breast cancer, 1960-1995. *Journalism & Mass Communication Quarterly, 76*(2), 229-249.

Corbin, J.M. (2003). The body in health and illness. *Qualitative Health Research*, *13*(2), 256-267.

Corbin, J. & Strauss, A.L. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. In J. A. Roth & P. Conrad (Eds.), *Research in the sociology of health care the experience and management of chronic illness* (pp. 221-249). London: Jai Press Inc.

Correa, T., Hinsley, A. W., & de Zuniga, H. G. (2010). Who interacts on the Web? The intersection of users' personality and social media use. *Computers in Human Behavior, 26*, 247-253.

Corrigan, P.W., Watson, A.C., Gracia, G., Slopen, N., Rasinski, K. & Hall, L.L. (2005). Newspaper stories as measures of structural stigma. *Psychiatric Services*, *56*(5), 551-556.

Coulson, N.S., Buchanan, H. & Aubeeluck, A. (2007). Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient Education and Counseling, 68*(2), 173-178.

Coyne, R. (2005). Cornucopia Limited: design and dissent on the Internet. Cambridge, Massachusetts: The MIT Press.

Creeber, G. (2001). *The television genre book*. British Film Inst.

Cresswell, A. (2009, September 21). Hormone replacement therapy study raises lung cancer fear, *The Australian.*

Cresswell, A. (2010, May 19). Heart attack danger for 'Generation Risk". *The Australian*. Retrieved from

http://www.theaustralian.com.au/news/nation/heart-attack-danger-for-generation-risk/story-e6frg6nf-1225868393943

Cullen, T. (2013), Health reporting: Opportunities and challenges. *Journalism Research and Investigation in a Digital World*, *1*(25), 232-242.

Cummings, J.N., Sproull, L. & Kiesler, S.B. (2002). Beyond hearing: Where real-world and online support meet. *Group Dynamics: Theory, Research, and Practice, 6*(1), 78-88.

Curry, P. & O'Brien, M. (2006). The male heart and the female mind: A study in the gendering of antidepressants and cardiovascular drugs in advertisements in Irish medical publication. *Social Science & Medicine, 62*, 1970-1977.

Daniel, M. (Producer). (1969-1976). *Marcus Welby, M.D.* [Television series]. Universal City, California: Universal Studios.

Dare, J. (2009). *The role of information and communication technologies in managing transition and sustaining women's health during their midlife years.* (Doctoral dissertation, Edith Cowan University). Retrieved from http://ro.ehtcu.edu.au/theses/582

Davis, A. (2010). Merging through media: Analyzing public relations framing and ethics through the 2010 Ticketmaster-Live national merger. *The Elon Journal of Undergraduate Research in Communications, (1)*2, 121-128.

Dayan, D. & Katz, E. (1987). Performing media events. In J. Curran, A. Smith & P. Wingate (Eds.), *Impacts & influences essays on media power in the twentieth century*. London: Methuen & Co. Ltd.

De Koning, E. & Weiss, R.L. (2002). The relational humor inventory: Functions of humor in close relationships. *American Journal of Family Therapy*, *30*(1), 1-18.

Dean, R.A.K. & Gregory, D.M. (2005). More than trivial: strategies for using humor in palliative care. *Cancer Nursing, 28*(4), 292-300.

Debatin, B., Lovejoy, J.P., Horn, A.K. & Hughes, B.N. (2009). Facebook and online privacy: Attitudes, behaviors, and unintended consequences. *Journal of Computer-Mediated Communication, 15*(1), 83-108.

Defense Advanced Research Projects Agency. (1981). *RFC793 – Transmission Control Protocol*. Marina del Rey, California Information Sciences Institute: University of Southern California.

Demeris, G. (2006). The diffusion of virtual communities in health care: Concepts and challenges. *Patient Education and Counseling, 62*, 178-188.

Dennis, C.L. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, *40*(3), 321-332.

Department of Environment and Conservation. (2011). *Seed notes for Western Australia No. 1 Introduction.* Retrieved from www.naturebase.net

Department of Immigration and Border Protection. (2013). *New Zealanders in Australia: Fact sheet 17*. Retrieved from http://www.immi.gov.au/media/fact-sheets/17nz.htm

Dickerson, S.S., Boehmke, M., Ogle, C. & Brown, J.K. (2006). Seeking and managing hope: Patients' experiences using the Internet for cancer care. *Oncology Nursing Forum, 33*(1), E8-E17.

Dickson, A., Knussen, C. & Flowers, P. (2008). 'That was my old life; it's almost like a past-life now': Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology & Health, 23*(4), 459-476.

DiNucci, D. (1999). Fragmented future. *Print, 53*(4), 221-222.

Djikic, M. & Oatley, K. (2004). Love and personal relationships: Navigating on the border between the ideal and the real. *Journal for the Theory of Social Behavior, 34*(2), 199-209.

Doka, K.J. (2014). *Counseling individuals with life threatening illness*. (2nd ed.). New York: Springer Publishing Company.

Donelle, L., & Hoffman-Goetz, L. (2008). An exploratory study of Canadian Aboriginal online health care forums. *Health Communication*, *23*(3), 270-281.

Donelle, L., Hoffman-Goetz, L. & Clarke, J.N. (2005). Ethnicity, genetics and breast cancer: Media portrayal of disease identities. *Ethnicity & Health, 10*(3), 185-197,

Drachler, M.L., Leite, J.C., Hooper, L., Hong, C.S., Pheby, D., Nacul, L. ... & Poland, F. (2009). The expressed needs of people with chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review. *BMC Public Health*, *9*(1), 458.

Drew, N. (2006). The seagull imperative. *The Australian Community Psychologist, 18*(1), 40-41.

du Pre, A. (2005). *Communicating about health: Current issues and perspectives* (2nd ed.). Boston: McGraw Hill.

Dwyer, C., Hiltz, R.S. & Passerini, K. (2007, August 9-12). Trust and privacy concern within social networking sites: A comparison of Facebook and MySpace. *Proceedings of the Thirteenth American Conference on Information Systems*. Keystone, Colorado.

Dwyer, S.C. & Buckle, J.L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1).

Ebbing, M., Bønaa, K. H., Nygård, O., Arnesen, E., Ueland, P. M., Nordrehaug, J. E. ... & Vollset, S. E. (2009). Cancer incidence and mortality after treatment with folic acid and vitamin B12. *JAMA*, *302*(19), 2119-2126.

Edith Cowan University. (2007). *Policy: Conduct of ethical human research*. Perth: Edith Cowan University Retrieved from http://www.ecu.edu.au/GPPS/policies_db/policies_view.php?rec_id=0000000021.

Edmonds Cookbook. (2005). *Classics New Zealander's favourite recipes*. Auckland: Goodman Fielder.

Eisenstein, C. (2011). *Sacred economics: Money, gift and society in the age of transition*. Berkley: Evolver Editions.

Ellison, N.B., Steinfield, C. & Lampe, C. (2007). The benefits of Facebook "friends": Social capital and college students' use of online social network sites. *Journal of Computer Mediated Communication, 12*, 1143-1168.

Emerson, R.M., Fretz, R.I. & Shaw, L.L. (2011). *Writing ethnographic fieldnotes*. New York: University of Chicago Press.

Entwistle, V. (1995). Reporting research in medical journals and newspapers. *British Medical Journal, 310*, 920-923.

Entwistle, V.A., France, E.F., Wyke, S., Jepson, R., Hunt, K., Ziebland, S. & Thompson, A. (2011). How information about other people's personal experiences can help with healthcare decision-making: a qualitative study. *Patient Education and Counseling*, *85*(3), e291-e298.

Erickson, T. (1999). Persistent conversation: An introduction. *Journal of Computer Mediated Communication, 14*(4).

Erickson, T. & Herring, S.C. (2005). Persistent conversation: A dialog between research and design. Paper presented at the *38th Hawaii International Conference on System Science*s, Hilton Waikoloa Village, Island of Hawaii (Big Island).

Erikson, I. (2004). Communicating existential issues through reading poetry. In F. Sampson (Ed.). *Creative Writing in Health and Social Care.* (pp. 38-50). London: Jessica Kingsley.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *BMJ, 328*(1166). doi: 10.1136/bmj.328.7449.1166.

Facebook. (2014). *Facebook reports second quarter 2014 results.* Retrieved from http://investor.fb.com/releasedetail.cfm?ReleaseID=861599

FarmVille. (2009). *Farmville*.[Adobe Flash]. San Francisco, California: Zynga. Retrieved from https://company.zynga.com/games/farmville

Felton, J.S. (1997). Morbidity, Mortality and the Media. *Occupational Medicine*, *47*(8), 507-507.

Fehr, E., & Gäechter, S. (2000). Fairness and retaliation: The economics of reciprocity. *The Journal of Economic Perspectives*, CESifo Working Paper, No. 336, 159-181.

Fernback, J. & Thompson, B. (1995). *Virtual communities: Abort, retry, failure?* Retrieved from http://www.nicoladoering.de/Hogrefe/fernback.htm

Ferne, T., Wall, T., Dubber, A., Thomas, L., Lambrianidou, M., Hills, M., … Klein, B. (2007). *Listener online engagement with BBC radio programming.* Arts and Humanities Research Council BBC Knowledge Exchange Programme: London.

Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health & Social Work, 24*(3), 220-231.

Fish World. (2010). *Fish World.*[Ontario, Canada: Big Viking Games. Retrieved from http://www.bigvikinggames.com/games/fish-world/

Francombe, J. (2010). I cheer, you cheer, we cheer: Physical technologies and the normalized body. *Television & New Media*.

Fremantle Heart Patients Support Group. (2012). *Our profile*. Retrieved from http://www.fremantleheart.asn.au/01.html

Freud, S. (1928). *Humour: Complete works* (Vol. XXI 1927 – 31, pp 161 - 6). London.

Frost, K., Frank, E. & Maibach, E. (1997). Relative risk in the news media: A quantification of misrepresentation. *American Journal of Public Health, 87*(5), 842-845.

Furlan, P. (2012). Who can you trust? Medical news, the public and what reporters think about public relations sources. *Pacific Journalism Review*, *18*(2). 102-117.

Furuse, K. (2007). Hybrid exchange forms between gift and commodity exchange: The market mechanisms for small businesses in Japan *21st Century COE Program of Hitotsubashi University (Japan)* (pp. 1-19). Tokyo: Musashi University.

Gackenbach, J. & von Stackelberg, H. (2007). Self online: Personality and demographic implications. In J. Gackenbach (Ed.), *Psychology and the Internet intrapersonal, interpersonal, and transpersonal implications,* (2nd ed.), pp. 55-71). Amsterdam: Elsevier.

Gangadharbatla, H. (2008). Facebook me: Collective self-esteem, need to belong, and Internet self-efficacy as predictors of the iGeneration's attitudes toward social networking sites. *Journal of Interactive Advertising*, *8*(2), 5-15.

Garcia, A.C., Standlee, A.I., Bechkoff, J. & Cui, Y. (2009). Ethnographic approaches to the Internet and computer-mediated communication. *Journal of Contemporary Ethnography 38*(1) 52-84. doi 10.1177/0891241607310839

Gary, J. & Remolino, L. (2000). Coping with loss and grief through online support groups. In J. Bloom & G. Walz (Eds), *Cybercounseling and cyberlearning: Strategies and resources for the millennium* (pp. 95-115). Alexandria, VA: American Counseling Association.

Genoni, P., Merrick, H. & Willson, M.A. (2006). Scholarly communities, e-research literacy and the academic librarian. *The Electronic Library, 24*(6), 734-746.

Gerhards, J. & Schäfer, M.S. (2010). Is the Internet a better public sphere? Comparing old and new media in the US and Germany. *New Media & Society*. *12*(1), 143–160.

Ghosh, R.A. (1998). Cooking pot markets: An economic model for the trade in free goods and services on the Internet. *First Monday*, *3*(3). Retrieved from http://firstmonday.org/issues/issue3_3/ghosh/index.html

Gibson, M. (2007). Death and mourning in technologically mediated culture. *Health Sociology Review*, *16*(5), 415-424.

Gielser, M., & Puhlmann, M. (2003). The anthropology of file sharing: Consuming Napster as a gift. *Advances in Consumer Research*, *30*, 273-279.

Goffman, E. (1959). *Presentation of self in everyday life*. New York: Doubleday Anchor Books Doubleday & Company Inc.

Goldsmith, B. (2010, June 2). Chocolate may cut cholesterol but only in some people. *The West Australian.*

Gouldner, A.W. (1960). The norm of reciprocity: A preliminary statement. *American Sociological Review*, *(25)*2, 161-178.

Granovetter, M. (1983). The strength of weak ties revisited. *Sociological Theory, 1*(1), 201-233.

Graydon, M. (2007). Don't bother to wrap it: Online Giftgiver and Bugchaser newsgroups, the social impact of gift exchanges and the 'carnivalesque'. *Culture, Health & Sexuality, 9*(3), 277-292.

Green, J. & Jenkins, H. (2009). The moral economy of Web 2.0: audience research and convergence culture. In J. Holt & A. Perren (Eds.), *Media industries: History, theory and method*. Malden MA: Wiley-Blackwell.

Green, L. (2010). *The Internet an introduction to new media*. Oxford: Berg.

Green, L., Bonniface, L. & McMahon, T. (2007). Adapting to a new identity reconstituting the self as a heart patient. *M/C Journal, 10*(2).

Greengard, S. (2011). Social games, virtual goods. *Communications of the ACM*, *54*(4), 19-22.

Gregory, C. A. 1982. *Gifts and commodities*. London: Academic Press.

Grilli, R., Ramsay, C. & Minozzi, S. (2009). Mass media interventions: Effects on health services utilisation. *Cochrane Database Syst Rev*, *1*(1).

Grimm, R., Spring, K. & Dietz, N. (2007). *The health benefits of volunteering: A review of recent research.* Corporation for National and Community Service.

Guyatt, G., Ray, J., Gibson, N., Cook, D., Ashpole, B., Baines, C., … Taylor, P. (1999,). A journalist's guide to writing health stories. *The American Medical Writers Association, 14*(1), 32-42.

Hall, M.H. (2001). Measurement issues in surveys of giving and volunteering and strategies applied in the design of Canada's National Survey of Giving, Volunteering and Participating. *Nonprofit and Voluntary Sector Quarterly*, *30*(3), 515-526.

Hallahan, K. (1999). Seven models of framing: Implications for public relations. *Journal of Public Relations Research*, *3*(11), 205-242.

Hammer, E. (1996). Anticipatory guidance for children with disabilities: What happens to families when a child has chronic problems? Paper presented at the *Infant Medical Health Advocacy Conference: Birth to Three...The Critical years*. Baylor University, Waco, Texas

Handy, F. & Srinivasan, N. (2004). 'Valuing volunteers: An economic evaluation of the net benefits of hospital volunteers. *Nonprofit and Voluntary Sector Quarterly, 33*(1), 28-54.

Harding, S. (2010). *The heart truth campaign: Exploring the success of the Red Dress (Master's Thesis). A*merican University, Washington D.C., United States of America. Retrieved from http://www.american.edu/soc/communication/upload/Samantha-Harding.pdf

Harrison, J. (2006). Web poetic and the gift economy: nzepc, PennSound and UbuWeb.Ka Mate Ka Ora: *A New Zealand Journal of Poetry and Poetics, 2*, 5-21.

Haythornthwaite, C. & Bregman, A. (2004). Affordances of persistent conversation: Promoting communities that work. In C. Haythornthwaite & M. M. Kazmer (Eds.), *Learning, culture and community in online education research and practice* (pp. 129-145). London: Peter Lang.

Haythornthwaite, C. & Kazmer, M.M. (Eds.). (2004). *Learning, culture and community in online education*. New York: Peter Lang.

Hearne, B. & Nielsen, A.L. (2004). Catch a cyber by the tail: Online orality and the lore of a distributed learning community. In C. Haythornthwaite & M. M. Kazmer (Eds.), *Learning, culture and community in online education* (pp. 59-87). New York: Peter Lang.

Heart Foundation Australia. (2009, October 9). *I wish I could have my heart attack again* [Video File]. Retrieved from http://www.youtube.com/watch?v=3sc0KzkHPGc

Heart Foundation. (2012). *Heart Foundation*. Retrieved from http://www.heartfoundation.org.au/Pages/default.aspx

Heart Foundation (2013). *Data and statistics*. Retrieved from http://www.heartfoundation.org.au/information-for-professionals/data-and-statistics/Pages/default.aspx

Heart Health. (2013). *Hollywood heart attack: A potentially deadly myth*. North American Precis Syndicate. Retrieved from http://www.napsnet.com/pdf_archive/64/67460.pdf

HeartNET. (2012). *Welcome to HeartNET*. Retrieved from http://www.heartnet.com.au/

Hei-Man, T. (2008). An ethnography of social network in cyberspace: The Facebook phenomenon. *The Hong Kong Anthropologist*, *2*, 53-76.

Heisler, M. (2010). Different models to mobilize peer support to improve diabetes self-management and clinical outcomes: evidence, logistics, evaluation considerations and needs for future research. *Family Practice*, *27*(suppl 1), i23-i32.

Hellyer, N.E. & Haddock-Fraser, J. (2010, October 21). Reporting diet-related health issues through newspapers: Portrayal of cardiovascular disease and Type 2 diabetes. *Health Education Research*, *(26)*1, 13-25.

Herring, S.C. (2001). Computer mediated discourse. In D. Schriffin, D. Tannen & H. Hamilton (eds.). *The handbook of discourse analysis,* (pp. 612-34). Oxford: Blackwell.

Herxheimer, A., McPherson, A., Miller, R., Shepperd, S., Yaphe, J. & Ziebland, S. (2000). Database of patients' experiences (DIPEx): A multi-media approach to sharing experiences and information. *The Lancet, 355*, 1540-1543.

Hinckley, D. (2012, February, 29). Davy Jones dead at 66: The Monkees frontman dies from heart attack. Music & Arts. *New York Daily News*. Retrieved from http://www.nydailynews.com/entertainment/music-arts/davy-jones-dead-66-monkees-frontman-dies-apparent-heart-attack-article-1.1030516

Hine, C. (2000). *Virtual ethnography*. London: Sage Publications Ltd.

Hockx, M. (2005). Virtual Chinese literature: A comparative case study of online poetry communities. *China Quarterly-London*, *183*, 670.

Hope, J. (2008 August 4). The Hollywood heart attack myth: Misleading scenes put lives at risk. *Daily Mail Online*. Retrieved from http://www.dailymail.co.uk/health/article-1041299/The-Hollywood-heart-attack-myth-Misleading-scenes-lives-risk.html#

Hotchkiss, R.B. & Fottler, M.D., with Unruh, L. (2009). Valuing volunteers: The impact of volunteerism on hospital performance. *Journal of Healthcare Management*, *34*(2), 119-128.

Hovelsrud-Broda, G. (2000). Sharing, transfers, transactions and the concept of generalized reciprocity. *Senri Ethnological Studies*, (53), 193-214.

Howard, J.A. (2000). Social psychology of identities. *Annual Review of Sociology, 26*, 367-393.

Høybye, M.T., Johansen, C. & Tjørnhøj-Thomsen, T. (2005). Online interaction. Effects of storytelling in an Internet breast cancer support group. *Psycho-Oncology*, *14*(3), 211-220.

Hunt, C. & Sampson, S. (2006). *Writing self and reflexivity.* Basingstoke: Palgrave Macmillan.

Hyde, D. (1983). *The gift: Imagination and the erotic life of property*. New York: Random.

Ibrahim, Y. (2007). Transformation as narrative and process: Locating myth and mimesis in reality TV. *Nebula: A Journal of Multidisciplinary Scholarship, 4*(4), 41-58.

Institute for Volunteering Research. (2012). *Volunteering stats*. Retrieved from http://www.ivr.org.uk/ivr-volunteering-stats

Internet World Stats. (2012). *Face book users in the world: Facebook usage and Facebook growth statistics by world geographic regions*. Retrieved from http://www.Internetworldstats.com/facebook.htm

Isupova, O.G. (2011). Support through patient Internet-communities: Lived experience of Russian in vitro fertilization patients. *International Journal of Qualitative Studies on Health and Well-being, 6*(3).

Jenkins, H., Li, X., Krauskorpf, A.D. & Green, J. (2009). If it doesn't spread, it's dead (part 4): Thinking through the gift economy. *Confessions of an ACA fan the official weblog of Henry Jenkins.* Retrieved from http://henryjenkins.org/2009/02/if_it_doesnt_spread_its_dead_p_3.html

Jewkes, Y. & Letherby, G. (2001). Insiders and outsiders: Complex issues of identification, difference and distance in social research. *Autobiography Studies*, *16*(2), 41-50.

Johnson, T. (1998, July 9). Shattuck Lecture - Medicine and the media. *The New England Journal of Medicine, 339*(2), 87-92.

Joinson, A. (2007). Disinhibition and the Internet. In J. Gackenbach (Ed.), *Psychology and the Internet intrapersonal, interpersonal, and transpersonal implications*. (2nd ed., pp. 76-90). Amsterdam: Elsevier.

Kahaner, I. (2012). *Writing your way out of darkness and into the light: using creative writing as a way to navigate through the grieving process*. Masters Thesis, California State University, Northridge. Retrieved from http://scholarworks.csun.edu:9000/bitstream/handle/10211.2/1216/Itay_Project_Final.pdf?sequence=1

Kahn, R.E. & Cerf, V.G. (1999). *What is the Internet (and what makes It work)*. Paper prepared for the Internet Policy Institute, December. Retrieved from http://www.cnri.reston.va.us/what_is_Internet.html7

Kanuha, V.K. (2000). "Being" native versus "going native": Conducting social work research as an insider. *Social Work, 45*(5), 439-447.

Kelleher, D. & Leavey, G. (Eds.). (2004). *Identity and health*. London: Routledge.

Kemp, D.E., Malhotra, S., Franco, K. N., Tesar, G. & Bronson, D.L. (2003). Heart disease and depression: Don't ignore the relationship. *Cleveland Clinic Journal of Medicine, 70*(9), 745-761.

King, S.A. & Moreggi, D. (1998). Internet therapy and self help groups – the pros and cons. In J. Gackenbach (Ed.), *Psychology and the Internet: Intrapersonal, interpersonal and transpersonal implications* (pp. 77-109). San Diego, CA: Academic Press.

Kobler, F., Riedl, C., Vetter, C., Leimeister, J.M. & Krcmar, H. (2010). Social connectedness on Facebook – an explorative study on status message usage. *Proceedings of the 16 Americas Conference on Information Systems (AMCIS)* (pp. 247-). Lima, Peru.

Kolko, B.E., Nakamura, L. & Rodman, G.B. (2000). Race in cyberspace an introduction. In B.E. Kolko, L. Nakamura & G.B. Rodman (Eds.), *Race in cyberspace* (pp. 1-14). New York: Routledge.

Kollock, P. (2002). The economies of online cooperation: Gifts and public goods in cyberspace. In M. Smith & P. Kollock (Eds.), *Communities in cyberspace*. Los Angeles: University of California Press.

Komter, A.E. (2005). *Social solidarity and the gift*. Cambridge: Cambridge University Press.

Korp, P. (2006). Health on the Internet: Implications for health promotion. *Health Education Research, 21*(1), 78-86. Retrieved from http://her.oxfordjournals.org/cgi/content/full/21/1/78

Kosicki, G.M., McLeod, D.M. & McLeod, J.M. (2011). Looking back and looking forward: Observations on the role of research methods in the rapidly evolving field of political communication. In E.P. Bucy & R.L. Holbert (Eds.), *The sourcebook for political communication research: Methods, measures, and analytical techniques.* New York, NY: Routledge.

Kovic, I., Lulic, I. & Brumini, G. (2008). Examining the medical blogosphere: an online survey of medical bloggers. *Journal of Medical Internet Research*, *10*(3).

Kozinets, R.V. (2002). The field behind the screen: Using netnography for marketing research in online communities. *Journal of Marketing Research, 39*(1), 61-73.

Kozinets, R.V. (2010). *Netnography doing ethnographic research online.* Los Angeles: Sage.

Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan

Kuiper, N.A. & Nicholl, S. (2004). Thoughts of feeling better? Sense of humor and physical health. *Humor, 1*(2), 37-66.

Lampel, J. & Bhalla, A. (2007). The role of status seeking in online communities: Giving the gift of experience. *Journal of Computer-Mediated Communication, 12*(2), 434-455.

Langer, R. & Beckman, S.C. (2005). Sensitive research topic: Netnography revisited. *Qualitative Market Research an International Journal, 8*(2), 189-203.

Larsson, A., Oxman, A.D., Carling, C. & Herrin, J. (2003). Medical messages in the media- barriers and solutions to improving medical journalism. *Health Expectations, 6*, 323-331.

Lasker, J.N., Sogolow, E.D. & Sharim, R.R. (2005). The role of an online community for people with a rare disease: content analysis of messages posted on a primary biliary cirrhosis mailing list. *Journal of Medical Internet research*, *7*(1), e10.

Lasnick, B. (2007). *A letter from your chronic condition and a reply*. [Blog Post]. Retrieved October 27, 2011 from butyoudontlooksick.com

Leask, J. & Chapman, S. (2002). 'The cold hard facts' immunisation and vaccine preventable diseases in Australia's newsprint media 1993-1998. *Social Science & Medicine, 54*, 445-447.

Leonie, S. (Producer) & Grimaldi, A. (Director). (1966). *The good, the bad and the ugly*. [Motion picture]. Italy: Produzioni Europee Associati (PEA).

Lifeline WA. (2013). *Crisis support*. Retrieved from http://www.lifelinewa.org.au/

Lippuner, R. (2004). Culture, space and everyday life. *Proceedings of the 30th Congress of International Geographical Union (IGU)*, Glasgow. Retrieved from http://WWW.uni-jena.de/Roland_Lippuner.html

Liszkiewicz, A. (2010). Cultivated play: FarmVille. *Media Commons: A Digital Scholarly Network*. Retrieved from http://mediacommons.futureofthebook.org/content/cultivated-play-FarmVille

Little, M., Paul, K., Jordens, C.F. & Sayers, E.J. (2002). Survivorship and discourses of identity. *Psycho-Oncology, 11*, 170-178.

Livneh, H. & Antonak, R. F. (2005). Psychosocial adaptation to chronic illness and disability: A primer for counselors. *Journal of Counseling & Development, 83*(Winter), 12-20.

Long, T., Taubenheim, A.M., Wayman, J., Temple, S. & Ruoff, B.A. (2008). The heart truth: Using the power of branding and social marketing to increase awareness of heart disease in women. *Social Marketing Quarterly*, *14*(3), 3-29.

Lum, T.Y. & Lightfoot, E. (2005). The effects of volunteering on the physical and mental health of older people. *Research on Aging*, *27*(1), 31-55.

Luoh, M.C. & Herzog, A.R. (2002). Individual consequences of volunteer and paid work in old age: Health and mortality. *Journal of Health and Social Behavior*, 490-509.

Maas, A.H.E.M. & Appelman, Y.E.A. (2010). Gender differences in coronary heart disease. *Netherlands Heart Journal, 18*(12), 598-603.

Macias, W., Stavchansky-Lewis, L.S. & Smith, T.L. (2005). Health-related message boards/chat rooms on the web: Discussion content and implications for pharmaceutical sponsorships. *Journal of Health Communication, 10*, 209-223.

Macnamara, J. (2010). *The 21st century media (r)evolution: Emergent communication practices*. New York: Peter Lang Publishing Inc.

Magnani, M., Montessi, D. & Rossi, L. (2012). Conversation retrieval for microblogging sites. *Information Retrieval*, *15*(3-4), 354-372.

Malhotra, R. & Stockdale, R. (2008). Developing an online community for people with Diabetes: A New Zealand case study. *International Journal of Principles and Applications of Information Science and Technology, 2*(1), 24- 39.

Malinowski, B. (1926). *Crime and custom in savage society*. New Brunswick, NJ: Transaction Publishers. (Original work published 1926)

Mann, C. & Stewart, F. (2000) *Internet communication and qualitative research: A handbook for researching online*. London: Sage Publications.

Mansfield. R. (2013, February 1). Re: *The health benefits of laughter*. [Blog Post]. Retrieved from http://www.goodtoknow.co.uk/wellbeing/179039/10-reasons-why-laughing-is-good-for-you

Markham, A.N. (2004). Representation in online ethnographies: A matter of context sensitivity. In S. Chen., J. Hall & M Johns (Eds.), *Online social research: Theory, methods, and ethics*, (pp. 141-155). London: Peter Lang Publishers

Markus, H. & Nurius, P. (1986). Possible selves. *American Psychologist, 41*(9), 954-969.

Martin, R.A. (2004). Sense of humor and physical health: Theoretical issues, recent findings, and future directions. *Humor, 17*(1), 1-19.

Mauss, M. (1990). *The gift: The form and reason for exchange in archaic societies* (W. Halls, Trans.). London: Routledge.

Mauss, M. (1925). The gift, trans. I. Cunnison. *Cohen & West, London*.

McCreaddie, M. & Wiggins, S. (2009). Reconciling the good patient persona with problematic and non-problematic humour: A grounded theory. *International Journal of Nursing Studies,* 46, 1079-1091.

McCreaddie, M. & Wiggins, S. (2008). The purpose and function of humour in health, health care and nursing: A narrative review. *Journal of Advanced Nursing, 61*(6), 584-595.

McKinnon, M.M. (2002). The participation of volunteers in contemporary palliative care. *The Australian Journal of Advanced Nursing, 19*(4), 38-44.

McMillan, D.W. & Chavis, D.M. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, *14*(1), 6-23.

Media+Doctor Australia (2013). *About media doctor*. Retrieved from http://www.mediadoctor.org.au/content/about.jsp

Medina, E.L., Loques Filho, O. & Mesquita, C.T. (2013). Health social networks as online life support groups for patients with cardiovascular diseases. *Arquivos Brasileiros de Cardiologia*, *101*(2), e39-e45.

Metcalfe, D., Price, C. & Powell, J. (2010). Media coverage and public reaction to celebrity cancer diagnosis. *Journal of Public Health, 33*(1), 80-85.

Miller, D. (2000). *Dying to care? Work, stress and burnout in HIV/AIDS*. London: Routledge.

Möntmann, N. (2009). New communities. *Public,* (39), 11-19

Mosca, L., Ferris, A., Fabunmi, R. & Robertson, R.M. (2004). Tracking women's awareness of heart disease. *Circulation, 109*, 573-579.

Mudur, G. (2005). The media must be the most important source of health information for the general public. *The PloS Medicine Debate*. Retrieved 7th August 2007, from www.plosmedicine.org

Mulhall, A. (2003). In the field: Notes on observation in qualitative research. *Journal of Advanced Nursing,* 41, 306-313.

Mutchler, J.E., Burr, J. A. & Caro, F.G. (2003). From paid worker to volunteer: Leaving the paid workforce and volunteering in later life. *Social Forces*, *81*(4), 1267-1293.

Nancy, J.L. (1991) *La communauté affrontée [The inoperative community].* (P. Connor, L. Garbus, M. Holland, S. Sawhney, Trans.) Minneapolis, MN : University of Minnesota Press.

Nardi, B.A., Schiano, D.J., Gumbrecht, M. & Swartz, L. (2004). Why we blog. *Communications of the ACM, (47*(12), 41- 46.

Narushima, M. (2005). 'Payback time': Community volunteering among older adults as a transformative mechanism. *Ageing and Society*, *25*(4), 567-584.

National Health and Medical Research Council, Australian Research Council, & Universities Australia. (2007). *Australian code for the responsible conduct of research*. Canberra: Australian Government.

Neuendorf, K.A. (1990). Health images in the mass media. In E. B. Ray & L. Donohew (Eds.), *Communication and health systems and applications*. London: Lawrence Erlbaum Associates.

New South Wales Government. (2012). *Cardiovascular disease (CVD) and smoking*. Retrieved from http://www0.health.nsw.gov.au/factsheets/general/cvd.html

Nielsen, J. (2006, October 9). *Participation inequality: Encouraging more users to contribute*. Nielsen Norman Group. Retrieved from http://www.nngroup.com/articles/participation-inequality/

Nyhof-Young, J., Friedman, A., Jones, J.M. & Catton, P. (2003). Partners in Caring: Administration of a Hospital-based Volunteer Program for the Education and Support of Cancer Patients. *The International Journal of Volunteer Administration, XXIV*(2), 73-82.

Office on Women's Health (OWH). (2014). *Make the call Don't miss a beat the myth of "The Hollywood Heart Attack"*. Retrieved from http://www.womenshealth.gov/heartattack/myth-of-the-hollywood-heart-attack.php

Ogilvie, R., McCloughen, A., Curtis, K. & Foster, K. (2012). The experience of surviving life-threatening injury: a qualitative synthesis. *International Nursing Review*, *59*(3), 312-320.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Casework Services for Parents of Handicapped Children*, 43, 13-16.

Ong, B.N., Jinks, C. & Morden, A. (2011). The hard work of self-management: Living with chronic knee pain. *International Journal of Qualitative Studies on Health and Well-being*, *6*(3).

Orwell, G. (1949). *1984*. New York: Harcourt.

Pandrini, M. & Ramilli, M. (2012) Raising risk awareness on the adoption of Web 2.0 technologies in decision making processes. *Future Internet, 4*, 700-718. doi: 10.3390/fi4030700

Park, N., Kee, K.F. & Valenzuela, S. (2009). Being immersed in social networking environment: Facebook groups, uses and gratifications, and social outcomes. *CyberPsychology & Behavior*, *12*(6), 729-733.

Parr, H. (2002). New body geographies: The embodied spaces of health and medical information on the Internet. *Environment and Planning D: Society and Space, 20*, 73-95.

Parrish, R.N. (2010). *Mothers' experiences raising children who have multiple disabilities and their perceptions of the chronic sorrow phenomenon* (Doctoral dissertation, University of North Carolina at Greensboro). Retrieved from http://libres.uncg.edu/ir/uncg/f/parrish_uncg_0154d_10388.pdf

Parrott, A.C. (1999). Does cigarette smoking cause stress? *American Psychologist, 54*(10), 817-820.

Patsos, M. (2001). The Internet and medicine: Building a community for patients with rare diseases. *JAMA, 285*(6).

Pearson, E. (2007). Digital gifts: Participation and gift exchange in Livejournal communities. *First Monday*, *12*(5).

Penner, L.A. (2002). Dispositional and organizational influences on sustained volunteerism: An interactionist perspective. *Journal of Social Issues, 58*(3), 447-467.

Phillips, S. (2007, July 25). A brief history of Facebook. *The Guardian*. Retrieved from http://www.theguardian.com/technology/2007/jul/25/media.newmedia

Picard, A. (2005). How can we improve medical reporting? Let me count the ways. *International Journal of Health Services, 35*(3), 603-605.

Pierret, J. (2003). The illness experience: State of knowledge and perspectives for research. *Sociology of Health & Illness*, *25*(3), 4-22.

Pirkis, J., Blood, R. W., Francis, C., Putnis, P., Burgess, P., Morley, B., … Payne, T. (2001). *A baseline description of how the Australian media report and portray suicide and mental health and illness* (Executive Summary). Canberra: Department of Health and Aged Care.

Polkinghorne, D.E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology*, *52*(2), 137.

Pope, C. (2005). Conducting ethnography in medical settings. *Medical Education, 39*(12), 1180-1187.

Poster, M. (2001). *What's the matter with the Internet?* University of Minnesota Press: Minneapolis.

Powdermaker, H. (1966). *Stranger and friend: The way of the anthropologist*. New York: WW Norton and Company.

Pownell, A. (2010, May 8). Red wine, chocolate not so sweet. *The West Australian*

Preece, J. (1998). Empathic communities: Reaching out across the Web. *Interactions*, *5*(2), 32-43.

Preece, J. & Maloney-Krichmar, D. (2003) Online Communities. In J. Jacko & A. Sears (Eds.) *Handbook of Human-Computer Interaction* (pp. 596-620). Mahwah NJ: Lawrence Erlbaum Associates Inc.

Preece, J., Nonnecke, B. & Andrews, D. (2004). The top 5 reasons for lurking: Improving community experiences for everyone. *Computers in Human Behavior, 2*(1), 201-223.

Pruulmann-Vengerfeldt, P., Tatsi, T., Runnel, P. & Aljas, A. (2012). Methodological approaches to understanding audience participation in museums. *Proceedings of the Transformative Museum (pp. 301- 346)*. Roskilde University: Denmark.

Raacke, J. & Bonds-Raacke, J. (2008). MySpace and Facebook: Applying the uses and gratifications theory to exploring friend-networking sites. *Cyberpsychology & Behavior*, *11*(2), 169-174.

Rabinow, P. (2007). *Reflections on fieldwork in Morocco*. Berkley CA: University of California Press.

Rafaeli, S. & Sudweeks, F. (1998). Interactivity on the Nets. *Network and netplay: Virtual groups on the Internet*, 173-90.

Ransohoff, D.F. & Ransohoff, R.M. (2001). Sensationalism in the media: When scientists and journalists may be complicit collaborators. *Effective Clinical Practice, 4*(4), 185-188.

Rau, P.L.P., Gao, Q. & Ding, Y. (2008). Relationship between the level of intimacy and lurking in online social network services. *Computers in Human Behavior*, *24*(6), 2757-2770.

Raymond, E.S. (2000). *The hacker milieu as gift culture. Homesteading the Noosphere*. (Version 3.0). Thyserus Enterprises. Retrieved from http://catb.org/esr/writings/homesteading/homesteading/index.html

Reeve, J. (2010). Interpretive medicine: supporting generalism in a changing primary care world. *Occasional paper (Royal College of General Practitioners)*, (88), 1.

Reeve, J., Lloyd-Williams, M., Payne, S. & Dowrick, C. (2009). Insights into the impact of clinical encounters gained from personal accounts living with advanced cancer. *Primary Health Care Research & Development, 10*, 357-367.

Reeves, S., Kuper, A. & Hodges, B.D. (2008). Qualitative research methodologies: Ethnography. *British Medical Journal*, *337*(7668), 512-524.

Reiner, R. & Zackman, J. (Writers). (2008, February 21). *The Bucket List*. In C. Zadan, N. Meron & A. Greisman (Producers). USA: Warner Bros Pictures.

Reinfeld-Kirkman, N., Kalucy, E. & Roeger, L. (2010). The relationship between self-reported health status and the increasing likelihood of South Australians seeking Internet health information. *Australian New Zealand Journal of Public health, 34,* 422-426.

Ren, Y., Kraut, R., Kiesler, S. & Resnick, P. (2012). Encouraging commitment in online communities. In R. E. Kraut, P. Resnick, S. Kiesler, M. Burke, Y. Chen, N. Kittur, ... & J. Riedl. (Eds).*Building successful online communities: Evidence-based social design*. (pp. 77-125). London: MIT Press.

ResMed CPAP Australia Pty Ltd (2012). *CPAP therapy*. Retrieved from http://www.cpapaustralia.com.au/

Rheingold, H. (1993). *The Virtual Community: Homesteading on the electronic frontier*. New York: Addison-Wesley.

Rheingold, H. (1996). A slice of my life in my virtual community. In P. Ludlow, (Ed.), *High noon on the electronic frontier: Conceptual issues in cyberspace*, (3rd printing 1999; pp. 413-436). London: The MIT Press.

Rheingold, H. (2001). *The Virtual Community: Homesteading on the electronic frontier*. Revised edition. Cambridge MA: The MIT Press.

Rittman, M., Boylstein, C., Hinojosa, R., Hinojosa, M.S. & Haun, J. (2007). Transition experiences of stroke survivors following discharge home. *Topics in Stroke Rehabilitation, 14*(2), 21-31.

Robotham, J. (2006). Australia's media reporting of health and medical matters: A question of quality. *The Medical Journal of Australia, 184*(9), 479-480.

Rochford, A. (Presenter). (2006-2009). *What's good for you.* [Television series]. Australia: Nine Network.

Rochlen, A.B., Zack, J.S. & Speyer, C. (2004). Online therapy: Review of relevant definitions, debates, and current empirical support. *Journal of Clinical Psychology*, *60*(3), 269-283.

Rodan, D. (2010, July 7-9). Remaking the obese 'self' in the biggest loser: Couples. *Proceedings of the ANZCA Media, democracy and change conference.* Canberra: Australia.

Rodan, D., Uridge, L.K. & Green, L. R. (2012). Negotiating a new identity online and off-line: The HeartNET experience. In P.H. Cheong., J.N. Martin & L.P. Macfadyen (Eds.), *New Media and Intercultural Communication.* Chicago: Peter Lang.

Rose, D. (2010, May 11). No heart benefits in chocolate, red wine. *The West Australian.*

Ross, C., Orr, E.S., Sisic, M., Arseneault, J.M., Simmering, M.G. & Orr, R.R. (2009). Personality and motivations associated with Facebook use. *Computers in Human Behavior*, *25*(2), 578-586.

Rossheim, B.N. & McAdams, C.R. (2010). Addressing the chronic sorrow of long-term spousal caregivers: A primer for counsellors. *Journal of Counseling and Development*, 88, 477-482.

Rossi, L. (2009). Playing your network: Gaming in social network sites. *Proceedings of DiGRA 2009*, *Breaking new ground: Innovation in Games, Play, Practice and Theory.* Brunel University, West London, United Kingdom.

Rossi, L., Magnani, M. & Ladarola, B. (2011). #Rescatemineros: global media events in the microblogging age. *Proceedings from Association of Internet researchers IR 12.0: performance and participation*: Seattle USA.

Roy Morgan Research (RMR). (2004). *Why Australians don't respect the media*. Retrieved from http://www.roymorgan.com.au/~/media/Files/Papers/2004/20040903.pdf

Sahlins, M. (1972). *Stone age economics*. Chicago: Aldine-Atherton.

Sahlins, M. (1965). On the sociology of primitive exchange. In M. Gluckman and F. Eggan (Eds.). *The relevance of models for social anthropology*. (pp. 139-227). London: Tavistock Publications.

Saltou, C. & Lallo, M. (2012, December 29). Stars mourn a giant of modern cricket. *Sport. The Sydney Morning Herald.* Retrieved from http://www.smh.com.au/sport/cricket/stars-mourn-a-giant-of-modern-cricket-20121229-2c06b.html

SANE Australia. (2009). Stigma, the media and mental illness. *Research Bulletin 10*. Retrieved from www.sane.org

Saunders, C. (2010, June 16). Dementia our forgotten epidemic. *The West Australian*. https://au.news.yahoo.com/qld/a/7406147/dementia-our-forgotten-epidemic/

Schoenbach, K. (2004). A balance between imitation and contrast: What makes newspapers successful? A summary of internationally comparative research. *Journal of Media Economics, 17*(3), 219-227. doi: 10.1207/s15327736me1703_

Schwartz, L.M. & Woloshin, S. (2004). The media matter: A call for straightforward medical reporting. *Annals of Internal Medicine, 140*(3), 226-228.

Schwitzer, G. (2004). TV: Ten troublesome trends in TV health news. *British Medical Journal*, *329*(7478), 1352.

Schwitzer, G. (2005). The agenda-setting role of health journalists. *The PloS Medicine Debate*. Retrieved 7th August 2007, from www.plosmedicine.org

Seale, C., Charteris-Black, J., MacFarlane, A. & McPherson, A. (2010). Interviews and Internet forums: A comparison of two sources of qualitative data. *Qualitative Health Research, 20*(5), 595-606.

Seale, C., Ziebland, S. & Charteris-Black, J. (2006). Gender, cancer experience and Internet use: a comparative keyword analysis of interviews and online cancer support groups. *Social Science & Medicine*, *62*(10), 2577-2590.

Shifman, L. & Blondheim, M. (2010). The medium is the joke: Online humor about and by networked computers. *New Media & Society*, *12*(8), 1348-1367.

Shuchman, M., & Wilkes, M.S. (1997). Medical scientists and health news reporting: A case of miscommunication. *Annals of Internal Medicine, 126*, 976-982.

Silver, D. & Garland, P. (2004). "sHoP onLiNE": Advertising female teen cyberculture. In P. N. Howard & S. Jones (Eds.), *Society online the Internet in context* (pp. 157-173). London: Sage Publications.

Silverstone, R. (1994). *Television and everyday life*. London: Routledge.

Smith, D.E., Wilson, A. & Henry, D.A. (2005). Monitoring the quality of medical news reporting: early experience with media doctor. *Medical Journal of Australia, 183*(4), 190-193.

Social Change Media. (2005*). Using media: A practical guide to using the media for community activists.* Retrieved from http://www.communitybuilders.nsw.gov.au/getting_organised/message/media1.html

Soffer, M. & Ajzenstadt, M. (2010). Stigma and otherness in the Israeli media's mirror representations of illness. *Qualitative Health Research, 20*(8), 1033-1049.

South-West Corridor Workforce Development Plan. (2009). *South-West Corridor Workforce Development Plan*. Perth: Department of Education, Employment and Workplace Learning.

Spurlock, M. (Producer & Director). (2004). *Super size me* [Motion picture]. United States: Samuel Goldwyn Films Roadside Attractions.

Stendal, K., Balandin, S. & Molka-Danielsen, J. (2011). Virtual worlds: A new opportunity for people with lifelong disability? *Journal of Intellectual and Developmental Disability*, *36*(1), 80-83.

Stepakoff, S. (2009). From destruction to creation, from silence to speech: Poetry therapy principles and practices for working with suicide grief. *The Arts in Psychotherapy, 362*(2), 105-113.

Stevenson, I. (Director). (2012). *The Biggest Loser*. [Television series]. Australia: Shine Australia for Network 10.

Stone, A. (1991). Will the real body please stand up? In M. Benedikt (Ed.), *Cyberspace: First steps* (pp. 81-118). Cambridge: MIT Press.

Streubert, H. & Carpenter, D. (1999). *Qualitative research in nursing: Advancing the humanistic imperative* (2nd ed.). Philadelphia, PA: Lippincott.

Stull, D.E., Starling, R., Haas, G. & Young, J.B. (1999). Becoming a patient with heart failure [Issues in cardiovascular nursing]. *Heart & Lung The Journal of Acute and Critical Care, 28*(4), 284-292.

Suarez, M. (2004). *Gift giving in the net. The gift economy "Shifting the paradigm to a woman based gift economy"*. Retrieved from http://www.gift-economy.com/athanor/athanor_018.html

Sunday Times. (2009, November 22). Bread cancer fear. *Sunday Times* (Western Australia). Retrieved from http://global-factiva

Suler, J. (2004). The online disinhibition effect. *CyberPsychology & Behavior, 7*(3), 321-326.

Suler, J.R. (2004). Extending the classroom into cyberspace: The discussion board. *CyberPsychology & Behavior, 7*, 397-403.

Swan, N. (2005). Evidence-based journalism: A forlorn hope? *The Medical Journal of Australia, 183*(4), 194-195.

Sweet, M.A. (2005). New website is no miracle cure. *The Medical Journal of Australia, 183*(4), 194.

Swinburn, B.A., Sacks, G., Hall, K.D., McPherson, K., Finegood, D.T., Moodie, M.L. & Gortmaker, S.L. (2011). The global obesity pandemic: shaped by global drivers and local environments. *The Lancet*, *378*(9793), 804-814.

Taylor, J. (2011). The intimate insider: negotiating the ethics of friendship when doing insider research. *Qualitative Research*, *11*(1), 3-22.

Taylor, S.E., Sherman, D.K., Kim, H.S., Jarcho, J., Takagi, K. & Dunagan, M.S. (2004). Culture and social support: Who seeks it and why? *Journal of Personality and Social Psychology, 87*(3), 354-362.

Thomas, P.A. (2010). Is it better to give or to receive? Social support and the well-being of older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *65*(3), 351-357.

Turkle, S. (1995). *Life on the screen in the age of the Internet*. New York: Simon & Schuster.

Uridge, L.K. (2007). *The use of the Internet as a bibliotherapeutic tool for parents with children with disabilities or special needs: An exploratory study*. (Master's Thesis) Retrieved from http://ro.ecu.edu.au/theses/283/

Uridge, L.K., Green, L., Rodan, D. & Cullen, T. (2014). A vulnerable community of heart patients' re/constructs media stories about cardiovascular disease. *Proceedings of the Australian and New Zealand Communication Association (ANZCA) Conference: The digital and the social: Communication for inclusion and exchange.* Swinburne University: Melbourne, Australia.

Uridge, L.K., Rodan, D. & Green, L. (2010). Negotiating conflict and negativity in an online community for recovering heart patients. In F. Sudweeks, H. Hrachovec, C. Ess (Eds). *Proceedings Cultural Attitudes Towards Communication and Technology,* Murdoch Univeristy, Australia.

Uridge, L.K., Rodan, D. & Green, L. (2012). A moderator's dilemma: Munchausen Syndrome by Internet? in C. Anyanwu, K. Green, J. Sykes (Eds), In *Proceedings of the Australian and New Zealand Communication Association Conference: Communicating Change and Changing Communication in the 21st Century*: Adelaide: South Australia.

Valenzuela, S., Park, N. & Kee, K.F. (2009). Is there social capital in a social network site? Facebook use and college students' life satisfaction, trust, and participation. *Journal of Computer‐Mediated Communication*, *14*(4), 875-901.

Valkenburg, P.M., Schouten, A.P. & Peter, J. (2005). Adolescents' identity experiments on the Internet. *New Media & Society*, *7*(3), 383-402.

Van Der Weyden, M.B. & Armstrong, R.M. (2005). Australia's media reporting of health and medical matters: A question of quality. *Medical Journal of Australia, 183*(4), 188-200.

van Gool, K. (2007). Funding public health in Australia. *Health Policy Monitors*, 9, 1-10.

Van Gorp, B. (2007). The constructionist approach to framing: Bringing culture back in. *Journal of Communication, 57,* 60-78.

van Uden-Kraan, C.F., Drossaert, C.H. C., Taal, E., Lebrun, C.E.I., Drossaers-Bakker, K.W., Smit, W.M. ... & Van de Laar, M.A.F.J. (2008). Coping with somatic illnesses in online support groups: Do the feared disadvantages actually occur? *Computers in Human Behavior*, *24*(2), 309-324.

Vasek, L. (2010, May 1). Pleas made for public health funding. *The Australian*. Retrieved from http://www.theaustralian.com.au/news/nation/plea-made-for-mental-health-funding/story-e6frg6nf-1225860823110

Veale, K.J. (2003). Internet gift economies: Voluntary payment schemes as tangible reciprocity. *First Monday, 8*(12). Retrieved from http://www.firstmonday.org/issues/issue8_12veale/#4

Veysman, B. (2010). 'Shock me, tube me, line me'. *Health Affairs, 29*(2), 324-326.

Vilhauer, R.P. (2009). Perceived benefits of online support groups for women with metastatic breast cancer. *Women & Health, 49*(5), 381-404. doi: 10.1080/03630240903228719

Vivian, N., & Sudweeks, F. (2003, June 24-27). Social networks in transnational and virtual communities. In *Proceedings of the Informing Science and Information Technology Education (InSITE) Conference*. Pori, Finland.

Waddington, D. (2004). Participant observation. In C. Cassell., & G. Symon (Eds.), *Essential guide to qualitative methods in organizational research*, (pp. 154-164). London: Sage Publications Ltd.

Wallace, P. (1999). *The psychology of the Internet*. Cambridge: Cambridge University Press.

Wallington, S.F., Blake, K.D., Taylor-Clark, K. & Viswanath, K. (2010). Challenges in covering health disparities in local news media: An exploratory analysis assessing views of journalists. *Journal of Community Health, 35*, 487-494.

Walstrom, M. (2004). Ethics and engagement in communication scholarship: Analyzing public, online support groups as researcher/participant-experiencer. In E.A. Buchanan (Ed), *Virtual research ethics: Issues and controversies* (pp. 174-202). Hershey, PA: Information Science Publishing.

Walther, J.B., Carr, C.T., Choi, S.S.W., DeAndrea, D.C., Kim, J., Tong, S.T. & Van Der Heide, B. (2010). Interaction of interpersonal, peer, and media influence sources online. In Z. Papacharissi (Ed.). *A networked self: Identity, community, and culture on social network sites*, (pp. 17-39). New York: Routledge.

Wang, W. & Taylor, P. (2009). Smokers can't blow off stress. *Pew Social and Demographic Trends*. Retrieved from http://pewsocialtrends.org/pubs/732/smoking-stress-quitting#continue

Wang, Y. & Fesenmaier, D.R. (2003). Assessing motivation of contribution in online communities: An empirical investigation of an online travel community. *Electronic Markets*, *13*(1), 33-45.

Wang, Z. & Gantz, W. (2007). Health content in local television news. *Health Communication, 21*(3), 213-221.

Weinstein, S .M. (2009). *B is for balance: A nurses guide for enjoying life at work and at home*. Indianopolis: Sigma Theta Tu International.

Wellman, B. & Hampton, K. (1999). Living networked on and offline. *Contemporary Sociology, 28*(6), 648-653.

The West Australian. (2010, March 30). Community cannot afford cuts to libraries. *The West Australian.*

The West Australian. (2010, May 19). *Five year heart warning for over 55's.*

Weiner, A. B. (1980). Reproduction: A replacement for reciprocity. *American Ethnologist*, *7*(1), 71-85.

Welser, H.T., Gleave, E., Fisher, D. & Smith, M. (2007). Visualizing the signatures of social roles in online discussion groups. *Journal of Social Structure*, *8*(2), 1-32.

White, M. & Dorman, S.M. (2001). Receiving social support online: Implications for health education. *Health Education Research, 16*(6), 696-707.

Whitehead, T. L. (2005). *Basic classical ethnographic research methods. Ethnographically informed community and cultural assessment research systems*. Maryland: Cultural Ecology of Health and Change.

Williams, G. (1984). The genesis of chronic illness: narrative reconstruction. *Sociology of Health & Illness, 6*(6), 175-200.

Williams, R.L. & Cothrel, J. (2000). Four smart ways to run online communities. *Sloan Management Review* (Summer), 81-91.

Willson, M.A. (2006). *Technically together: Rethinking community within techno-society.* New York: Peter Lang.

Wilson, A., Bonevski, B., Jones, A. & Henry, D. (2009). Media reporting of health interventions: Signs of improvement but major problems persist. *PLoS One, 4*(3), e4831.

Wilson, A., Robertson, J., McElduff, P., Jones, A. & Henry, D. (2010). Does it matter who writes medical news stories? *PLoS Medicine, 7*(9).e1000323.

Wohn, D. Y., Lampe, C., Wash, R., Ellison, N. & Vitak, J. (2011). The" S" in social network games: Initiating, maintaining, and enhancing relationships. In *System Sciences (HICSS), 2011 44th Hawaii International Conference on* (pp. 1-10). IEEE.

Wolcott, H. F. (1999). *Ethnography: A way of seeing*. Oxford: AltaMira Press.

Woodward, K. (2002). *Understanding identity*. London: Arnold.

Wright, K. (2002). Social support within an online cancer community: An assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. *Journal of Applied Communication Research, 30*(3), 195-209.

Wright, K.B. (2005). Researching Internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, *10*(3), 00-00.

Wright, K.B. & Bell, S.B. (2003). Health-related support groups on the Internet: Linking empirical findings to social support and computer-mediated Communication Theory. *Journal of Health Psychology, 8*, 39-54.

Yoshida, K.K. (1993). Reshaping of self: A pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health & Illness, 15*(2), 217-245.

Zeng, L. (2014). *The impacts of design on voluntary participation case studies of Zimuzu and Baike*. Master's Thesis, London School of Economics and Policitcs. Retrieved from http://www.lse.ac.uk/media@lse/research/mediaWorkingPapers/MScDissertationSeries/2013/95-Zeng.pdf

Zhang, J., Saltuklaroglu, T., Hudock, D. & Kalinowski, J. (2011). University students' familiarity with famous people who stutter. *Canadian Journal of Speech-Language pathology and Audiology, 35*(1), 40-44.

Ziebland, S. & Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the Internet affect people's health? *Milbank Quarterly*, *90*(2), 219-249.

Zrebiec, J.F. & Jacobson, A.M. (2001). What attracts patients with diabetes to an Internet support group? A 21 month longitudinal website study. *Diabetic Medicine, 18*(2), 154-158.

Zynga. (2014). *FarmVille*. Retrieved from https://company.zynga.com/games/farmville

APPENDICES

Appendix 1: Risk Assessment

Researcher: Lynsey URIDGE
Title of Research: The identity of the heart patient in the context of the
                         gift economy: HeartNET and media framing

The main risks identified are:

Risk	Positive Action
Potential Risk of Harm or Injury to researcher or participants in study	All participants in this research will be informed of the Occupational Safety and Health Policy issues while on the University Campus and all efforts will be made to ensure the interviews take place in a safe and risk free environment. All potential hazards will be identified and the relevant Safety and Health Officer will be notified in accordance with the University's policy
Potential breach of privacy	All participants will be informed in writing prior to the commencement of the interviews that all data will be kept secure, confidentiality of the source of the material will be maintained and no identifiable data will be used in any part of the research or any subsequent publications. At the completion of the research all documentation and discs will be shredded or cut up.
Potential Distress to Participants in this study	The risk of potential distress to any participant should be no greater than normal. If any participants how distress, the interview will be stopped and the researcher will seek medical advice if required. A card containing the name and contact details of a local crisis care helpline (http://www.lifelinewa.org.au/) will be given to the participant.
Informed consent	Participants prior to taking part in this research will have given their informed consent. No information will be withheld from the participants. All questions participants may have will be answered to the best of the researcher's knowledge. An alternative contact, namely the researcher's supervisor, will be contacted if required to answer any queries the participant may have. Participants will be made aware that they are able to withdraw from the study at any time without prejudice. At no time will participants be asked to partake in

	any unpleasant or harmful incidents or stimuli. No participants will be asked any inappropriate or unpleasant questions, and all questions will have been approved by the ECU Ethics Committee.
Tape recordings of transcripts	Participants will be aware prior to commencement of the interview that the proceedings will be recorded. Consent to tape the interview will be obtained prior to commencement of the interview. No identifying information will be retained when the interviews are transcribed. The master disc containing the interviewee's names and corresponding number will be kept separate from all other documentation in a secure environment and destroyed by crushing or cutting up on completion of the research.
Ethical Implications	Prior to undertaking any research an application to undertake research with human subjects will be obtained from the Ethics Committee, Edith Cowan University, Perth WA.

Appendix 2: Information Letter

To whom it may concern:

This letter introduces Lynsey Uridge, a PhD candidate at Edith Cowan University, Perth, Western Australia. As part of her research Ms. Uridge is interviewing people about their heart disease, heart story and the processing and internalising of media messages and their use or non-use of HeartNET for heart health support. The title of this research is as follows:

The identity of the heart patient in the context of the gift economy: HeartNET and media framing

This study is longitudinal and will involve you completing an initial screening questionnaire take about 5-10 minutes. You will then be asked to participate in an initial in-depth interview of approximately 1 hour's duration which will investigate online support, the media and the gift economy. In around 6-12 months' time you will be approached to see if you are prepared to participate in a further 1 hour in-depth interview of around the same duration.

Both interviews will be recorded digitally and transcribed so the researcher has access to your comments. The recording will be kept in a locked cabinet in the researcher's office and destroyed after five years in accordance with the Universities ethical guidelines. The results of this questionnaire and the in-depth interviews will be included in Ms. Uridge's PhD thesis and any related publications. Confidentiality of information will be strictly maintained and no identifying information will be included in any publications.

Lynsey is doing this research as part of the requirements of her PhD studies at Edith Cowan University. You can also speak to Dr Debbie Rodan at Edith Cowan University. Dr Rodan's contact details are provided below. If you have any queries or would like to speak to an independent person about this research please contact:

Ms Kim Gifkins
Research Ethics Officer
Edith Cowan University
Joondalup Drive
Joondalup Western Australia 6027
Tel: (+61 8) 6304 2170
Fax: (+61 8) 6304 2661
Email: research.ethics@ecu.edu.au
Participants are advised that they are free to withdraw from this research without prejudice in any way and that they do not need to give any reason for their decision. Thank you in advance for participating in this research.

Lynsey Uridge: Researcher	Dr Debbie Rodan Supervisor
Edith Cowan University	Senior Lecturer
Faculty of Education & Arts	Edith Cowan University
2 Bradford Street	Faculty of Education and Arts
Mt Lawley WA 6050	2 Bradford Street
(08) 9370 6337	Mt Lawley 6050
lynseyu@our.ecu.edu.au	(08) 9370 6415
	d.rodan@ecu.edu.au

Appendix 3: Screening Questionnaire

Dear_____

You have been recommended to the research team by _____as a potential participant for the following research project:

The identity of the heart patient in the context of the gift economy: HeartNET and media framing

Please complete the following short questionnaire and return it in the envelope enclosed. The answers found provided in this questionnaire will determine if you meet the criteria to be included in this research.

I will get in touch with you shortly regarding your interest in this research. Thank you.

What is your full name?	
Are you currently undergoing treatment for a cardiovascular related condition?	Yes/No
What type of heart condition do you have?	Heart Attack Angina High Cholesterol Stroke Other?
When was your condition diagnosed?	Between 0-6 months Between 6-12 months Between 12-18 months Between 18- 24 months Longer than 2 years Longer than 5 years
Do you have Internet access?	Yes/No
Where do you gain your Internet access	Home Work Library Office Internet Café Other

How often do you use the Internet	Daily Once a week 2-3 times a week Once a month Never
What Health Information do you look for on the Internet?	
Do you belong to any online support groups? If so, which ones?	
Are you interested in participating in the current research?	Yes/No
If yes, please provide contact details at the end of this research	
If no, thank you for your time	

Name:

_____

Email Address:

_____

Phone Number:

_____

Lynsey Uridge: Researcher	Dr Debbie Rodan Supervisor
Edith Cowan University Faculty of Education & Arts 2 Bradford Street Mt Lawley WA 6050 (08) 9370 6337 lynseyu@our.ecu.edu.au	Senior Lecturer Edith Cowan University Faculty of Education and Arts 2 Bradford Street Mt Lawley 6050 (08) 9370 6415 d.rodan@ecu.edu.au

Appendix 4: In-depth Interview Information Letter

Dear_____,

Re: Intended research project:
The identity of the heart patient in the context of the gift economy: HeartNET and media framing

Thank you for taking part in this in-depth interview.

Lynsey Uridge is currently enrolled in a PhD degree at Edith Cowan University, Perth, Western Australia. As part of her research she is requesting that you take part in 2 in-depth interview of approximately 1 hour's duration. Each interview will be audio recorded and later transcribed so Lynsey can record all the details of the conversation without the distraction of needing to clarify things that you have said. Confidentiality will be strictly maintained and no identifying information will be included in Lynsey Uridge's PhD Thesis and any related publications.

Any data collected will be treated in the strictest confidence and will only be available to the researcher and her supervisors. All data collected will be kept in locked storage and when the research is completed will be destroyed.

Participants are advised that they can withdraw their consent to participate in the in-depth interview without prejudice at any time and they do not have to give a reason or justification for their decision.

Any questions regarding this project can be directed to Lynsey Uridge on 9370 6337 or via email at lynseyu@our.ecu.edu.au. You can also speak to Dr. Debbie Rodan at Edith Cowan University. Dr. Rodan's contact details are provided below. If you have any concerns or complaints about the research project or would like to speak to an independent person, please contact:

Ms Kim Gifkins
Research Ethics Officer
Edith Cowan University
Joondalup Drive
Joondalup Western Australia 6027
Tel: (+61 8) 6304 2170
Email: research.ethics@ecu.edu.au

This research project has been approved by the ECU Human Research Ethics Committee.

Thank you in advance.

Lynsey Uridge

Lynsey Uridge: Researcher	Dr Debbie Rodan Supervisor
Edith Cowan University	Senior Lecturer
Faculty of Education & Arts	Edith Cowan University
2 Bradford Street	Faculty of Education and Arts
Mt Lawley WA 6050	2 Bradford Street
(08) 9370 6337	Mt Lawley 6050
lynseyu@our.ecu.edu.au	(08) 9370 6415
	d.rodan@ecu.edu.au

Appendix 5: In-depth Interview Consent Form for Participants

CONSENT FORM

Please complete the following consent form, if the interview is by telephone then return the following consent form in the envelope provided. You may keep the duplicate copy.

The identity of the heart patient in the context of the gift economy: HeartNET and media framing

I_____ (participant) have the read the accompanying information sheet and any questions I may have, have been answered to my satisfaction.

I understand that if I have any further questions I may contact the research team at any time if I wish to for further information about this ongoing research. I agree to participate in this research realising that I may withdraw at any time without any disadvantage or prejudice to myself. I also understand that participation in this research project will involve being interviewed, and that this interview will be audio recorded. I understand that after transcription the audiotapes will be erased. I agree that the research data gathered from this study may be published providing participants names are de-identified and further that no identifying information about any participants is included.

Participant's signature: _____ _____Date_____

Researcher's signature: _____Date_____

Lynsey Uridge: Researcher	Dr Debbie Rodan Supervisor
Edith Cowan University	Senior Lecturer
Faculty of Education & Arts	Edith Cowan University
2 Bradford Street	Faculty of Education and Arts
Mt Lawley WA 6050	2 Bradford Street
(08) 9370 6337	Mt Lawley 6050
lynseyu@our.ecu.edu.au	(08) 9370 6415
	d.rodan@ecu.edu.au

Appendix 6: Questions – In depth Interview 1

1. How did you feel when you were first diagnosed with heart disease?

2. What impact has it had on your life?

   a. Socially

   b. Any other ways

3. Has your view of yourself changed since your heart event?

4. Do you belong to any support groups?

   a. You don't belong to?

5. What sort of health information do you look for?

6. Think back to before your heart event.

   a. Do you remember noticing heart advertising?

   b. Can you give me an example?

   c. Has there been any change since your heart event?

Appendix 7: Questions – In depth Interview 2

1. Has there been any change in your health status since we last chatted?

2. Since being diagnosed with your heart problems are there things you would do differently?
   a. What sorts of things?
   b. Why?

2. Is there anything you do now, that you didn't do before your heart event?

3. I know you are involved in supporting roles in the church, at the local hospital, HeartNET – what led you … or prompted you to get involved?
   a. Why do you keep doing this?

4. You often hear about stories in the newspaper or on the news, about people who have had a heart problem – do you think this is helpful or depressing?
   a. in what way?
   b. Why do you feel that?

5. Can you recall any news/ television stories about heart disease?
   a. What made you notice or look at that particular story?
   b. Why?

6. Can you tell me your feelings about the way the media newspaper, television portrays heart disease?