



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

Research Commons

<http://researchcommons.waikato.ac.nz/>

## Research Commons at the University of Waikato

### Copyright Statement:

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

The thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of the thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from the thesis.

# **Communication Networks of Men with Prostate Cancer**

A thesis

submitted in partial fulfilment

of the requirements for the degree

of

**Master of Management Studies**

at

**The University of Waikato**

By

DOROTHY RUTH BROWN



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

2013

## **Abstract**

Prostate cancer can be a difficult disease to manage but men who are diagnosed with it have networks of others around them who can be ready to offer support through the treatment. The effectiveness with which these networks can be mobilised is partly determined by the willingness of men to disclose their diagnosis. The main purpose of this research was to determine both the structure and content of the networks of men who have recently had a biopsy for prostate cancer.

This qualitative study was conducted from an egocentric network perspective in which nodes and ties are fundamental features; nodes being the individuals or groups within a network and ties the relationships between them. All men who were on the waiting list for a prostate biopsy were eligible to be included in this study. A total of 41 men participated and completed a semi-structured interview that sought to elicit who were in the men's networks and what was talked about. Particular emphasis was placed on the types of relationships together with the context in which they existed. Only 22 interviews from participants who received a positive biopsy were used for the analysis. A thematic analysis of the transcriptions enabled assessments to be made of which individuals and organisations were important and their relationships to the ego at this point in the medical process.

The findings revealed that network structure is comprised of both general and health communication networks. General networks were those in everyday life and were determined by relationship status, employment status and geographical proximity of the men's immediate family. Health communication networks were based around health issues and the factors which influenced these were men's previous medical experience or whether they had medical professionals in their immediate family.

Network content is the communication which occurs between individuals and the major theme concerns disclosure. The men's decision about whether to disclose their prostate issues to others in their networks was based on the perceived presence of four factors in others: homophily, close proximity, strong ties and the

professional or personal medical experience of others. Discerning if one or more of these factors were present in others, the men were increasingly likely to disclose about their own health. The second theme examined the tensions which existed between the benefits and barriers to disclosure. This depended on individuals and the context and were managed by the men when assessing each situation on a case-by-case basis.

Theoretical implications of this research concern the recognition and functionality of health communication networks together with the four factors of disclosure. Future research would be focused around a longitudinal study to assess the dynamic nature of egocentric networks in responding to chronic illness. In addition, networks of single men and the value of siblings could be identified. Emphasis on the practical implications involve identifying and promoting favourable opportunities for disclosure to benefit the men who can receive support from their networks.

## Acknowledgements

My networks changed in ways I could never have dreamed of; they included every one of the following special people. Each one of them is the very best of what I could ever have hoped for and I am privileged; my thanks to:

Dr. John Oetzel, a master supervisor, who, with endless patience, has seen the way through messy drafts, endless questions and all the usual stuff of study. Dr. Margaret Richardson, co-supervisor, who offered to supervise because she saw something special in the project. She was never too busy for a coffee and so willingly shared the spare desk in her office. John and Margaret as supervisors together are the greatest!

The mediocre teacher tells, the good teacher explains, the superior teacher demonstrates and the great teacher inspires.

(William Arthur Ward)

Dr. Shiv Ganesh, senior lecturer, for revealing the world in another way, a networks way. Dr. Rachael Jones, mentor, who showed me that academia can be enthralling.

Dr. Adam Davies, consultant urologist, who grasped the meaning of what this research was all about and then put his hand up to be involved. Lisa Smidt-Archer, nurse manager, and her team of consultant urologists for enthusiastically running with this project while making rooms and advice freely available. My pilot-study men without whom this project would not have taken off. My patients, for their honesty and willingness to be interviewed at one of the most difficult times in their lives. Keith Beck, ex CEO of the Prostate Cancer Foundation, for being eager to work with a novice researcher.

The core of all my networks: my daughters, Hannah, Abby and Rosie who have each given more than I ever thought possible; Wendy Oed, best friend, for being around through the highs and lows. To complete my networks, I valued the enthusiasm and advice of Graham Harbutt, Margaret Vick, Robyn Couchman, Heather Morrell, Susan Mellsopp and Gwenda Pennington.

# Table of Contents

<b>Abstract</b>	<b>ii</b>
<b>Acknowledgements</b>	<b>iv</b>
<b>Table of Contents</b>	<b>v</b>
<b>List of Figures</b>	<b>ix</b>
<b>List of Tables</b>	<b>ix</b>
<b>Chapter 1: Introduction</b>	<b>1</b>
1.1 Men's Health and Prostate Cancer	2
1.2 Networks	4
1.3 Previous Literature	5
1.4 Rationale	7
1.5 Purpose and Research Questions	9
1.6 Preview of Thesis	10
<b>Chapter 2: Literature Review</b>	<b>11</b>
2.1 Prostate Cancer	11
2.1.1 Medical Overview	11
2.1.2 Incidence	12
2.1.3 Risk Factors	14
2.1.4 PSA Testing and the Medical Situation	15
2.1.5 PSA Screening and the Political Situation	16
2.1.6 Psychological Overview	18
2.1.7 Summary	18
2.2 Men's Health and Communication in New Zealand	19
2.2.1 Stage in Life	19
2.2.2 Individual Characteristics	20
2.2.3 Communication Style	22
2.2.4 Disclosure	23

2.2.5	Summary	25
2.3	Networks for Understanding Men’s Communication.....	25
2.3.1	Structure of Networks	26
2.3.2	Content of Networks	32
2.3.3	Psychological Perspective	32
2.3.4	Sociological Perspective	33
2.3.5	Communication Perspective	37
2.3.6	Summary	38
2.4	Conclusion of Literature Review.....	38
<b>Chapter 3: Methods</b> .....		<b>39</b>
3.1	Introduction.....	39
3.2	Justification for Methodology.....	39
3.2.1	Semi-Structured interviews	41
3.2.2	Timing	41
3.2.3	Free Recall	42
3.2.4	Older People	43
3.3	Participants.....	44
3.3.1	Ethics Approval	44
3.3.2	Eligibility of Participants	44
3.3.3	Final Participants	45
3.4	Data collection.....	48
3.4.1	Interview Guides	48
3.4.2	Procedures	50
3.5	Role of the Researcher.....	51
3.6	Data Analysis.....	52
3.6.1	Thematic Analysis	52
3.6.2	Procedure	53
3.7	Summary of Methods.....	56

<b>Chapter 4: Findings</b> .....	<b>57</b>
4.1    Research Question 1.....	58
4.1.1    Nodes in Men’s Communication Networks	58
4.1.2    Ties in Men’s Communication Networks	69
4.1.3    Summary of Research Question 1	72
4.2    Research Question 2.....	72
4.2.1    Context for Disclosure	73
4.2.2    Benefits of Disclosure	76
4.2.3    Barriers to Disclosure	86
4.2.4    Summary of Research Question 2	91
4.3    Research Question 3.....	92
4.3.1    Homophily	92
4.3.2    Close Proximity	93
4.3.3    Strong Ties	94
4.3.4    Alter’s Professional or Personal Experience of Cancer	94
4.3.5    Summary of Research Question 3	95
4.4    Summary of Findings.....	97
<b>Chapter 5: Discussion</b> .....	<b>99</b>
5.1    Research Question One.....	99
5.1.1    General Communication Networks	99
5.1.2    Health Communication Networks	103
5.2    Research Question Two.....	107
5.2.1    Disclosure	107
5.2.2    Social Support	110
5.3    Research Question Three.....	111

5.4	Implications.....	114
5.4.1	Theoretical Implications	114
5.4.2	Research Implications	115
5.4.3	Practical Implications	117
5.5	Limitations.....	120
5.6	Future Directions.....	121
5.7	Conclusion.....	123
<b>References.....</b>		<b>125</b>
<b>Appendix A: Glossary.....</b>		<b>139</b>
	Medical.....	139
	Communication.....	140
<b>Appendix B: Interview Questions.....</b>		<b>141</b>

## List of Figures

Figure 1: Larry's Network .....	59
Figure 2: Robert's Network .....	60
Figure 3: Edward's network.....	63
Figure 4: Donald's network .....	64
Figure 5: Charles' network.....	67
Figure 6: John's network.....	68
Figure 7: Frank's network.....	71

## List of Tables

Table 1: Participant Demographics .....	46
Table 2: Participant Details .....	47

## **Relationships**

Relationships, spider's webs,  
Linked around the clock,  
Connections that define us,  
Security in shock.

Ties to our Creator,  
Hold our anchors tight,  
Family, friends and neighbours,  
Stabilise in fright.

When we lose our bearings,  
Or sometimes lose the plot,  
Our shrinking world forgets all those,  
Encountered since our cot.

No splendid isolation,  
Adrift, alone, without.  
We're cradled in the thoughts,  
Of hundreds round about.

Relationships, tangled webs,  
Essential, typical.  
Don't forget to share your thoughts,  
It is reciprocal!

Bob Mills  
First volunteer in the pilot study

15 June 2012

Unpublished

## Chapter 1: Introduction

Few would dispute the need for effective communication in everyday life, but the ubiquitous stereotypical belief is that New Zealand men are strong, fit and healthy and do not communicate effectively. This paradox remains at the heart of this research. If men become ill their ability to communicate well determines to a large extent their long-term well-being; effective communication leads to better health outcomes (Boehmer & Clark, 2001). Communication is an indispensable part of health care and affects how we look after ourselves and each other to achieve good health and manage bad health (Coon, McBride-Wilson, & Coleman, 2007).

Older men have been a neglected group with respect to health care and psychosocial support (Kampf, 2010). Assumptions have been made that wives are able, willing and expected to look after their husbands should they become ill and in many instances women provide support very well (Bloch et al., 2007; Wellman & Wortley, 1990). However, not all men have the support of a female partner. Men may have been bereaved, divorced, or gay. They may live a long distance from their children or wider family and so do not receive this kind of support. Furthermore, the stereotype of the New Zealand male as strong, healthy and self-sufficient, combined with the social stigma of prostate cancer, does not foster a context in which men communicate their needs or feelings when they are diagnosed with prostate cancer. Therefore, the main purpose of this research is to find out how men who have recently had a biopsy for prostate cancer that later was determined to be positive, communicate within the network of others around them.

In my previous career as a Radiation Therapist, my interest in health communication originated from working in what I considered an imbalance in the western view of medicine. Patients with cancer would have the disease treated with all that western medicine was able to deliver - the latest technology in diagnostic tests, treatment machines and pharmacology. The patients would be subject to multiple treatment regimens for as long as they were able to tolerate them. They would, however, be relatively devoid of holistic support as their emotional and to a lesser extent, social needs, went unmet. In my experience a

few oncology centres might have offered the services of a part-time dietician, physiotherapist or social worker, but very rarely dedicated counsellors or psychologists. Not only was it the patient who received incomplete care, but their spouse, partner and wider family were neglected, if not invisible. I saw patients with a wholeness that seemed to elude western medicine and my solution was to explore in depth what makes effective communication realising that with communication comes support and better health care.

This introduction provides, firstly, an overview of men's health and prostate cancer, networks and social support. A brief discussion of existing research in these four areas is next; followed by the rationale and importance of this study when placed in the New Zealand context. Finally, the purpose and three research questions are explained followed by an overview of the entire thesis. Definitions of both medical and communication-related terms used in the text can be found in Appendix A on page 139.

## **1.1 Men's Health and Prostate Cancer**

This study will contribute to the topical debate about men's health in New Zealand. This country has been slow to create a public forum about men's health. In 1994 the Men's Health Forum was adopted in the UK and in the same year the annual National Men's Health Week was started in the USA. Eight years later, in 2002, six leading men's health organisations from around the world collaborated to launch International Men's Health Week which stimulated interest in men's health throughout Europe and further afield to include Australia. Eventually, in 2010, New Zealand adopted the nation-wide, annual Men's Health Week (Menshealthweek, 2013) which is a dedicated week for the promotion and education of men's health issues in the media.

Since 2010, the media in this country has promoted discussion of men's health with prominent men such as television personality Paul Holmes and ex-All Black Buck Shelford fronting men's health campaigns. Prostate cancer has been the target of one such campaign, Blue September, promoted by the Prostate Cancer Foundation (Prostate Cancer Foundation of New Zealand, 2010). Prostate cancer, in the minds of the general public, has come to represent men's health issues although men's health is concerned with a broader set of issues relating to the male anatomy which includes male genitalia and hormone-related diseases.

Increasing numbers of men around the world (except in Asia) are now being diagnosed with prostate cancer than at any time in the past (Blakely, Shaw, Atkinson, Cunningham, & Sarfati, 2011; Center et al., 2012). The incidence of prostate cancer is rapidly increasing (Center et al., 2012; Hsing, Tsao, & Devesa, 2000), which is proving a considerable burden on both a national and global scale. In New Zealand in 2011 around 3000 new cases of prostate cancer were registered with the Ministry of Health (2008) and prostate cancer was the fourth largest cause of mortality of cancer, after lung, colorectal and breast cancer (Ministry of Health, 2008).

Prostate cancer, like many other types of cancer, is a challenging disease to diagnose and treat. It affects men mainly over the age of 60 and the lifetime risk of being diagnosed with prostate cancer is 12% (Smart, 2008). Treatment is usually one of five options: surgical removal, hormone therapy, chemotherapy, radiation therapy or watch and wait (Peyromaure & Bodon-Gibod, 2007). Recent advances in the management of prostate cancer have included more sensitive tests and sophisticated treatments such as remote controlled or robotic surgery. Many treatments are successful; 93% of all men diagnosed with prostate cancer survive at least five years and 72% survive 10 years (Roesch et al., 2005) with a 4% lifetime risk of dying from it (Smart, 2008), although the quality of life after treatment is debatable (Roth, Weinberger, & Nelson, 2008; Zhou, Penedo, Lewis, et al., 2010).

There are, however, several complications associated with the symptoms of the disease and side effects of the treatments (Eton & Lepore, 2002; Roth et al., 2008) and for the man diagnosed with prostate cancer the challenge lies in how to cope with life (Arrington, Grant, & Vanderford, 2006; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Roesch et al., 2005; Zhou, Penedo, Bustillo, et al., 2010). Many men present to their general practitioner (GP) for a routine prostate check-up without any symptoms (Etzioni, Cha, Feuer, & Davidov, 1998). Subsequent tests can indicate the need for further investigations which will confirm the presence or absence of cancer, all while many patients feel completely well without any symptoms. This situation can rapidly become difficult for both the man and his family to manage as fear and anxiety are natural responses to the shock and uncertainty at this early stage in the medical journey (Halbert et al., 2010).

Management of the psychosocial aspects of prostate cancer, together with the social stigma of the disease, is a considerable challenge for everyone (Roth et al., 2008). One way to help overcome difficulties is to use an existing resource freely available to everyone; the man's own social network. Most men, in addition to their family, have an established set of friends who to a greater or lesser extent are involved in their lives. Within these networks are resources such as material support (for example meals or transport), information and companionship provided by individuals. It is the utilisation of these networks combined with the physical treatment that men have the best chance to cope with and survive prostate cancer.

## **1.2 Networks**

Networks are fundamental to everyday life. Society is highly integrated with a multitude of networks such as electrical networks, television, social, terrorist, ecosystems and cellular biology. They exist on many levels: global, national, organisational, individual or microscopic. This research focuses on communication networks at the individual level of analysis. Communication networks are "patterns of contact between communication partners" (Monge & Contractor, 2001, p. 440); the relationships between people and the context in which they exist and in its most simple form is an egocentric network (Prell, 2012). An egocentric network positions the individual at the centre of the network and others within it - from the core to the periphery. Networks can be broadly classified to include parent/child, sibling, extended kin, neighbour and friend (Wellman & Wortley, 1990), although there are many other typologies (Stephens, Alpass, Towers, & Stevenson, 2011).

Analysing networks, particularly communication networks, is challenging due to their complex and dynamic nature. Relationships and contexts are rarely static and networks reflect this chaotic existence. In the management discipline, network analysis has traditionally been used to understand how organisations function and relate to each other on an organisational level (Powell, 1990; Stohl, 1993, 1995). At an individual level, network analysis provides a unique perspective on relationships between people as the focus is not on individuals themselves; rather the ties between them. Communication network analysis shows what the actual relationships are like (Wellman, 1997) and the reality of how they function on a day to day basis, taking into account the social context. Network analysis uses

information gained at an individual level and integrates it to create a perspective of communication at a network level.

In order to visualise networks, authors have separated them into two components: structure and content (Haines, Beggs, & Hurlbert, 2008; Wellman, 1997). The structure is the way networks are set up; the physical properties which includes individuals and the relationships between them; content refers to the communication that happens within them. One function of networks is the provision of social support which can take many forms (Burlinson, 2008; Cohen & Wills, 1985; Wellman & Gulia, 1999); individuals can provide emotional support by affirming and listening and material support with practical help. Information support is the provision of quality timely information (Borgatti & Cross, 2003) and companionship is getting alongside others, sometimes through difficult situations.

### **1.3 Previous Literature**

Research on prostate cancer generally falls into four broad categories: medical, psychological, social and communication. Most of the stages in the medical journey have been researched from screening and early detection (Dale, Sartor, Davis, & Bennett, 1999; Durham, Low, & McLeod, 2003; Kampf, 2010) through treatment (Roth et al., 2008; Smart, 2008) to cancer survivorship and return to work (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013; Harden et al., 2008; Lepore & Helgeson, 1998; Zhou, Penedo, Bustillo, et al., 2010). Of current interest in the medical community is the issue of overdiagnosis of prostate cancer (Vickers, Roobol, & Lilja, 2012) where asymptomatic men were diagnosed and treated. The complications, both physical and emotional, were more debilitating for the men than when they were undiagnosed and symptom free. More importantly, the prognosis for treating asymptomatic men may not be much better than if they had not been treated and is the cause of much debate.

The psychological aspect includes studies covering the stigma associated with prostate cancer (Chapple & Ziebland, 2002; Clarke, 1999; Else-Quest, LoConte, Schiller, & Hyde, 2009), emotional responses to the diagnosis (Helgason, Dickman, Adolfsson, & Steineck, 2001), coping and adjustment through treatment (Bloch et al., 2007; Lepore & Revenson, 2007; Roesch et al., 2005) and the quality of life afterwards (Eton & Lepore, 2002). The social aspect has been

addressed with the provision of and seeking social support (Arrington et al., 2006; Balderson & Towell, 2003; Heaney & Israel, 2002; Scignaro, Barni, & Magrin, 2011) including the information needs of patients (Boberg et al., 2003; Visser & Van Andel, 2003). In the communication field research on communication with wives and doctors is prolific and to a lesser extent communication with wider families and support groups (Boehmer & Clark, 2001; Edwards & Clarke, 2004; Klemm, Hurst, Dearholt, & Trone, 1999; Ong, De Haes, Hoos, & Lammes, 1995; Poole et al., 2001; Song et al., 2012; Thaxton, Emshoff, & Guessous, 2008).

All these individuals and groups comprise part of an individual's health network providing help to overcome disease and regain good health. Viewing health by looking at networks provides a unique and interesting perspective on communication and its value in health care. Network analysis originated in the 1970s as a serious field of study (Prell, 2012) with early work on social relationships in communities (Burt, 1984; Granovetter, 2003; Wellman, Wong, Tindall, & Nazer, 1997) and since then has successfully been applied in the management field (Stohl, 1995) and in other disciplines. A more recent application of network analysis is in communication, (Monge & Contractor, 2001; Reinard, 2001) especially in personal (Feld, Sutor, & Hoegh, 2007; Wellman, 2007b) and online networks (Durant, McCray, & Safran, 2012; Mo, Malik, & Coulson, 2009; Shim, Cappella, & Han, 2011).

Social support is a primary function of communication networks and the positive aspects of social support have been extensively researched (Cohen & Wills, 1985). Recent interest has emerged in the negative aspects of social support and the perceived rather than received aspects (Haber, Cohen, Lucas, & Baltes, 2007). Social support and the networks that provide it are crucial in health care and as a consequence health communication is becoming recognised as an emerging and important area of communication (Kreps, Bonaguro, & Query Jr, 2003). Networks in the health field have been researched mainly in public health with analysis of the dispersal of diseases in the general population (Luke & Harris, 2007).

Although there is a vast range of research in both prostate cancer and network analysis little effort has been made to combine the two fields. Network analysis of health issues incorporates the interpersonal aspect but provides a different perspective by broadening the focus. An egocentric level of analysis (Wellman,

1997) views health from one person's perspective and considers how networks function in health issues. To conduct a study at the point of biopsy rather than after diagnosis is unique. Biopsies provide a distinct and different perspective to any other stage in the patient's medical journey; they signify the start of a long period of uncertainty and significant life changes. Another unique aspect of this research is the use of a network rather than an individual perspective on health care. Finally, little research on networks and prostate cancer fields has originated in New Zealand partly due to male stereotypes which apply particularly to health issues.

#### **1.4 Rationale**

Assumptions have been made about how men need or do not need help in times of ill health. New Zealand men are often stereotyped as self-sufficient with a make-do attitude; for example, sporting injuries are a badge of honour and ill health is perceived as a weakness (Tagg, 2008). Men have a different way of talking and relating than women as their choice of words tends towards a more confrontational style with less discussion and more monologue, less feelings-based and more issue-based (Consedine, 2011; Sloan, Gough, & Conner, 2010). New Zealand men prefer not to discuss their feelings. The traditional perception of stereotypical roles has hindered the help men are offered and can receive.

Men have been marginalised in the psychosocial aspect of cancer care in both the medical and academic literature (Kampf, 2010). Gender bias has ensured women have been disproportionately researched and supported with men receiving little acknowledgment and less support. Not only are men marginalised but the lack of emphasis on the psychosocial aspect of men undergoing treatment and living with cancer remains under-addressed, researched and funded.

Prostate cancer predominantly affects men over 60 years of age and older people are a vulnerable group in society, particularly those who are dependent on others (Wenger, 2002). They have diminished communication networks due to spousal and friend bereavement and increased complications associated with loss of mobility and friends (Stephens et al., 2011). As Wenger (2002) observed, "the lives of older people who must depend on others are very different from those of individuals who remain independent" (p.261). Networks of older people can

consist more of those who are able to offer support in some way and less of their own peer group who may also be dependent.

Viewing health from a communication network perspective is an excellent way to understand how relationships work and how networks provide support in the event of ill health. Networks expose the real world of relationships and health showing to what extent they are integrated into life. However, as Luke and Harris (2007) contended, we “know little about how social networks shape health communication among family members, friends, health professionals and community organisations” (p.144). The interplay between networks, health and people still remains a challenge at best and a mystery at worst.

The future direction of health communication is encouraging patients to take responsibility for themselves. Networks are an effective way to facilitate this as “communication research will increasingly be used to identify the information needs of consumers and suggest strategies for encouraging consumers to take control of their health and health care” (Kreps et al., 2003, p. 17).

Advances in the medical management of cancer have led to the increased sensitivity of diagnostic tests, more treatment choices and a decrease in the side effects of treatment. However, an ageing population and improved diagnostic testing in New Zealand are leading to an increase in the incidence of prostate cancer and its psychosocial complications. Despite a lack of agreement about the rates, the magnitude of the psychological problem is recognised. Bloch et al. (2007) claimed 20% of men diagnosed with prostate cancer report depression of whom 50% were severely affected; Balderson and Towell (2003) asserted 38% of patients had depression and anxiety at some stage throughout the process. In the face of a new diagnosis stress and misunderstanding increase and relationships become strained as all parties are subject to the same stressors. In addition, the need for psychological help occurs not just around the time of diagnosis but through all stages of the disease (Bloch et al., 2007). Few oncology wards, outpatient or radiation therapy clinics in New Zealand have a dedicated counsellor to help with these issues.

Networks are an under-utilised resource; they are readily available as nearly everyone has others around them who can provide a wide variety of resources. If these networks are understood and accessed the benefits to individuals,

communities, organisations and the health care system are immeasurable. Networks not only reduce the burden to health care organisations, they also ensure the individual has an improved quality of life by coping better as “self-management interventions have shown consistent positive effects across a range of chronic illnesses and have a great potential as a cost-effective method of providing support to people affected by cancer” (Chambers et al., 2011, p. 2). Addressing the psychosocial aspect of cancer care ensures an improved health outcome for men with prostate cancer. Men are able to cope and have a better prognosis when their psychological needs are met.

## **1.5 Purpose and Research Questions**

This research applied network analysis to men with prostate cancer in order to identify others with whom they have a relationship. Identifying who is in the networks gives an impression of the structure of the individual’s network. Building on the structure, consideration is then given as to what is discussed among each of these individuals; this is the content of networks. This in turn leads on to the identification of what social support is available within the network. The purpose of this study is two-fold: a) to identify the communication networks of men recently diagnosed with prostate cancer; and b) to distinguish some of the factors men take into account when choosing to, or not to disclose about their prostate issues to others in their networks.

Three research questions (RQ) addressed this two-fold purpose:

RQ1: What factors shape the structure of men’s communication networks prior to being diagnosed with prostate cancer?

RQ2: For men who are faced with a diagnosis of prostate cancer, what are their perspectives about disclosing their health status and receiving social support?

RQ3: How do men resolve tension between the benefits of disclosure and the barriers to disclosure?

## **1.6 Preview of Thesis**

By assessing the communication networks of men with prostate cancer it is possible to understand the relationships men have with others around them and the contexts in which these relationships exist. This research aims to understand not only networks but also the factors involved in men's decisions about whether or not to disclose about their prostate issues. This thesis is contained in five chapters. Following the introduction, the second chapter is a literature search concentrating on the main issues of prostate cancer, men's health and network analysis. The third chapter is a description of the methods used for this qualitative study, which was semi-structured interviews and thematic analysis. The findings chapter outlines the themes associated with the three research questions and the final chapter is a discussion which includes the conclusion.

## **Chapter 2: Literature Review**

The aim of this research is to establish the nature of communication networks in men with prostate cancer and how these networks influence communication about prostate cancer. By identifying how men actually communicate about their health and how much psychosocial support is accessed within their networks it will be possible to identify how networks can be better utilised to help men manage the treatment for prostate cancer more effectively. This chapter introduces prostate cancer by providing a medical overview, setting it first in a global and then in a local context. The next section addresses how men in New Zealand manage and communicate about their own health. The third section, introduces networks as a way to understand men's communication, and is discussed from the theoretical viewpoint of both structure and content. Finally, the nature of social support as one aspect of the content of networks is considered from psychological, sociological and communication perspectives.

### **2.1 Prostate Cancer**

As noted in the opening chapter, prostate cancer is becoming more prevalent as the population ages. This section provides an overview of the medical aspect of prostate cancer including the incidence of the disease and its risk factors. The history and recent debate about prostate specific antigen testing and screening is reviewed and the chapter concludes with a psychological overview of prostate cancer.

#### **2.1.1 Medical Overview**

The prostate gland, found only in men, is situated around the urethra where it emerges from the bladder. The function of the gland is to produce prostate specific antigen (PSA), a fluid that is a component of semen. Diseases of the prostate consist of both benign and malignant conditions. Benign conditions include chronic prostatitis (inflammation of the prostate), prostatic hyperplasia (proliferation of normal cells in the prostate) and prostatic enlargement. Malignant conditions, cancer, occur when abnormal tumour cells replicate, proliferating at such a rapid rate they go out of control threatening life. Cancer constitutes about 45% of all Trans Rectal UltraSound (TRUS) biopsies performed on the prostate (Smart, 2008). For some, prostate cancer can be indolent, passive and slow-

growing with symptoms that are slow to appear. On the other hand, active and more rapidly growing tumours can metastasise quickly requiring aggressive treatment such as a prostatectomy. Presenting symptoms of prostate cancer include dysuria (obstruction of the flow of urine), pain and problems of erectile dysfunction.

Options for the medical treatment of prostate cancer are well established and patients have four treatment choices: hormone replacement therapy, radiation therapy, prostatectomy or brachytherapy (Eton & Lepore, 2002; Health Committee, 2011; Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000; Peyromaure & Bodon-Gibod, 2007). A fifth choice, watch and wait, is also available to the urologists. The method of treatment is dependent on factors such as age, extent and location of the tumour, previous medical history and comorbid conditions. Physical complications of prostate cancer treatment include infection, urinary incontinence and bowel and erectile dysfunction. On-going psychological complications such as depression, anxiety and lack of ability to cope are also prevalent. Survival rates are high compared to other forms of cancer; in 2003, the American Cancer Society stated that 93% of all men diagnosed with prostate cancer will survive at least five years and 72% will survive 10 years (Roesch et al., 2005).

Prostate cancer is a challenging disease to both diagnose and treat, due in part to the interrelated nature of the symptoms and the psychological complications. In addition to the challenge at an individual level, the incidence of prostate cancer on a world-wide scale is also of significant concern.

### **2.1.2 Incidence**

The burden of prostate cancer is increasing world-wide. Prostate cancer is the second most common cause of cancer with 899,000 new cases in 2008 (Center et al., 2012) and the sixth leading cause of death from cancer in men with 258,000 deaths in 2008 (Ferlay et al., 2010). The worldwide burden of prostate cancer is expected to grow to an estimated 1.7 million new cases and 499,000 new deaths by 2030, simply due to the growth and ageing of the global population (Center et al., 2012).

These global incidence trends are reflected in New Zealand. It has the second highest age-standardised incidence rate of prostate cancer in the world of 104.4 per 100,000 people for the period 2000 to 2004 (Ferlay et al., 2010) during which approximately 3000 new cases were diagnosed each year. The incidence of prostate cancer doubled between 1956 and 1991 (Ministry of Health, 2008). Since 1993, the age-standardised incidence rate increased rapidly but has recently decreased from a peak of 115.4 in 2009 to 97 in 2011. However this rate is projected to rise, once again increasing the burden on the health system. In 2008 NZ\$52 million was spent treating prostate cancer in New Zealand (Ministry of Health, 2008). According to the World Health Organisation mortality rates in New Zealand for the period 2000 to 2006 was 16.9% per 100,000, the 14<sup>th</sup> highest of 52 countries. It had decreased by 2.8% per year on average between 1998 and 2007 (Center et al., 2012) with 560 men dying of the disease in 2008 accounting for 15% of all deaths from cancer.

The incidence of prostate cancer is projected to increase partly due to the ageing population. In 2010 almost half of New Zealand's population were over 40 years old – 33% was in the 40 to 64 years age bracket – and 14% was over 65. By the year 2036 1.54 million people will be aged 40 to 64 and 1.2 million will be over 65. The highest rate of growth for those over 65 will be between 2011 and 2036 as the baby boomers move into this age group (Statistics New Zealand, 2011).

Furthermore, due to the promotion and adoption of a healthy lifestyle, more men are living longer and are therefore being diagnosed with diseases of old age such as prostate cancer. Prostate cancer is a disease associated with older men; 12 out of 13 men develop prostate cancer after the age of 75. Media campaigns such as “5+ A day”, promoted since 1994, encouraged individuals of all ages to eat five servings of fresh fruit and vegetables a day (5+ A Day Charitable Trust, 2013). Another campaign, ‘Push Play’, initiated in 2004 by Sport and Recreation New Zealand, endorsed the need to exercise for at least 30 minutes each day (Bauman et al., 2003). Both these campaigns proved successful with a large number of people of all ages adopting a more active and healthy lifestyle (Bauman et al., 2003; Sport New Zealand, 2013). Older men also engaged with these mass campaigns and saw the need to take responsibility for their own well-being. Of those who participated in the Push Play campaign 66% were over 34 years of age (G.McLean, personal communication, March 22, 2013).

Individuals now live longer than those in previous generations. During the 1990s and 2000s a rapid growth in the number of people in the 40 to 65 age group could be partly attributed to these types of campaigns (Cavill & Bauman, 2004; Vaughan & Hansen, 2004). Active involvement in campaigns such as these reduced the likelihood of acquiring diseases such as cancer. Prostate cancer has two dominant factors known to increase the risk of acquiring it, age and heredity.

### **2.1.3 Risk Factors**

Prostate cancer as mentioned previously is an age-related condition (Harden et al., 2008; Kampf, 2010). The incidence of prostate cancer increases with age; for men over 65 years of age, the incidence is 14 times higher than for those between 45 and 64 years (Ministry of Health, 2008). The youngest age at which prostate cancer was diagnosed in 2009 in New Zealand (the most recent statistics available) was one man in the 35 to 40 years bracket. The greatest proportion (23%) diagnosed are between 65 and 70 years of age. In Europe the mean age of patients diagnosed with prostate cancer is above 72 years (Peyromaure & Bodon-Gibod, 2007). According to Smart (2008) the mean age of death from prostate cancer is 76 although significant numbers of men die from the age of 60. However, projections of the age bracket associated with the highest rate of diagnosis will soon change from the 65 to 70 bracket to the 45 to 64 years age bracket by 2016 (Ministry of Health, 2008).

Other factors in acquiring prostate cancer are heredity, ethnicity and the environment. A family history increases the likelihood of developing prostate cancer with a 5% to 10% inherited component. The risk of developing prostate cancer is doubled with immediate family less than 70 years old and when two first-line relatives (father or brother) are diagnosed (Peyromaure & Bodon-Gibod, 2007). At an annual prostate check-up GPs refer 13% of their patients for a Prostate Specific Antigen (PSA) test but in the event of family history of prostate cancer the referrals rise to 91% (Durham et al., 2003). Ethnicity is a lesser known risk factor as coloured people, especially from the Caribbean, have an abnormally high incidence of prostate cancer (Center et al., 2012; Peyromaure & Bodon-Gibod, 2007). To date no environmental factors are known to increase the risk. In order to identify the risk to the individual of acquiring prostate cancer PSA testing has been recently adopted by GPs.

#### **2.1.4 PSA Testing and the Medical Situation**

In all men, a small amount of PSA escapes into the bloodstream and it is this component which makes PSA testing possible. A PSA test is reasonably sensitive and by analysing an elevated level of PSA in the bloodstream medical providers can identify the potential presence of prostate cancer. The concentration in the blood serum tends to be proportional to the clinical stage of the disease although raised levels of PSA only indicate the presence of an abnormality; not the presence, absence or aggressiveness of cancer in particular. The PSA test is not cancer-specific but can provide a definitive diagnosis for other diseases of the prostate (Kampf, 2010); for example, prostatic infection which is a benign condition is responsible for 40% of high PSA results (Smart, 2008). An abnormal PSA test result would indicate the need for a biopsy which is the only definitive test for prostate cancer. At-risk patients who have an annual check-up and routine PSA test are diagnosed earlier than those who do not have a check-up.

General practitioners in New Zealand have offered PSA testing since 1993 (Smart, 2008). GPs request a PSA test if the patient is considered to have a high risk of acquiring prostate cancer, if the man is symptomatic, or has a family history of the disease. The man himself may wish to monitor his own health status and request a PSA test. The frequency of PSA testing is lower in New Zealand than in Australia and is influenced by social class; men in higher social classes are more likely to request a PSA test than those in lower socio-economic classes (Sneyd, Cox, Paul, & Skegg, 2007).

Until 2011 it was widely believed PSA testing led to the early detection of cancer and a decrease in the mortality rate. Testing was seen as being responsible for a significant increase in the incidence of prostate cancer; that is, prostate cancer is more likely to be diagnosed in recent years than compared to the past when PSA testing was not done. However, recent research has demonstrated that PSA screening has led to an increased likelihood of unnecessary surgery and it does not lead to earlier detection (Kampf, 2010). PSA testing can be responsible for overdiagnosis and over-treatment.

Overdiagnosis is the “detection of prostate cancer through PSA testing that otherwise would not have been diagnosed within the patient’s lifetime” (Etzioni et al., 2002, p. 981). Many men are symptom free at an annual prostate check-up and

Etzioni et al. (1998) claim about 75% of prostate cancers would never be diagnosed as men were symptom-free at presentation. The overdiagnosis debate is a worldwide and highly topical medical debate relating to various illnesses. Due to fairly crude diagnostic tools prostate cancer is proving a classic example of a disease being overdiagnosed. The extent of the problem is such that Prorok, Miller, and Kramer (2012) estimated in a longitudinal trial 21% of PSA screen-detected prostate cancers were overdiagnosed. The PSA test is not sensitive enough to definitively diagnose prostate cancer and can also produce spurious results, but many GPs request a routine test based solely on the patient's age. Patients with a high PSA then have a biopsy which is returned as positive and treatment commences despite many men being symptom-free. These men are not in need of treatment as their quality of life is high; however, the treatments have both acute and chronic side effects, significantly reducing the quality of life. In effect, many patients are being unnecessarily treated and the benefits rarely outweigh the side effects. They may have lived for years and even decades longer without being aware of prostate cancer and the likelihood of these men dying from an unrelated cause is high.

The medical, and especially urological, community are divided on the efficacy of PSA testing. The debate continues to polarise opinions with an increasingly strong lobby claiming there should not be a debate about overuse of PSA testing and overdiagnosis. They believe the current situation using PSA tests is getting out of hand and the extent of PSA testing should be drastically reduced. Given the widespread adoption of PSA testing, the following section turns to the place of PSA screening in New Zealand.

### **2.1.5 PSA Screening and the Political Situation**

A PSA screening programme would aim to diagnose and treat prostate cancer before the patient presented with symptoms. The most at-risk population would be identified and called up regularly, usually annually, to have a variety of tests which may include a PSA test and a digital rectal examination (DRE). Those with positive results would progress to a biopsy, definitive diagnosis and subsequent treatment. Prostate cancer screening is more cost-effective when compared to breast and cervical cancers, yet both breast and cervical cancers have a national screening programme in this country but prostate cancer does not. Smart (2008) postulated that 450 men would have to be screened to save one man from dying.

In contrast, 1700 and 800 women respectively would have to be screened for breast cancer and cervical cancer in order to save one woman from dying.

Prostate cancer detection and treatment is currently an issue of political importance. In November 2010, the current national government convened a select committee on health to evaluate the early detection and treatment of prostate cancer. The multi-disciplinary group of health professionals presented the report to parliament in July 2011 (Health Committee, 2011) and all 17 recommendations were accepted by the government. The report concluded that population-based PSA screening is not warranted as the evidence is not strong enough to justify the expense; therefore, no national screening programme is currently operating in New Zealand despite active lobbying to the government.

The issue of whether or not to introduce a national screening programme remains a highly contentious debate at both national and local levels with some groups believing routine screening for all men in the high risk age bracket is not justified financially. Other groups believe it should be offered as part of a conscientious and developed country. This issue remains equivocal with developed countries adopting a variety of approaches; some have a national screening programme and others offer PSA testing on a self-presenting basis. A contentious debate in medical, political and academic circles considers not just about the adoption but also the content of a screening programme and whether a PSA test alone is sufficient or more effective in conjunction with a DRE (Smart, 2008).

Government responsibility for implementing a national screening programme has been replaced with individual responsibility in the area of personal health. By adopting the first recommendation of the Early Detection Report (Health Committee, 2011) the government encourages GPs to “provide men with initial consultations about the advantages and disadvantages of screening and treatment for prostate cancer” (p.9), albeit often in a routine cardiovascular risk assessment consultation. Recommendation 2 states men are encouraged to “seek up-to-date evidence-based information from their general practitioners” (p.9). Men are expected by the government to take responsibility for being informed about their own health and treatment options. They are also presumed to manage the social and psychological aspects of having prostate cancer, aspects such as stigma, anxiety and depression.

### **2.1.6 Psychological Overview**

The symptoms of prostate cancer directly challenge the male identity (Chapple & Ziebland, 2002; Clarke, 1999). In this country masculinity is expressed as being fit and healthy, macho and self-sufficient and pride is considered of value as it gives a man social status (Cupples, Guyatt, & Pearce, 2007). One feature of masculinity is the perception it is unnecessary to consult a doctor or go to hospital. Prostate cancer challenges the self-belief associated with masculinity as the man is forced to seek advice and support from others; symptoms can make the issue physically and socially awkward for men. Moreover, the social stigma associated with prostate cancer is considerable; erectile dysfunction and the sexual connotation result in the perception it is socially unacceptable to discuss this either in public or in private. Stigma can lead to self-blame, social isolation, depression and even mortality (Else-Quest et al., 2009; Kunkel et al., 2000; Llorente et al., 2005).

It is well researched that many individuals react to a diagnosis of cancer with shock, disbelief and anger (Bloch et al., 2007). The period around the diagnosis is critical as cancer-related stress levels are higher within one year of diagnosis than at later stages of the disease (Halbert et al., 2010). The prevalence of anxiety, depression and fear in men recently diagnosed with prostate cancer is also well documented. Balderson and Towell (2003) indicated 38% of prostate cancer patients reported psychological distress while Halbert et al. (2010) claimed that 30% of men diagnosed with prostate cancer had sufficiently high distress scores to indicate the need for psychological intervention. Bloch et al. (2007) claimed 20% reported depression of which 50% were severely depressed. Dale et al. (1999) concluded after a study on 96 men, that at the time of a diagnosis “all the emotional reactions to prostate cancer were deeply negative” (p.181). Clinical depression is a problem not just for the patients but is diagnosed in 21% of adult relatives of patients around the time of diagnosis (Edwards & Clarke, 2004). Psychological issues are widespread and at times can have serious implications.

### **2.1.7 Summary**

Prostate cancer is increasing in both prevalence and incidence mainly due to the ageing population which is the major risk factor associated with a positive diagnosis. PSA testing is provided to men in the high-risk categories but without the support of a nation-wide screening programme in New Zealand; both PSA

screening and testing are eliciting some very emotive debates. Severe psychological reactions to the diagnosis of prostate cancer are prevalent in many patients with feelings of anxiety, depression and fear. If and how men communicate these feelings associated with the diagnosis of prostate cancer are considered next.

## **2.2 Men's Health and Communication in New Zealand**

Communication is fundamental in the effective diagnosis and treatment of prostate cancer and health in general. Communication needs to exist between medical staff and patients in order to find out about and treat the issue. At an individual level ineffective health communication results in misunderstandings and incorrect diagnoses. The following section identifies how men communicate particularly around issues of men's health and prostate cancer and factors which influence this communication include the stage of life, individual characteristics, communication style and disclosure.

### **2.2.1 Stage in Life**

Every stage in life is filled with gains and losses (Harden et al., 2008); gains such as a qualification, children and promotion and losses may include the death of parents, unrealised potential and illness. In later life the losses outweigh the gains and this stage of life, variously termed middle age or young-old, in which men acquire prostate cancer can be particularly changeable and traumatic (Harden et al., 2008; Wenger, 2002). Chronic and acute medical issues combined with retirement can be significant events. Compounding medical issues complicate the life stage as "older men who are experiencing physical decline as a result of ageing may find it difficult to manage an additional burden of prostate cancer treatment regime" (Harden et al., 2008, p. 8). Various treatment options are possible, but a course of radiation therapy may require daily visits to an oncology centre for up to six weeks. As these centres are sparsely scattered the men may be living away from home for the course of treatment. Radiation therapy is particularly demanding on older people; the physical and mental adjustment to a chronic illness is a process and one that can be lengthy in older people.

Prostate cancer is primarily a disease of men over 60 who may be facing retirement or have already retired. Retirement is a significant life event for many men with the result that network composition and size can change significantly

(Van Tilburg, 1992) and the work context may have provided a network which contained strong ties. Communication networks according to Monge and Contractor (2001) are the exchange of messages between individuals who are connected within a relationship. Tie strength is the sense of a special and close relationship (Wellman & Wortley, 1990) and these two factors combined to provide a context which fostered meaningful relationships at work. Retirement may result in a change or loss of these relationships. Men with weak ties and loose-knit networks may lose connection with others at this time and this may result in chronic social isolation (Heaney & Israel, 2002).

Networks can demonstrate resilience through an event such as retirement and results in individuals maintaining many of the same friends and network structure they had before retirement. Individuals tend to get involved in the community at this time of their life (Stephens et al., 2011). Retirement and illness can occur simultaneously and have a significant impact on the ability of men to manage this stage in life as “large scale social upheavals and transitions profoundly disrupt patterns of social organisations established in earlier life” (Berkman, Glass, Brissette, & Seeman, 2000, p. 852). Different stages in life influence the way networks are structured. Men with prostate cancer diagnosed at retirement age have the potential for significant difficulty with their network structure and communication within it. External events and individual characteristics contribute to determining men’s communication around health issues.

### **2.2.2 Individual Characteristics**

Individual characteristics also influence men’s ability to communicate and determine the extent to which support in networks is accessed and perceived as positive. These characteristics include emotional intelligence, locus of control, self-efficacy, health literacy, support seeking and shyness.

Emotional intelligence, the ability to handle relationships and manage one’s own emotions, will contribute to the overall ability to receive emotional help and have positive social relationships (Lopes et al., 2004). An individual with a high emotional intelligence is more likely to see the need for help and therefore seek it.

Locus of control is another factor which influences communication around health issues. This is the extent to which an individual maintains an inward or outward

control of events. Inward control is the perception they are in control of a situation and outward control relates to others being in control (Burlison & Mortenson, 2003; Wallston, Wallston, Kaplan, & Maides, 1976). Individuals can influence their own health management by understanding the share they can be responsible for, an inward locus of control, but also the part only others can play. By adopting this perspective they can assume a proactive approach to their own responsibilities and can achieve better health care.

Health concerns can be multiplied when men feel the situation is getting out of control and for those with little self-efficacy this can occur very quickly. Self-efficacy is the belief in one's capacity to adapt and manage new tasks (Harden et al., 2008). The demands of managing not only their own changing health situation but also the health system can add demands and stress on the patient and their family. Communication self-efficacy is the belief that one's communication competence aids coping at this time (Zorn, Roper, Broadfoot, & Weaver, 2006) reducing stress.

The ability to communicate effectively is also influenced by an individual's health literacy and the ability to obtain, process and understand basic health information and services (Davis, Williams, Marin, Parker, & Glass, 2002). This can range from the practical (e.g., the ability to navigate through the hospital and find the correct clinic) to the knowledge of when and how to question medical professionals. Individuals with low health literacy tend to rely on medical professionals for information (Gaglio, Glasgow, & Bull, 2012), and those with high health literacy aid the process through the medical journey and system. Programmes which encourage health literacy in the older population have been shown to improve the effectiveness with which men access health information (Manafa & Wong, 2012).

Shy people are less liable to talk in social settings and seek health-related advice (Daly, 2011). Consequently, they are more likely to manage their diagnosis and treatment by themselves or with one other person in their networks. These are several of the many individual characteristics which contribute to how men communicate about their health issues and these features also play a part in their individual style of communication.

### **2.2.3 Communication Style**

The style men use for communicating directs their communication of health issues to some extent. Communication style is a very nebulous concept with little cohesion in definition bringing a different emphasis depending on the context in which it is applied, such as in health (Worchel et al., 1995), sales (Williams & Spiro, 1985) and politics (Jagers & Walgrave, 2007).

Unravelling generalisations Hawkins, Weisberg, and Ray (1980) elaborated on four styles of communication in the context of marriage. The two most extreme, based on level of disclosure and the importance of other's experience, are conventional and contactful. A conventional communication style is characterised by avoiding or glossing over issues with little regard for the importance of the experience of others. Some men will act as if nothing is bothering them in the face of health issues; they will ignore the issue and fail to disclose their concerns thereby creating a distance between themselves and the other person. There may be occasions when this is a suitable and possibly the best approach.

A contactful style according to Hawkins et al. (1980) is the highest form of interaction which demonstrates explicit verbalisation and high levels of disclosure; this style considers the experiences of others as valuable. Other men communicate their health concerns by disclosing their feelings and when they need emotional support they tend turn to women: wives, mothers and sisters (Wellman & Wortley, 1990). Exhibiting the characteristics of the contactful style of communication is considered preferential for good health and well-being of both individuals and marriages (Hawkins et al., 1980).

Different styles of communication are manifested in a variety of ways. In general men and women communicate using language differently (Mulac & Lundell, 1986) with men perceived as more diffident, less skilled, restless and loud in their communication style than women (Briton & Hall, 1995). Men are less inclined to share emotions and health concerns with others preferring instead informational and material exchanges (Arrington et al., 2006; Bloch et al., 2007; Seale, Ziebland, & Charteris-Black, 2006; Sloan et al., 2010; Wellman & Wortley, 1990). Consequently the preference for these types of exchanges makes the concept of disclosure very challenging for men.

#### **2.2.4 Disclosure**

Cancer can be very traumatic, especially in the early stages at biopsy and diagnosis. The topic can be a very difficult subject to talk about and there are many issues related to stress and fear associated with the diagnosis, treatment, stigmatisation and lack of information. There appears to be no literature on disclosure at the point of biopsy with virtually all research being conducted around the time of diagnosis. Therefore, the following section addresses the issue of disclosure from the point of diagnosis of prostate cancer.

Men with prostate cancer are in the position to choose whether to disclose or not. Gray et al. (2000) claimed “the more visible a disorder, the more symptoms present and the sicker people are the greater likelihood that individuals will disclose their condition to others” (p.273). Prostate cancer patients have no visible disorder, are often symptom free and usually do not feel sick. They are in the position, unlike many other patients with cancer, of being able to make a choice about whether or not to disclose.

Some men have difficulty discussing their own health issues; Lepore and Revenson (2007) found 33% of men with prostate cancer have difficulties talking about it and 67% of spouses had difficulty or avoided talking about the prognosis or death with the husband. The difficulty extended beyond the patient and spouse and affected the wider family. Disclosure is a highly significant part of the process of illness adjustment as the ability or willingness to disclose is closely integrated with the individual’s mental health.

A variety of motives influence whether men choose to disclose. First, disclosure assists in the process of adjusting to illness. In order to mentally adapt to cancer individuals need to cognitively process the diagnosis; for some people the process is linear - thinking precedes talking; while for others this part involves sharing with others and so the mental processing occurs during and after talking about the issues. To integrate their experience of cancer into their thinking and everyday life men need to go over their cancer experience confronting and contemplating it. The ability to do this can prove very challenging and is often an on-going process due to the changeable nature of the disease (Gray et al., 2000; Lepore & Revenson, 2007).

Secondly, men actively seek support and understanding because their thoughts and feelings are validated by others who are close (MacGeorge, Feng, & Burleson, 2011); they can be loved, encouraged and supported through the medical process (Stephens et al., 2011). Reinforcing assists in the process of illness adjustment. Finally, disclosure can also result in identifying others who have been through a similar experience (Grunfeld et al., 2013) but have been unwilling or unable to disclose. Shared meaning and similar experience are very potent factors in enabling men to process their health issues.

Despite the perceived benefits of disclosure significant barriers exist to confiding with others. The shock associated with a diagnosis of cancer can contribute to a considerable time spent processing the information and feelings (Edwards & Clarke, 2004) and incomplete processing of the diagnosis can result in negative emotions and intrusive thoughts (Halbert et al., 2010; Lepore & Helgeson, 1998). When intrusive thoughts about the cancer pervade everyday life and are not processed or resolved the individual feels overwhelmed and unable to cope and in the longer term suffers poor mental health. Another barrier to the men's willingness to disclose are social constraints which are external circumstances influencing an individual's behaviour (Lepore & Revenson, 2007). Social constraints are evidenced by the perception that others are uncomfortable being with and listening to the individual. In addition, others are not fully supportive when talking (Lepore & Helgeson, 1998), they get distracted and uncomfortable.

Given the nature of social constraints, when men do choose to share they often choose carefully who they disclose to. Most married men talk primarily with their wives (Arrington et al., 2006); however the wife is often suffering the same stressors as her husband so she may be unable to provide meaningful support in the relationship at this critical time (Edwards & Clarke, 2004). Men can also confide in their wider family, usually their children and occasionally siblings. They may then disclose to a few other men with whom they are in close contact. Spousal constraints can lead to increased tensions and may prove more difficult to cope with than constraints from a friend (Lepore & Helgeson, 1998). For those who are in employment, a few colleagues or the manager may be told voluntarily or on a need-to-know basis. Much of the literature on disclosure addresses married men; the situation around disclosure for men who live by themselves

appears to be an under-researched area. Little is known about whether they disclose and to whom.

Assumptions are made that disclosure should be encouraged and will be beneficial both for the men themselves and also for the others in their networks. Failure to disclose meant men were more likely to have intrusive thoughts and avoid situations in which they may have to talk about cancer (Grunfeld et al., 2013; Lepore & Helgeson, 1998). Further, failure to disclose has been strongly correlated with poor mental health as disclosure facilitates the ability to process the diagnosis resulting in better mental health (Halbert et al., 2010). Disclosure and prostate cancer involves not only the patient but the network as a whole as “coping with cancer involved the mutual influence of cancer survivors and members of their social network as they cognitively and behaviourally engage the stressors posed by the illness” (Lepore & Revenson, 2007, p. 317). Engaging strategic people within a network creates potential to be effective in combating cancer.

### **2.2.5 Summary**

This section has identified some factors which contribute to men’s ability and willingness to communicate. By examining factors such as life stage, individual characteristics, communication style and disclosure it is possible to understand why some men communicate as they do when they are diagnosed with cancer. Viewing communication from an individual perspective enables some understanding of the way men process their own health and communicate about it. Considering men’s communication from another perspective, that of a network, complements this view.

## **2.3 Networks for Understanding Men’s Communication**

Networks are described in terms of both structure and content by traditional network theorists. Structure refers to the way in which a network is organised (the physical design) and content refers to the communication and relationships inherent within the network. Both are covered in the next section; the first section on structure explains the theoretical nature of networks using two classic structural theories, one by Granovetter (1973) and the other by Burt (1984). This is followed by a brief description of network features. The impact of significant life events is described followed by an explanation of the dynamic nature of

networks in the context of network structure. This section concludes with a discussion on virtual networks whose importance has increased since the proliferation of new communication technology. The second section on content covers one aspect of networks, social support, and is discussed from three perspectives: psychological, social and communication.

### **2.3.1 Structure of Networks**

Use of the concept of structure is one way to perceive networks; this approach has a long history within the social science tradition and network analysis in particular. The number of papers published since 1982 in the social science literature on social networks has risen exponentially (Knoke & Yang, 2008). Social network analysis has gained enormous popularity since 1993 when Putman authored books on social capital (Prell, 2012). Qualitative network analysis seeks to identify who are in networks, what position and roles individuals hold and their relationships with others. Quantitative research uses ratios, frequency and a range of actors (others) in a network. Both qualitative and quantitative research are complementary with the former often leading to the latter (Prell, 2012).

Early work by social network theorists was conducted in the management field. Granovetter (1973) analysed the strength of the social ties in the process of finding a job where strength is considered the emotional intensity and frequency of relationships. Individuals who see each other often and share deeply (i.e. a lot of information across a variety of topics) constitute a strong relationship. In contrast, individuals who meet rarely and share little have weak ties. Granovetter (1973) postulated the theory of weak ties in which they were more likely than strong ties to be the source of information about finding a job. In this theory, the importance of the personal experience of individuals is closely bound to the larger-scale aspects of network structure.

Another classic network theorist, Burt (1984), developed the structural holes theory which focused on the patterns of relationships among individuals in an ego's network other than with the ego themselves. Structural holes existed where two other people in a network are not connected with each other. Burt (1984) found that a network with many structural holes provided more information on social resources and so gave individuals a competitive advantage over others

without holes, such as promotion or other rewards within the organisation (Knoke & Yang, 2008; Prell, 2012). Having a structural hole provided competitive advantage. Both strength of ties and structural holes contribute to the patterns of relationships which characterise networks.

### ***2.3.1.1 Structural Features of Networks***

This sub-section briefly identifies some distinctive features of networks. First, the challenge of defining boundaries is discussed and applied to an ego-centric network, this being one type of network. The importance of nodes and ties to network analysis is explained and in conclusion consideration is given to the strength and closeness of the ties within it the network.

Networks can also be analysed as a whole or in part. Analysis of entire networks provides a comprehensive understanding of the structure of relationships within a system (Wellman, 1997) and attempts to take one part of the web of networks to analyse the relationships within it. Networks are limited and defining the boundaries can prove a considerable challenge as to who is considered in the core and who is on the periphery of the network (Borgatti & Halgin, 2011). Despite this challenge one strength of network analysis is ascertaining the people who are actually in the networks (Silverman, 2011).

Whole networks do not feature in an egocentric network and this literature review will focus on the interpersonal level of relationships with particular emphasis on the ego-centred network. Egocentric networks identify others, the alters, from one person, the ego's perspective (Borgatti, Jones, & Everett, 1998) and provides insight into how the network functions at the most basic level. In the area of health egocentric networks can examine the support offered. Social support is one function of communication networks facilitated through the relationships within network.

Fundamental components of social network analysis are nodes and ties. Nodes are the individuals or groups within a network and ties are the relationships between these individuals or groups. The emphasis is on the pattern of relationships between people rather than individual, group or organisational attributes themselves (Haythornthwaite, 1996; Monge & Contractor, 2001).

Some structural characteristics of networks are assigned to the ties between individuals and other features are assigned to the nodes or individuals themselves (Monge & Contractor, 2001). An important feature of network analysis is that ties are not binary in that they are either present or absent; rather they demonstrate strength or weakness (Leik & Chalkley, 1997; Parks, 2011). Characteristics of a strong tie are a sense of the relationship being intimate and special; the desire to be together as much as possible and mutuality in the relationship where the needs of the other are known and met (Wellman & Wortley, 1990). Weak ties, on the other hand, are connections without significant meaning.

The number of strong ties or significant others in an ego-centric network tend to be only small. Wellman and Wortley (1990) established the mean number of others that Americans discuss important matters with is 2.1 therefore concluding that individuals have two intimate ties and seven close friends. Intimate and close networks are generally not large and men usually communicate primarily with their wife or partner (Bloch et al., 2007; Borgatti & Halgin, 2011; Coon et al., 2007; Halbert et al., 2010).

Strong ties help networks to function most effectively. With health issues spousal and other strong ties provide a significant level of support to men both in managing the physical treatment and mental state in coping with illness (Cohen & Wills, 1985; Halbert et al., 2010; McLaughlin, Vagenas, Pachana, Begum, & Dobson, 2010; Wright, Sparks, & O'Hair, 2008). Wherever alters are positioned in an ego's network, close to the ego as a strong tie, or towards the periphery as a weak tie, resources are available in networks (Granovetter, 2003; Haythornthwaite, 1996).

Reciprocity is another feature of networks and shows the extent to which a relationship is bi-directional. Most ties are asymmetric in nature; resources such as information and time flow predominantly in one direction from one person to another (Haythornthwaite, 1996; Wellman, 1997). Individuals who are in a position to both give and receive resources equally in an existing reciprocal relationship and for relationships to mature there needs to be some degree of reciprocity (Heaney & Israel, 2002; Wright et al., 2008). Reciprocity and strength are measures assigned to ties, closeness and density are network measures assigned to the nodes or individuals.

Closeness, in part, determines the availability of and access to resources in a network. If individuals are well connected as work colleagues or neighbours, resources are more easily accessed. Network analysis also reveals the density of the network and the proportion of members who are tied to each other. A dense network provides many inter-related actors and therefore increases the likelihood of resources being available (Haythornthwaite, 1996). Relationships at an interpersonal level shape how networks function as well as events in the life of the individual.

### ***2.3.1.2 Influence of Significant Life Events on Networks***

Networks evolve in everyday life. Researchers have used contexts such as child-bearing (Ridgeway & Smith-Lovin, 1999), families and children (Leik & Chalkley, 1997), members of communes (Martin & Yeung, 2006 ) and ageing (Feld et al., 2007; Wellman et al., 1997) to research the impact of these events on networks. The natural process of ageing and life itself results in changes to the network of people around an individual.

Significant events in life have the potential to cause disruption not only to individuals but also to their networks. Significant events may be perceived as positive or negative. It is not just the presence or absence of an event but also the magnitude that determines the impact on individual relationships and networks; the more significant the event, the greater the impact on networks.

Those in the older age group are subject to a distinctive set of life events which influence an individual's networks, such as a change in the marital or employment status or moving house. A change in marital status includes divorce (Wellman et al., 1997) or widowhood (Morgan, Neal, & Carder, 1996; Van Der Gaag & Snijders, 2005). In the event of a change in marital status Wellman et al. (1997) noted the turnover of intimate ties within a 10 year period increased from 62% to 94%. Further life changes at this time may include employment. Men retire at the age when a diagnosis of prostate cancer is most common and so can lose regular contact with their workmates as noted previously. Moving house can also alter the structure and content of networks significantly.

In addition to employment or marital changes serious illness can impact on networks (Perry & Pescosolido, 2012). During the adjustment period demands are made on the networks to provide extra resources in order to collectively battle the

disease. The network is responsive to these demands as ties and nodes are fluid, some people become more involved and others less so, but embeddedness in networks has been shown to minimise stressful events (Cohen & Wills, 1985). Embeddedness is the extent to which individuals are inter-related in a network creating stability and a core set of ties (Feld et al., 2007; Martin & Yeung, 2006 ). Family is usually well-embedded in networks showing resilience over time (Morgan et al., 1996; Wellman et al., 1997).

Networks have traditionally been analysed from a static perspective, one that views the network at a given point in time with little regard for change over time (Leik & Chalkley, 1997; Stohl & Stohl, 2007; Wellman & Wortley, 1990). However, networks are fluid with a continuous movement of new people joining and others leaving (Morgan et al., 1996). Several studies researched the individual commitment and proportion of alters who remained in a given network over time. Wellman et al. (1997) found 62% per cent of intimate ties turned over in a 10-year period just in everyday life without the occurrence of significant events. According to Morgan et al. (1996) two interviews six months apart identified that 55% of individuals in a network were named at both points in time. Whole networks are inherently unstable or dynamic (Leik & Chalkley, 1997; Morgan et al., 1996; Wellman et al., 1997) and the changing nature of ties at various levels; individual, dyadic and group (Martin & Yeung, 2006 ) contributed to the dynamic nature of the whole network (Feld et al., 2007).

Older men live and work in changing contexts and these can influence the structure of networks. A changing employment status with impending retirement or changes in the family structure can each have an impact on their networks as can a change in health status. Changes in men's working status such as reduced hours or retiring also influence networks. Changing demands on their time and effort can alter the time available for others in their networks and the way they communicate with them.

In the event of a diagnosis of an illness networks as well as individuals respond. As people have a need for medical information and management of the disease (Arrington et al., 2006), networks evolve to include more health professionals such as hospitals and support organisations than previously. As these organisations become integrated into the health network it adjusts; some groups or

individuals are included, others move out. The circumstances are especially challenging at this time and many men are only just able to cope with the current situation of illness. A changing health status encourages men to seek more information on the internet, not only for medical information gathering, but also for support groups.

### ***2.3.1.3 Virtual networks***

Online support in the health field is often based around those with a similar diagnosis and groups have proliferated in recent years. Online support groups are functional as forums for sharing information and supporting others although some groups are open to all, others are for members only. These groups offer general health related support in many fields including psychology (Forster, 2004) and cancer (Durant et al., 2012; Shim et al., 2011; Thaxton et al., 2008). Virtual groups are now an integrated part of health networks. Companionship and connection for people with cancer are also provided through the groups (Klemm et al., 1999; Mo et al., 2009). However, many elderly people are bereaved and together with a declining quality of life and less mobility find the ability to access and use online options can be challenging; 40% of men access the internet through the services of a friend or relative (Seale et al., 2006). Many of these groups are based overseas but few are centred in New Zealand with a specific focus on prostate cancer.

The value of the internet as a resource for the patient in managing prostate cancer is increasingly recognised. In a comparative analysis of face-to-face interviews and online cancer support groups, Seale et al. (2006) noted that 38% of men in America with prostate cancer used the internet primarily to access medical information and not for support. Between 2008 and 2010 men accessing general cancer-related searches on the internet increased by 183% (McHugh et al., 2011). Kassan et al. (2012) claimed 84% of men with prostate cancer used the internet to access a prostate cancer screening decision aid to empower them in their decision-making for treatment options.

Networks can be understood by perceiving them as structural units. Further understanding can be gained by characterising the contents of networks therefore enabling a more comprehensive picture of networks to be identified.

### **2.3.2 Content of Networks**

As mentioned previously networks are comprised of both structure and content. The structural component is the physical composition and the functional component is the content of networks; how they work. Social support is a key functional aspect of health networks and literature indicates the valuable role it plays. Lin, Ensel, Simeone, and Kuo (1979) defined social support as “perceived or actual instrumental and/or expressive provisions supplied by the community, social networks and confiding partners” (p.109). Concepts of social support are multifaceted and dynamic, evolving with changing situations and individuals. Social support within networks has been viewed traditionally from either a psychological or a sociological perspective (Stephens et al., 2011). The psychological perspective focuses on the perceived ability of helpful persons or behaviours in a network to give to others (MacGeorge et al., 2011). Alternatively, the sociological perspective seeks to identify the links between social integration and health outcomes. A fresh approach to social support is from a communication perspective; the emphasis moves from the perception of conventional social support to communication and how effective communication facilitates and encourages well-being. All three approaches; psychological, sociological and communication are complementary but different ways of viewing the complex nature of social support. They are essential for the overall well-being of individuals. All three are described in more detail now.

### **2.3.3 Psychological Perspective**

The psychological perspective of networks is concerned with the way social support is received and perceived as support. Support is important to the individual in their psychological adjustment to a chronic illness. The on-going psychological demands of being diagnosed with cancer was identified by the Midland Cancer Network (2009), a multidisciplinary group of health professionals, who concluded in a report about implementing a psycho-social assessment tool that “worry and anxiety were experienced by participants almost at all stages throughout the cancer journey” (p.9). For an individual the psychological impact involves the reduction in distress, anxiety, depression and mortality and an increase in the ability to cope leading to recovery from disease. Living with cancer requires accommodation of intense emotions and continual management to be able to cope on a day-to-day basis.

Support received from others at this time, where supportive actions have been provided by network members and been positively received by the individual, has been the traditional focus in literature (Haber et al., 2007). Perceived support, on the other hand, is a subjective judgement of the receiver as to whether he considers he will receive support in the future based on existing social relations (MacGeorge et al., 2011). A strong correlation exists between perceived support and the emotional well-being of men with prostate cancer; perceiving low levels of support equates to poorer emotional well-being (Zhou, Penedo, Bustillo, et al., 2010). Overall, perceived rather than actual support is the key factor in producing positive health outcomes in a variety of situations, populations and health outcomes.

A psychological perspective of networks focuses on support as actual or perceived, a crucial difference to the ability of an individual living and coping with cancer. A sociological perspective builds on the relationship aspect of providing support, the kind of support offered and by whom. It also considers how individuals' integration into networks influences this support.

### **2.3.4 Sociological Perspective**

Social support is the product of relationships whereby individuals help and provide comfort to others. The emphasis of the sociological perspective of social support has been on interpersonal relationships; specifically the support-based impact of one relationship on others and the wider network (Heaney & Israel, 2002). According to Wellman and Gulia (1999) social support is comprised of distinct categories: emotional aid, material aid (goods, services and money), information and companionship. Wellman and Wortley (1990) distilled 18 different types of social support into these four basic categories which encompassed an extensive range of theoretical and practical forms of support.

Traditionally the provision of social support has been linked to the relationship of the ego to the alter and network analysis categorises these types of relationships. Burt (1984) cited 10 kinds of relationships: "spouse, parent, sibling, other family, co-worker, member of group to which you belong, neighbour, friend, professional advisor and other" (p.335). Wellman (2007b) noted "people have many ties with different types of ties providing different kinds of supportive resources" (p.6). Network analysis assumes the type of relationship implies provision of resources

appropriate to the relationship; emotional support is provided in the kin relationship and instrumental support would tend to emerge from a neighbour or co-worker relationship. Research has also been limited by the perception that these functional roles of support and the provision of support remain fixed over time when in fact they are susceptible to change. Support is a dynamic process constantly evolving with changing circumstances and people (MacGeorge et al., 2011). Social support is crucial for the well-being of men in general (McLaughlin et al., 2010) and those with prostate cancer in particular (Zhou, Penedo, Lewis, et al., 2010) as social support plays a critical role in their adjustment to cancer.

Effective social support can be broadly evaluated by measuring well-being but well-being is such a ubiquitous term. Ereaud and Whiting (2008) clarified it as the state of good emotional health. The ability to access social resources is crucial to the well-being of patients and particularly those with chronic conditions such as cancer. However, for social support to be deemed effective it must not only impact the individual but also their social and family well-being. Indeed, social and family well-being is a significant predictor of distress (Balderson & Towell, 2003); an individual with a positive sense of wellbeing is less likely to suffer distress.

In addition to the provision of social support the sociological perspective emphasises the importance of social integration to well-being. Social integration is the extent to which individuals are connected in a network which provides a sense of belonging, shared social activities and common interests (Stephens et al., 2011). Active involvement with family members, friends, neighbours or community groups provides meaningful roles and companionship (Berkman et al., 2000). The degree to which an individual is socially integrated is an important predictor of health as social integration has been shown to correlate strongly with health outcomes. Social integration leads to favourable physical and mental health outcomes (Berkman et al., 2000; Seeman, 1996; Stephens et al., 2011) and helps avoid negative outcomes (Cohen & Wills, 1985). On the other hand decreasing levels of social integration lead to increased levels of mortality (Seeman, 1996).

Despite the benefits of social support and social integration an individual's experience of social relations may not always be positive. Extensive research since the 1970s has correlated social support and social integration with positive

outcomes and improved health. MacGeorge et al. (2011) view this as a significant feature of social support, especially when the intention of others is to be helpful (Heaney & Israel, 2002). However, the presence of social undermining has recently been shown to have more impact on relationships than the presence of social support.

Social undermining, like social support, is variously defined but is considered “behaviour intended to hinder, over time, the ability to establish and maintain positive interpersonal relationships” (Duffy, Ganster, & Pagon, 2002, p. 332). Social undermining includes criticism, dislike, or inhibiting instrumental goals (Oetzel, Duran, Jiang, & Lucero, 2007) and is perceived as unwanted by the recipient (Brooks & Dunkel Schetter, 2011). Social undermining, particularly in marriage, can add significant stress and tension as undermining devalues both the partners and the relationship leading to psychological difficulties such as the inability to cope and feeling overwhelmed. In a cancer-related scenario social undermining is associated with a poorer medical outcome and increased complications (Brooks & Dunkel Schetter, 2011).

Social isolation is one form of social undermining imposed on an individual by others. Social isolation is negative social support and leads to a reduction in connection with others in the network and is experienced as loneliness. Isolation is a significant risk associated particularly with older people due to medical conditions which can restrict mobility and create financial hardship (Allen, 2010). Lack of companionship due to the death of family and friends also restricts integration into society and leads to isolation. Older people have fewer friends and stable contact with family (McLaughlin et al., 2010) and are more at risk of social isolation (Stephens et al., 2011). Zhou, Penedo, Bustillo, et al. (2010) concluded “there may be subsets of survivors of prostate cancer who are isolated from their social environment and are, consequently, faced with a particularly difficult adjustment period following their cancer treatment” (p.6). Despite successful treatment, social isolation can remain a significant threat to the patient’s quality of life.

Another negative aspect of social undermining is social withdrawal, or the intentional withdrawal from society to become isolated. In contrast, social isolation is not intentional on the part of the individual. Cancer patients can

experience significant social difficulty. Others in networks “often in subtle but unmistakable ways, distance themselves from the dying” (Spiegel, Bloom, & Yalom, 1981, p. 81) by failing to provide support. They react to the word *cancer* and do not know how to converse about cancer or respond to the individual who is diagnosed with it (Allen, 2010). People with any stage of cancer experience this form of social undermining. Men with prostate cancer can intentionally withdraw from society due to socially unacceptable symptoms or side effects of treatment which can continue for many years (Arrington et al., 2006; Kampf, 2010; Roth et al., 2008; Zhou, Penedo, Bustillo, et al., 2010).

The effect of negative social relations can profoundly affect the physical and mental health of an individual. Negativity has been shown to have a stronger effect on health related outcomes than social support (Brooks & Dunkel Schetter, 2011; Heaney & Israel, 2002), and Oetzel (in press) concluded it is “more important to avoid negative interactions than to have positive interactions” (p.21). Negative communication and relationships can have a greater impact and last longer than the positive experience of social support. This perspective is shared by Lepore and Revenson (2007) in relation to constraints who noted that “relative to social support, the level of social constraints is often a stronger and independent predictor of mental health outcomes” (p.325).

Social constraints and isolation are forms of negativity and in order to counter negative social effects buffering can be effective against the “deleterious effects of social negativity” (Brooks & Dunkel Schetter, 2011, p. 912). Buffering is the provision of people, coping strategies and effective social support to counter stressful life events (Boehmer & Clark, 2001; Cohen & Wills, 1985; Lin, Woelfel, & Light, 1985; Zhou, Penedo, Lewis, et al., 2010). It is demonstrated by individuals who offer support in the form of emotional or material aid (Wright et al., 2008) and in the event of a diagnosis of cancer buffering serves to “protect survivors from experiencing the full brunt of cancer” (Zhou, Penedo, Bustillo, et al., 2010, p. 2). Receiving a diagnosis of cancer can be a shock and having others alongside at this time helps the individual feel affirmed and able to process information.

Psychological and sociological support constitute the traditional perspectives on conceptualising an important function of networks, that of the provision of social support. A third newer perspective of social support is one of viewing communication as a resource in networks.

### **2.3.5 Communication Perspective**

Recently the role of communication within social networks has been of considerable interest (Berkman et al., 2000) as social support is viewed differently from a communication perspective. A communication perspective is where “messages, interactions and relationships are the foundational components” (MacGeorge et al., 2011, p. 323).

From a network viewpoint communication is perceived not just between two or more individuals but as a flow through networks and as such is a resource embedded in networks creating value (Coleman, 1988; Haythornthwaite, 1996; Leana & Pil, 2006; Reinard, 2001; Seibert, Kraimer, & Liden, 2001). To describe communication as a flow implies a continuous, almost imperceptible, movement throughout a network. Perceiving communication as a resource, similar to more tangible resources such as material aid, creates a different and valued perspective. Value is created from benefits which can be derived by sharing this resource; in the health context these can be increased health literacy, information flow (Borgatti & Halgin, 2011), better stress management and improved health outcomes. Effective communication in men with prostate cancer contributes to a sense of well-being; to reduce distress in men with anxiety and depression by helping them to process their experience (Bloch et al., 2007; Heaney & Israel, 2002; MacGeorge et al., 2011).

Communication in networks also provides information. In the current medical and political climate responsibility for managing individual health and decision-making on treatment options lies firmly with the patient. In the context of prostate cancer men need to obtain information about the disease and its treatment (Arrington et al., 2006; Boberg et al., 2003) from health professionals. Furthermore, networks function to provide resources and medical information informally from others who have been through a similar experience.

At an individual level communication revolves around “interaction, cooperation, support and confirmation” (Zorn et al., 2006, p. 121). The interrelationships between individuals in a network determine the effectiveness of communication and in turn the well-being of individuals and couples. Research on communication between couples in a marriage coping with prostate cancer overwhelmingly identified a lack of communication as a common difficulty with communication decreasing over time often leading to strain in the marital relationship (Boehmer & Clark, 2001; Song et al., 2012). Characteristics such as age, stage, symptoms and uncertainty of the disease affect the ability of partners to communicate (Song et al., 2012) and can compromise the effectiveness of treatments.

### **2.3.6 Summary**

Networks are comprised of two distinct yet interrelated functions of structure and content. The structural component features an egocentric level of network which contains nodes and ties. The content and relationships within the network can be viewed from three different perspectives: sociological, psychological and communication. Separating networks into structure and content creates an artificial division, which can prove useful for analysis but in reality networks are wholly integrated; individuals and their relationships are part of the whole context. Including a communication perspective to the two traditional views of content does not negate them; rather all these viewpoints collectively contribute to the broad scope and richness of perceiving networks. Networks are sufficiently complex and dynamic structures to warrant multiple interpretations.

## **2.4 Conclusion of Literature Review**

The management of prostate cancer is continually evolving as PSA tests and screening provides increased sensitivity of diagnosis on the one hand, but contributes to overdiagnosis and unnecessary treatment on the other. Prostate cancer is a complex disease; multiple issues arise for both the individual and family and everyone’s ability to cope with the disease adds considerable strain. Network analysis can be used to understand how men communicate around issues of health and how the networks provide functions which may help them process their experience. The methods used in this research to understand how and why men communicate as they do, are examined in the next chapter.

## **Chapter 3: Methods**

### **3.1 Introduction**

The purpose of this study is two-fold; to identify the general and health communication networks of men recently diagnosed with prostate cancer and to distinguish some of the factors men take into account when choosing, or not, to disclose about their prostate issues to others in their networks. This chapter details the methods used to conduct the research and relates it to the three research questions: What factors shape the structure of men's communication networks prior to being diagnosed with prostate cancer; for men who are faced with a diagnosis of prostate cancer what are their perspectives about disclosing their health status and receiving social support; and how do men resolve the tension between the benefits of, and barriers to disclosure?

Contained within the following five sections is a justification for using qualitative research and a discussion on the use of interviews and thematic analysis. The second section discusses the participants, their eligibility and demographic details. This is followed by a description of the method of data collection, role of the researcher and a description of the data analysis.

### **3.2 Justification for Methodology**

This research constitutes an exploratory study. As Prell (2012) noted qualitative research often precedes quantitative research and the exploratory nature of this study reveals the broad extent of the topic identifying areas of strength and potential avenues of interest for further study. The three research questions provided a broad base for an exploratory study by assessing both the structure and content of networks.

Analysing communication and relationships is a complex and challenging process as they are both constantly changing in response to multiple factors both internal and external. Context, communication and relationships are intricately woven together and there is an inherent danger associated with taking communication out of context misrepresenting individuals or their message. However, the limitations of pulling apart and analysing something as complex as human interaction and relationships is identified and acknowledged. Qualitative research takes this kind

of multifaceted context into account by accommodating complex social situations (Denscombe, 2008) and as a consequence the research contains a richness and depth not otherwise achieved (Silverman, 2011).

Qualitative research also lends itself to perceiving communication from a network perspective, in which the individuals themselves and the relationships between them are the primary focus. Relationships or ties can be analysed using quantitative research methods such as equations and ratios but underlying feelings and motives would be undervalued (Monge & Contractor, 2001). Qualitative research enables an understanding of how individuals construct their networks and how they perceive the roles and resources of others.

Interviews offer considerable advantages over surveys as the preferred method of gathering data. Interviews provide an opportunity for the interviewer to acknowledge the sensitivity of the medical context in which the participants are placed (Tong, Sainsbury, & Craig, 2007) as the researcher is “attuned to the intricacy of the subject matter” (Denscombe, 2008, p. 174). In this research participants were individuals awaiting results from a biopsy examination. Most patients anticipating a diagnosis are anxious (Midland Cancer Network, 2009) and thus interviews were ideal as they could be conducted in a supportive, trusting atmosphere with full assurance of confidentiality.

Interviews allow for an effective way to gather confidential data from participants. Individual networks are unique and only the participants know their own networks; they are the best and indeed only people to have this information (DiCicco-Bloom & Crabtree, 2006; Silverman, 1993). Face-to-face interviews also facilitate the observation of non-verbal communication. New Zealand men are stereotyped as poor communicators perceived to converse only about a few topics and in a limited way (Seale et al., 2006). The interviewer has an opportunity to observe the participants in a manner which contributes significantly to understanding the nuances of meaning and to explore and better understand the participants’ perspective. Interviews also facilitate further questioning to encourage or clarify meaning and in a medical context this is particularly important (Britten, 1995).

Interviews yield a richness of data where information obtained has significant meaning and is saturated; a stage is reached in the interviews where little new

information comes to light (Reinard, 2001). Richness can also be achieved by analysing the content of the interviews on two levels: manifest and latent (Boyatzis, 1998). Analysis of the manifest content requires interpreting the obvious meaning of the words spoken. Latent content is the denotative meaning behind the words, underlying meanings, the ideas and assumptions (Braun & Clarke, 2006). Both layers of meaning complement each other and contribute to the richness of the data. In the following section the value of semi-structured interviews, the timing of them and the use of free recall is discussed. Finally, a section highlighting why interviews are best with older people is examined.

### **3.2.1 Semi-Structured interviews**

Interviews can be structured to varying degrees: fully structured, semi-structured or completely unstructured. The semi-structured interview was chosen as most suitable for this research and comprised a standard set of questions but provided opportunity for further probing questions to build on these (Britten, 1995). Semi-structured interviews therefore offered a loose framework but with a “certain degree of standardisation” (Wengraf, 2001, p. 62) within which the researcher exercised discretion in asking probing questions. Warren (2002) considered semi-structured interviews a guided conversation which facilitates probing questions by providing space and encouragement for the participant to go further and deeper.

Probing questions arise from the need to clarify a point, understand a new perspective or provide more information (Britten, 1995; DiCicco-Bloom & Crabtree, 2006). Deeper questions add value to semi-structured interviews in egocentric network research as they facilitate greater understanding of the relationships between the ego and alters and can include the nature of reciprocity, proximity and strength. Further questions clarify gaps in the story as to who and what is not talked about with the aim to discover rather than confirm what is already known (Denscombe, 2008). Often what is not talked about is of considerable significance adding balance to the story. The timing of interviews is crucial in network analysis and a further discussion on this is in the next section.

### **3.2.2 Timing**

To establish a baseline perspective of networks near the start of the patient’s involvement in the health system, an ideal time to interview men would be immediately after the diagnosis of cancer when their recall is most accurate.

However, Jenkins, Hurst, and Rose (1979) ascertained that recall is incomplete to the extent that four to six months prior to the present point in time there was a 34% to 46% decrease in the number of events recalled. Recall is known to diminish at a rate of 5% per month; the longer the time between events, the more likelihood of not being able to remember. Unreliability in recounting the past is well known (Wellman, 2007a); therefore, asking the men to recall networks from some point of time in the past may prove to be inaccurate. To achieve maximum reliability the men were asked about people in their present networks but it was considered impossible to implement this due to the probable stress of the participants having just received a diagnosis. The time before a diagnosis, between the initial consultation with a specialist and the biopsy was therefore considered the best alternative time in which to conduct the interview.

The waiting period between consultation and biopsy can be between two weeks and three months. This period of waiting can be stressful for many men and therefore is critical in the process of health management (Bloch et al., 2007; Roth et al., 2008; Visser & Van Andel, 2003). Anxiety and even severe depression may arise from not knowing the diagnosis, fear of the disease, treatment options and a future requiring major adjustments. Indeed, between 23% and 49% of cancer patients are diagnosed with clinical depression at this juncture in the medical process (Edwards & Clarke, 2004).

### **3.2.3 Free Recall**

Free recall is preferable to using a name generator for understanding who is part of the participant's networks. A name-generator (Burt, 1984) uses questions which encourage specific and limited answers such as "name all persons with whom you discussed important matters" (Marsden, 1988, p. 63). By restricting options opportunities for the researcher to use the richness of the stories are limited. Free recall, on the other hand, occurs when the participant is given the freedom to recall names of others in their network without any prompting or restriction on time or numbers (Prell, 2012). Free recall enables the participant to take control of the type and amount of information disclosed equipping them to decide on the relative importance of the individuals. The data elicited from the recall provides a depth to understanding the relationships with and roles of others in the networks.

### **3.2.4 Older People**

Giving participants the opportunity to talk freely about their relationships creates value from the interviews. However, all the participants in this research will probably be over 45 and interviews with older people can be challenging. Older people can be intrinsically motivated to participate in an interview for both social and emotional reasons. Being older means they are at risk of social isolation due to bereavement or physical limitations. Isolation can be experienced as loneliness (Stephens et al., 2011) and for many different reasons they may rely on others visiting them. Older people are known to be more willing to admit women than men into their homes (Wenger, 2002) and are generally comfortable with face-to-face communication. Also, if the interviewer is an older woman and can be trusted a high success rate in terms of relevant data gained from the interview is likely to be achieved (Wenger, 2002). However, social problems such as lack of transport or financial burdens may affect their ability to fully participate in or be focused for the interview.

Another motivation for their willingness to be interviewed is their emotional situation. By nature of their age this group has increased potential to suffer emotional as well as physical isolation. They can be stunned by shock or be in a period of disbelief (Ray, 1994) at this time in their medical journey. Being able to process any information by talking with others is imperative for well-being but the prevalence of having no one to confide in increases with age; 16% of men with prostate cancer aged between 50 and 59 have no one to confide in, which rises to 25% in the 70 to 80 age bracket (Helgason et al., 2001). The men may be motivated to participate in an interview if they consider the interviewer is likely to fulfil the role of confidant.

The interview may be complicated by the participant's medical situation. An individual who has chronic comorbid conditions (Koopman-Boyden & Waldegrave, 2009) or is vision- or hearing-impaired (Shuy, 2002) can present challenges requiring special consideration throughout the interview. But as Wenger (2002) concluded, "most older people do not suffer from infirmities that interfere with the interview process" (p.267) as some older people are able to live independently. Given the possible complications the benefits gained by using interviews were considered to outweigh the barriers. The next section details the

ethics approval and the study participants: their eligibility, demographic and personal characteristics.

### **3.3 Participants**

Obtaining access to patients on a medical waiting list is also challenging. Privacy law in New Zealand states that no medical information is to be given to a third party without the express permission of the patient themselves. The researcher was not able to have direct access to potential participants therefore a urologist became involved who enlisted patients for this study. Gaining ethics approval for the recruitment and the eligibility of patients is considered in the next section.

#### **3.3.1 Ethics Approval**

Ethics approval was obtained from the University of Waikato Ethics Committee and Ministry of Health (MOH) ethics approval was also sought. After an initial application outlining the broad scope of the research the MOH concluded that ethics approval from them was not necessary as this research was deemed communication-based and not medical. The need for MOH approval was waived with the MOH being satisfied the university ethics approval was sufficient. A patient information sheet was given to the men at the start of the interview detailing the format of the research and content of the interviews. Written consent was gained from the participants for the recording of the interviews and also approval for the researcher to obtain the diagnoses. All participants were assigned a number and their personal information remained confidential in a locked drawer in the researcher's office.

#### **3.3.2 Eligibility of Participants**

All male patients who were referred by a urologist for a prostate biopsy were eligible for inclusion in the study. There was no preference based on demographic factors such as age, socio-economic group, marital status or ethnicity and both public and private patients were eligible to participate. An all-inclusive criteria basis was used for two reasons; this research was primarily an exploratory study and the inclusion of all patients simplified the study. The criteria gave a broad perspective of prostate cancer patients and their communication networks; the limited number of patients on the waiting list together with the difficulty of access indicated that eligibility should be as broad as possible.

### **3.3.3 Final Participants**

Table 1 overleaf gives a brief profile of all 22 participants in the positive cohort then table 2 provides a summary of each of the participants' relationship and employment status, children, grandchildren and organisational affiliation. All names are pseudonyms.

Table 1: Participant Demographics

<b>Demographic</b>	<b>Criteria</b>	<b>Participants Total = 22</b>
Location	Within main city boundary	15
	Rural	2
	Outlying townships	5
Age	Range: 59-81yrs Average: 68 yrs.	
	51- 60	3
	61 -70	11
	71-80	6
	81-90	2
Ethnicity	Pakeha	5
	New Zealander	3
	European	8
	Maori	5
	Refused	1
Working status	Work full time	9
	Partially retired	4
	Fully retired	9
Relationship status	Partner	17
	Single: Separated, divorced or widowed	5
Organisational Affiliation	0	6
	1	6
	2	3
	3	7
	+	
Children	Range : Number of children 0 – 8	
	0	3
	1	0
	2	4
	3	5
	4	4
	5	1
	6	1
	7	2
	8	1
9	1	
Grandchildren	Range: Number of grandchildren 0 – 25	
	0	4
	1 – 5	9
	6 – 10	3
	11 – 15	4
	16 – 20	1
	21+	1
Computer proficiency	No answer	3
	None	2
	Limited / reasonable	10
	Competent / advanced	7

Table 2: Participant Details

1.	James	62 years. Single. Separated. Good relationship with ex-wife. All 4 children and 5 grandchildren live in NZ. Works full time and very social with several good friends.
2.	Robert	67 years. Single. One married son. Works full time. Wide circle of friends and a member of many organisations.
3.	John	71 years. Living with a partner. 2 children living in America. Retired 3 years ago. Involved in 4 clubs.
4.	William	69 years. Married. All 2 children and 4 grandchildren living in NZ. Works full time. No organisational involvement but regular attender at gym. Well-connected socially and technologically.
5.	Richard	69 years. Married. 6 children, 2 in Australia. 14 grandchildren, 3 in Australia. Retired. Involved in 3 clubs
6.	David	59 years. Maori. First wife died. Married for the second time. 7 children and 14 grandchildren from both marriages. Half from each set is in NZ and Australia. Works full time. Not in any organisations but very social with family and work colleagues.
7.	Charles	74 years. Married for 53 years with 3 children and 5 grandchildren most living in NZ and some living in Australia. Retired. Involved in 2 clubs with wife.
8.	Thomas	80 years. Maori. Widower. 8 children, 2 live locally and the rest in Australia. 10 grandchildren all in Australia. Beneficiary. Involved in many organisations
9.	Frank	75 years, English, living with a partner. 0 children, 1 sister. Retired professional. Not involved in any organisation. Severely restricted socially due to unrelated chronic condition.
10.	Michael	81 years, Married. All 4 children, 12 grandchildren and 6 great-grandchildren living in NZ. Retired. Not involved in any organisations.
11.	Ronald	59 years, single, 3 children, 2 in NZ and 1 in Australia, 2 grandchildren both in Australia. Works full time. 2 previous prostate biopsies.
12.	Larry	66 years, Married for third time. 3 children and 3 grandchildren. Working full time and involved in 1 organisation.
13.	Donald	68 years. Married. 3 children and 5 grandchildren all living in NZ. Working full time. Not involved in any organisations.
14.	Joseph	60 years, partner. 2 children and 1 grandchild all living in NZ. Working and a member of a professional organisation.
15.	Gary	60 years, Maori, married with 5 children and 9 grandchildren half living in Australia. Full time work and involved in 2 sports clubs. Previous biopsy.
16.	George	68 years, separated, 3 children, 1 in Australia and 9 grandchildren all in NZ. Retired. One organisation. 2 previous prostate biopsies.
17.	Kenneth	76 years, Married. All 3 children and 2 grandchildren live in NZ. Works part-time and involved in 2 sports clubs and 2 organisations.

18.	Paul	72 years, Maori, married, 7 children and 25 grandchildren a few in Australia. Retired although runs own small business. Involved in several organisations
19.	Edward	63 years, Married. 2 children and 1 grandchild in Australia. 3 siblings in NZ. Self-employed. Involved in 3 organisations.
20.	Jerry	73 years, married with 4 children and 11 grandchildren half of whom live in Australia. Retired. Involved in local church.
21.	Stan	57 years. Married, 5 children, 14 grandchildren and 2 great grandkids. Half Maori and half English. Works fulltime involved in 0 organisations.
22.	Dennis	66 years, Living with a partner. No children and one sister in Australia. Retired. One organisation

### **3.4 Data collection**

The next section describes the method of data collection, construction of the interview guides and the procedures used to obtain the data. The role of the researcher is explained in the following section.

#### **3.4.1 Interview Guides**

Prior to the research commencing, a series of open-ended questions (see Appendix B) was formulated relating to the three research questions. The interview questions were broadly divided into two sections; the first relating to men's general, everyday conversation and relationships and the second more specifically about their communication around health.

A pilot study was then conducted to test the questions. Four men aged between 50 and 75 were selected from a group of church friends, agreed to participate and were then interviewed for one hour. The interview was recorded and brief points made into field notes at the conclusion. The interview questions were evaluated by the men for clarity, ambiguity and coverage of the research questions. The assessment also included the appropriateness of the probing questions which arose during the interview. Feedback was requested as to the participants' perception of the interview and improvements which could be made. Notes were taken by the researcher throughout the debriefing (Tong et al., 2007). As a result of the pilot study, the interview questions were revised and two more questions were added.

The introductory question provided an opportunity for the participant to transition into the context of the interview. The next four questions were generally used to answer RQ1. The second question established the communication networks in which the participant operated and also the importance of specific individuals and organisations to the ego at the early stage of interaction with the medical system. This overview indicated network features such as physical proximity.

The next two questions provided some understanding of the background of the participant, their interests and emphasis of what is important to them and to what extent health networks are already in existence. A probe was listed that indicated the level of reciprocity between the participant and others. Asking for the participant to recall examples of recent conversations with others in the network gave an impression of who was important to them and to what extent family members were part of the core group.

The fifth question relating to communication technology identified how familiar the participants were using technology as a means to communicate with others. It also established the existence and dimensions of any virtual relationships such as strength, reciprocity and frequency. The second section of the interview changed the emphasis to a focus on communication around health. Specifically, four questions were created to address the second research question.

The sixth question provided an introduction to the subject of men's health and a perspective on how health issues had been incorporated into their lives and networks. The next question referred to their positive or negative experiences of health communication and level of reciprocity. By asking who the men chose to disclose to about their own health in questions eight and nine it was possible to assess not only the willingness of the participant to communicate about health topics but also the extent of their health network and the strength or weakness of ties in it. The motivations for the men's decisions to disclose were therefore revealed.

The remaining questions were created to address RQ3. Questions 10 and 11 ascertained the participants' perspective of perceived support and who may provide it. Asking question 12 together with the probing questions about electronic communication gave an idea of their reliance on technology for

communication. Concluding questions 13 and 14 enabled the participants to add to the discussion should they be aware of further relevant comments.

### **3.4.2 Procedures**

Following the pilot study the research project was presented at a monthly research forum of five urologists and a practice nurse. The proposed method was discussed and approval gained to use the urologists' patients as participants. Verbal approval was also given by the urologists for the researcher to access clinic lists, patients' medical information and their diagnoses. Public patients, whose initial consultations took place in the urology outpatient department at the hospital, were then biopsied in one of two private clinics. A complex arrangement existed between the local District Health Board (DHB) and two private urology providers who were contracted to perform biopsies for the DHB.

At the research forum one consultant urologist volunteered to be involved in this research. He explained the study to all new patients at their initial consultation and asked if they would be interested in participating in the research. He also rang all patients who were already on the waiting list to ask if they would like to be involved. A patient information brochure was handed or sent to all who agreed and their names and contact details were passed on to the researcher. The researcher then contacted the patients (who from now are referred to as men throughout the rest of this study) to explain more about the study and arranged the most convenient time and place to be interviewed prior to their biopsy. The men were given the choice of location for the interview - either in their own home or the private urology consulting rooms. Out-of-town men were given the additional options of a telephone or skype interview. The researcher gained credibility at the start of the interview by emphasising her medical background and willingness to listen to their medical stories.

Interviews were conducted with 41 men in a three month period between July and October 2012. It was expected that about 50% of the biopsies would be positive and 22 men were subsequently confirmed to have a positive diagnosis. Their interviews were then used in this research. The remaining 19 interviews were stored safely. Despite the wastage of interviews in this stage of research it was considered preferable to interview at this time rather than immediately following

diagnosis when the stress levels could be higher and the men could be making decisions about treatment.

At the interview each man was given a participant information sheet which described the research and their rights. Following a discussion with the researcher the consent form was explained. In accordance with the requirements for ethics approval and in order to proceed with the interview the man had to grant permission for the interview to be recorded and access given for the researcher to obtain the diagnosis. The interview took between 30 and 60 minutes and was recorded using a digital recorder. A digital recording offered superior sound quality and ease of transcription using a computer. The men were also told that if their wives attended the interview they could not participate in the discussion.

Between one and three weeks after their biopsy the men were given the definitive diagnosis by their urologist. The researcher obtained a list of men who had a confirmed diagnosis of cancer from the nurse in charge of the urology clinic. The positive cohort consisted of 22 men diagnosed with prostate cancer and the other 19 men comprised the negative cohort as they either had no abnormal cells or a benign condition of the prostate.

All the men were sent a letter thanking them for participating in the study. The negative cohort received this one month after the biopsy and the positive cohort approximately six months later giving them time to adjust to the diagnosis and progress with treatment.

### **3.5 Role of the Researcher**

As a woman and researcher, I conducted this research from the perspective of a middle class, educated and professional background. I had two roles in this study; one of a medical professional, albeit slightly out of date, and the second of researcher. I worked for 20 years as a Radiation Therapist so I have medical knowledge of the disease and the treatment process of prostate cancer. This role ensured I had credibility in the eyes of the men; I was perceived as legitimate, trustworthy and understanding.

In my second role as a researcher, I represented the University of Waikato which gave me credibility and impartiality. Being impartial was of considerable benefit both to me and the men. I was neither related to nor known to the men or their families and as a consequence was perceived to be neutral without judgement or prejudice. I believe being a mature female researcher brings extra opportunities and dimensions to the research process. The men were willing to be involved in this research and felt more comfortable talking to a woman than a man; due to my gender they talked more openly. Most of the men said they would not be willing to talk to a younger woman as they considered the subject matter was too sensitive. Both these roles were made clear to each man prior to them making a decision about being involved in the study. This information was contained in the participant information sheet and later reiterated verbally at the start of the interview.

For each man I hoped to achieve a broad understanding of the important people in their lives; together with the roles they performed. I was reluctant to enter into too much detail about individuals, preferring instead a network-based approach. I also hoped to examine health perspectives and incorporate this into the broader picture of their networks. I wanted to achieve a balance in terms of showing understanding of their medical situation but without lengthy discussions about it. I was aware of not wanting to be misunderstood as to my meaning of communication and its relevance to networks so I was careful to ensure the meaning was shared with the men. Finally, I was aware that this research was biased towards New Zealanders. Other cultures have very different social and family arrangements and networks. I considered that the interview questions and my communication style would accommodate Maori or other ethnic groups.

### **3.6 Data Analysis**

An explanation of and justification for using thematic analysis is provided in this portion of this chapter. A description of the procedure used to analyse the interview data is offered.

#### **3.6.1 Thematic Analysis**

As this research was an exploratory study thematic analysis was considered the most appropriate method for analysing the data (Bloch et al., 2007). Thematic analysis is the process of organising, interpreting and analysing data by coding

information into themes (Braun & Clarke, 2006). Some of the benefits of using thematic analysis include flexibility of interpretation, the ability for the simultaneous collection and analysis of the data and making sense of and bringing cohesion to the data.

An inductive process starts with the collection of data followed by development of the themes and then construction of the theory. This approach permits a broad and flexible interpretation in order to conceptualise and interpret the data so maximum information can be gleaned from the men's stories (Braun & Clarke, 2006). This approach emphasises conceptual flexibility which is breaking down the data and naming all the parts with any number of codes permitting a broad scope initially (Strauss & Corbin, 1990). Interpreting the data requires willingness to be open-minded about the information without bias.

Furthermore, thematic analysis allows for both the collection and analysis of data to occur simultaneously (Tuckett, 2005). Because the approach is an inductive one the process of data analysis and gathering is not a linear progression from one part of the process to the next; rather it is cyclical in nature. Analysing data can inform the interview questions as well as in reverse constituting the iterative nature of this research. Questions are refined as the research process continues and the researcher learns more about the subject (DiCicco-Bloom & Crabtree, 2006). The analysis is circular, progressing from codes to patterns then themes, revisiting previous data and interpreting it in the light of new information giving a sense of moving back and forward between the entire data set (Braun & Clarke, 2006).

A significant step in the process, collating themes, also ensures cohesion and structure emerge from disparate data. Some data is not typical of the entire set and the structure associated with themes permits utilisation of the non-representative data. All these factors contribute to utilising the richness of the data and demonstrate the value of thematic analysis. The procedure for analysing the data is detailed next.

### **3.6.2 Procedure**

At the time of the interview the men had not received a diagnosis; this was obtained about three weeks after biopsy. The researcher obtained diagnoses and ascertained which group, positive or negative, each man was in. The interviews from those in the negative cohort were not used further for this project. The men

who were diagnosed with cancer were grouped in the positive cohort and their interviews transcribed and analysed using thematic analysis. Braun and Clarke (2006) detailed six phases necessary to process data using thematic analysis; the procedure for explaining this research will follow these steps.

### ***3.6.2.1 Phase 1: Familiarising yourself with the data***

For ease of transcribing the digital recording of each interview in the positive cohort was relayed through an audio amplification programme which reduced any extraneous noise. The interviews were then transcribed to the level of ah's, um's and pauses. Every transcript was then copied as a backup and all the transcripts were also amalgamated into one mega-transcript. The researcher listened to the interviews and also read the transcripts prior to analysing any data. The recordings and data were kept in the locked drawer in the researcher's office.

### ***3.6.2.2 Phase 2: Generating initial codes***

The transcripts were read and track changes were used to highlight any general points of interest. These points were chosen with no bias providing a sense of how the man and his networks functioned, who was in them and what was important to him. Initially, themes were created by breaking down transcripts into 'bite-sized' bits, phrases or a section of conversation creating codes (Owen, 1984; Ryan & Bernard, 2003). In a second reading, another level of track changes indicated the initial codes. When reading the transcript and it was indicated the man had strong feelings about a topic clarification was gained by listening to the interview again which gave an indication of the forcefulness of speech. Forcefulness or intensity, the power with which the meaning is communicated, can be revealed as pauses as in natural transitions, changes in voice tone or the use of metaphors (Ryan & Bernard, 2003). The use of digital recordings ensured it was easy to listen to specific parts of the interview. The initial codes were then collated into categories (Aronson, 1994). A summary of each man and his network was created identifying both individual and network characteristics of nodes and ties.

### ***3.6.2.3 Phase 3: Searching for themes***

Themes are recurring patterns drawn from the transcripts of the interviews and is "a way of making sense of unrelated material" (Boyatzis, 1998, p. 4). In order to identify possible themes a number of strategies were employed. From the initial coding a selection of words was generated which seemed to represent broad

concepts across each of the transcripts. The selection included words such as *worry, tell, think, do, feel, group, mate, work, other, cancer, wife, son* and *daughter*. In order to get an understanding of the men's networks as a whole, themes needed to be considered not only throughout each individual story but across all the transcripts. A word search was also conducted on the mega-transcript noting the repetition of the word and the frequency with which it was used. Recurrence of the word (Owen, 1984) was also identified which gave an impression of the same meaning of a word and was especially important as it placed the word in context which is an essential component of network analysis. Due to the emphasis on context lots of time and diligence was taken to try and comprehend the circumstances of the men. Track changes in the mega-transcript and tables of repetition, recurrence and context in a separate new document were used to record the results in this phase of the analysis.

#### ***3.6.2.4 Phase 4: Reviewing themes***

The track changes and tables were then collated into possible broad concepts. It was important to keep focused on the communication perspective: the who, how, when, where and why of ties and nodes throughout this step in the process. Themes needed to be identified which were consistent with the essence of the research and the three research questions. A constant evaluation and flow back and forth between the men's summaries from phase two and the track changes and tables of phase three characterised this stage in the analysis.

#### ***3.6.2.5 Phase 5: Defining and naming themes***

Themes were identified and matched with the research questions. As Ryan and Bernard (2003) noted "not all themes are equally important" (p.103) and so an assessment was made of the relative importance of the themes by understanding the nature of each one both in its individual context and within the whole picture.

#### ***3.6.2.6 Phase 6: Producing the report***

Writing up the findings captured the sense of how the men engaged in the topic by matching relevant quotes with the themes and research questions. Information which could not be neatly categorised into an existing theme was retained in another document and included in the final write up. It was considered important to include non-standard responses to enable a holistic understanding of the men's communication and networks.

### **3.7 Summary of Methods**

This chapter on the methods used for this qualitative research has explained the rationale for using semi-structured interviews with emphasis given to the timing of the interviews and free-recall type questions. Older people can be particularly challenging to interview which was acknowledged. The second section described the reasons behind the choice of thematic analysis to analyse the data.

Involvement of the men was then considered; both the ethics approval needed to obtain their participation and the eligibility criteria for them. Finally, the analysis of the data using thematic analysis was explained. Having given an account of the methodology of the study, attention is given to the findings from the interviews in next chapter.

## Chapter 4: Findings

The purpose of this study is two-fold: to identify the communication networks of men recently diagnosed with prostate cancer and to distinguish some of the factors men take into account when deciding whether or not to disclose their prostate issues to others in their networks. The following chapter on findings discusses the main themes which emerged after conducting a thematic analysis on the interview transcripts of the men who were given a diagnosis of prostate cancer.

The opening section of this chapter addresses the first of three research questions: what factors shape the structure of men's communication networks prior to being diagnosed with prostate cancer? The next section focuses on the content of networks; specifically, how communication flows through and between individual in answer to the second research question: for men who are faced with a diagnosis of prostate cancer, what are their perspectives about disclosing their health status and receiving support? Finally, the third research question is: how do men resolve tension between the benefits of disclosure and the barriers to disclosure?

Pseudonyms assigned to the men and some brief details about each were included in the methods chapter. Diagrams of some of the men's networks are used in the early part of this chapter to demonstrate how their networks are individual and distinctive (see figures 1 to 7). For ease of understanding each diagram has a simple key attached; each item in the key refers only to a node the man referred to in the interview. In many instances, the demographics revealed family members who were not mentioned during the interview and so these nodes were not included in the diagrams. Additionally, when the man suggested a whole group rather than individuals within it, small circles within a larger circle were used to represent the group as a node.

## **4.1 Research Question 1**

What factors shape the structure of men's communication networks prior to being diagnosed with prostate cancer?

The following section addresses network structure and is comprised of two parts; first, a description of the nodes which are the individuals or groups in the network and are the foundation of the structure. The second part explains the ties in the men's networks.

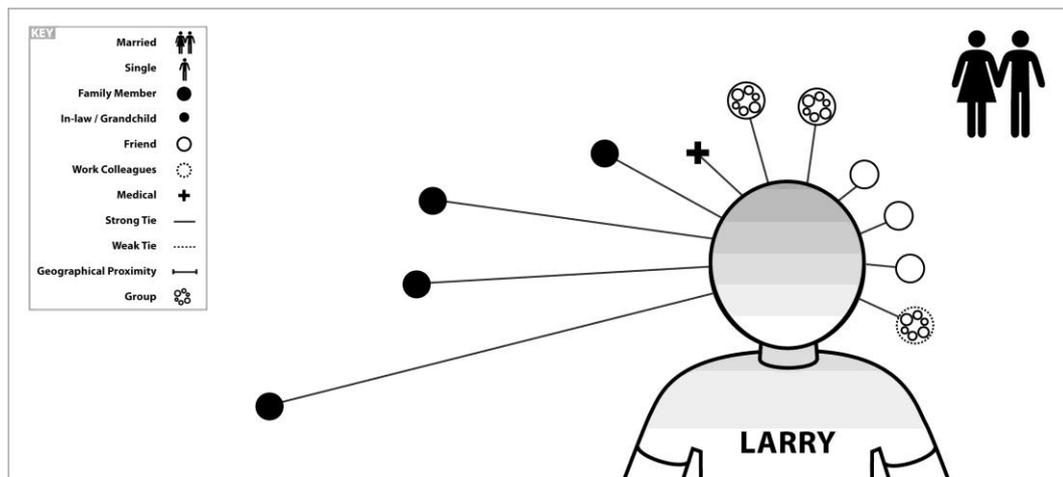
### **4.1.1 Nodes in Men's Communication Networks**

This section identifies two different types of nodes in the ego's network: first the ego himself and then groups as nodes. The findings identified the ego's network was comprised of nodes based on his relationship status, employment status, and previous medical experience.

#### ***4.1.1.1 Ego as a Node in the Networks***

Network structure varied according to the men's relationship status. Seventeen men lived with a partner usually their wives and five were single. Networks for both these groups of men tended to be small with strong ties limited to immediate family. Michael's circle of others was simply "mainly family and the lady next door." Michael and his wife looked after the neighbour as she had recently had a stroke and her immediate family lived out of town. Larry, whose network diagram (figure 1) is illustrated overleaf, had a close network of family but also an extensive number of colleagues and friends:

I'm used to working in charge of 68 people all the time you know and I play bowls so down at the bowling club. There's 60 or 80 people there we socialise quite a bit. And so there's quite a range of people that we meet and there's basically no secrets.



*Figure 1: Larry's Network*

Wives were of considerable importance to men facing the prospect of a chronic illness. Significantly, many men stated their wives were the only family member to be part of their health network. Richard commented: “apart from my wife obviously knows. I haven’t told anyone” while Jerry stated: “Oh my wife. That’s about all. I haven’t mentioned it to anyone else. Oh no use worrying about it.” A wife was a convenient logical person to include in their networks, providing all the support that was needed.

Conversely, the men who lived alone identified themselves as being single and one had never been married while others were widowed, separated or divorced. The networks for single men can be more extensive as with James who worked full-time and had been divorced for many years: “I’ve got a whole lot of mates. Well I frequent the bar quite a bit I’ll go and have a beer every night and I’ve got a whole heap of mates that I’ve known for years and years. You know, all been at work.” Another single man, Robert, who worked full time, found time to be an active member of six different organisations. He had friends or acquaintances all over the city having lived in one place since the age of 21 but he had regularly changed the groups he participated in:

A couple of years ago, I re-joined them again but I meet them every Friday night over at the Cosmopolitan club. So I said I’d go over there every Friday evening. I’ve recently joined the snooker club there and am a member of the Working Men’s Club now.

Robert's network was comprised entirely of local nodes as shown in figure 2 below:

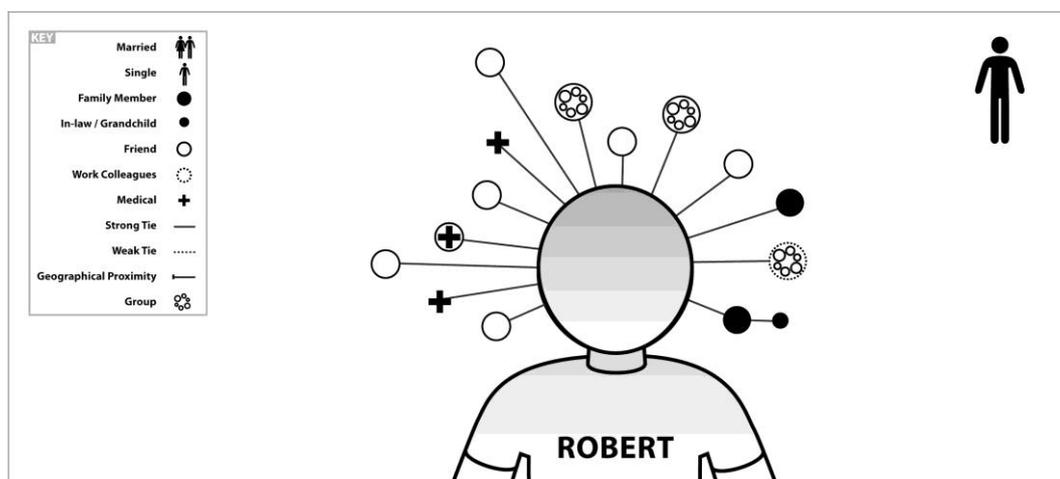


Figure 2: Robert's Network

George, who also lived alone, retired as a carpenter four years ago and began to pursue an interest in music more deeply. He had a much smaller and closer network than Robert:

Oh well I've got two daughters I keep in touch with. And my son is in Aussie. I'm pretty close to my daughters and ring them up often and they come and see me. I'll go and see them. And the neighbours, I get on with them alright. I live by myself.

Network structures were quite different depending on the primary relationship of the men. Married men tended to have more family-focused, smaller and closer networks than the men who lived by themselves who had more friend-based extensive networks. Some married men had a limited network of a wife and family who provided for all their needs; social, emotional, physical and intellectual. There was little incentive to have other nodes in the network; single men, however, were forced to find social connection and meaning with others.

In addition to their relationship status, men's employment status also influenced the structure of networks; whether the man worked fulltime, part-time or was retired. The employment status of men was largely age related; those who were

working full-time were under the age of 70 and those above this age were semi-retired and working a few hours a week or were completely retired. The number of hours worked tended to shape the nature of their networks. The few men who worked full time had networks centred on family and work colleagues with few if any social friends. David travelled all over the country in a demanding, fulltime job “and when I get home I just love being home. I love it. I just get home and I just love being in my family circle you know. Just being with my family and relaxing.” He still had time and energy to foster some friendships but his family was his main focus. Donald reiterated the feeling that the demands of fulltime work together with living and working in different cities ensured leisure time was spent with the family “and by the time I’ve travelled back and forth up to city A in the weekends I’d just be happy enough to sort of stay at home.”

The networks of men who had semi-retired usually comprised family and friends from interest-based groups; most men did not refer to previous colleagues as the part-time job was a different job or in a different industry to the fulltime work they had previously been involved in. John retired as a farm consultant three years ago and then worked a few hours a week as a property manager. His networks included being a member of a professional organisation, a running club and a church. Charles, who was 74, discussed his new part time job with his bowling mates:

We talk about how we’re going with economics and they’re saying we’re thinking of selling our house and going down and get a bit of money and just to make life a bit easier. I work two days; two half days a week and I’ve just said to them I’ve got another job. “Charles, at your age going out working again.”

George was single and a semi-retired carpenter and his family were the only people he communicated with. He did not mention any work colleagues, “nobody else. Only my family. Keep to myself.” For the men who worked part-time work was purely for income generation. Retired men had the time and inclination to develop hobbies, which for several brought a significant change in networks with new friends. Charles, who five years ago at the age of 75 joined a bowling club and rapidly became a champion which required that he go to matches both at home and away therefore got to know many others in the club. As a result his

networks of friends changed considerably. He noted, “since I’ve more or less retired or got into bowls, we [him and his wife] got a lot more new mates and we talk about your health or different conversation.”

The amount of time committed to work, in part, determines the structure of networks. Those who worked fulltime tended to have networks centred on their immediate family with fewer other people. Semi-retired and retired men were able to cultivate friendships from the interest-based hobbies they were involved in and had a more extensive network which involved both family and friends.

The structure of communication networks was also influenced by the extent to which the man had previous involvement with the medical profession. The majority of men in this research had a concurrent medical condition or a previous diagnosis of prostate cancer and so the health communication network of these men was well-established. Some men already possessed an extensive health network which included the GP and several specialist physicians and departments. Those men who had been recently diagnosed with an unrelated illness, required intensive and on-going treatment or had a serious accident were most likely to have a health network containing a large number of nodes of health professionals. The more demanding or difficult the management of their health the more absorbing and extensive their health networks became. Edward had an accident which resulted in a serious head injury approximately two years ago. He spent one year undergoing rehabilitation and as a consequence was familiar with primary and secondary health care and the Accident Compensation Corporation (ACC):

I really felt I should write a letter to the Ministry of Health or to the ACC minister and that just to say things that were not easy and not really picking holes in anybody in particular, but yeah just pointing out issues that I felt, cause I was lucky to be honest.

Edward had extensive interaction with many medical and academic individuals as he was also involved in head injury research. His network is illustrated in the following diagram:

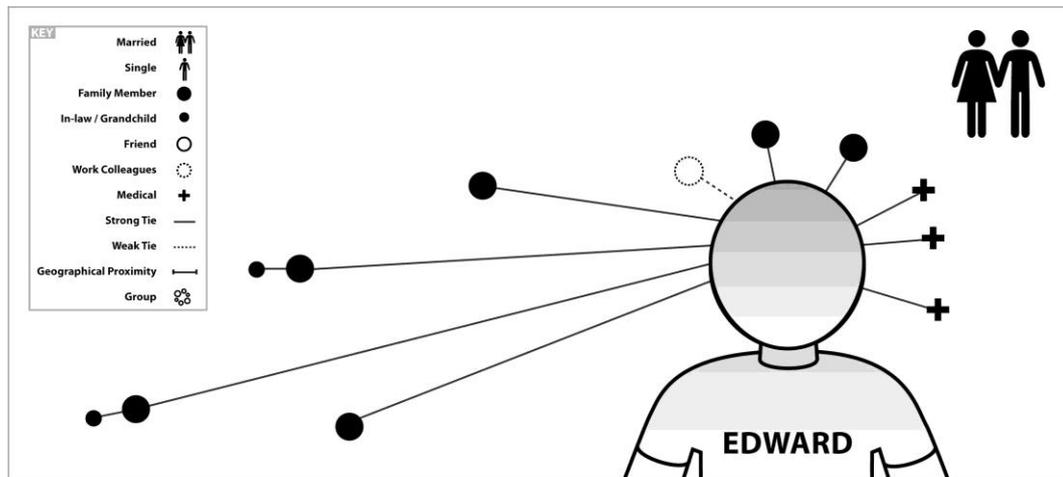


Figure 3: Edward's network

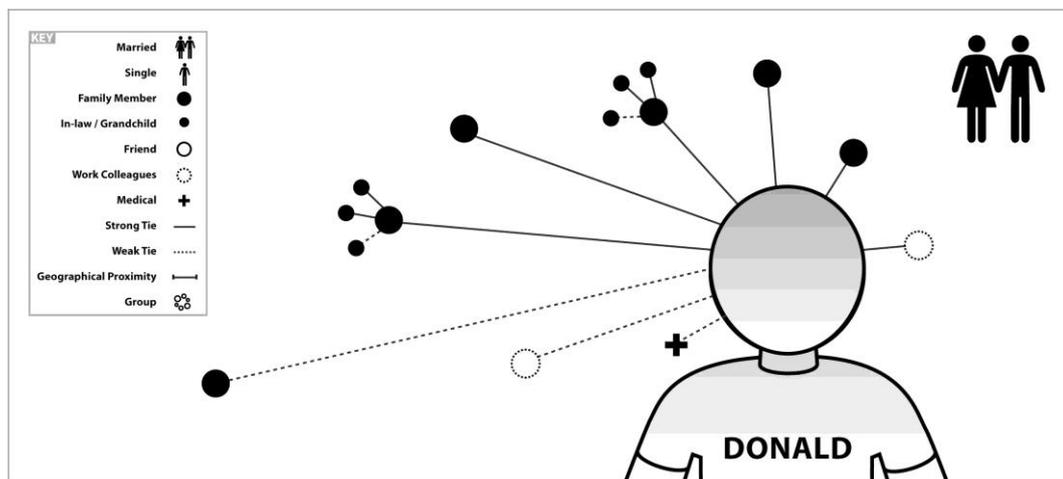
Another man, Frank, had a chronic and unrelated medical condition which had recently started to severely restrict his quality of life, making face-to-face interaction almost impossible. He had come to live in New Zealand two years ago and as a consequence his networks were limited to people with whom he could use technology such as skype and emails. Unfortunately not all his family and friends were proficient with skype and so some individuals dropped out of his networks.

Another group of more fortunate men had been very healthy throughout their lives and so had little contact with the medical system; they had few health-related nodes in their communication networks. James was a farm manager with an active job and was very fit and healthy. He had little previous involvement with the health system and the biopsy had thrown him into a world with few contacts:

My doctor is hard to get through to. You know, he never says anything. You know you'd go into him and he'd oh okay and he'd just write a script out and away you go. I just go in and get my blood pressure done every three months and you know get my pills. Nah I've had no communication with anyone really. No one.

Recent ill-health changed nodes in his own network as Donald observed. His long-standing networks, shown below in figure 4, were reduced due to an anti-social symptom of prostate cancer, polyuria (passing an excessive amount of urine). He had an extensive and busy social life having previously been active in a local organisation for a number of years and as president for the last five:

I was on the committee for something like 10 or 12 years but then when I did start to have prostate problems and that I sort of gave up all this, gave up drinking you know. Just have a couple of beers and you're running to the loo all the time so it became a bit of a social issue. So I tend to probably become a wee bit antisocial to some degree.



*Figure 4: Donald's network*

Men's networks were also impacted by the ongoing medical conditions of their wives. Larry's wife had previously been very fit and healthy with travel to visit family overseas being a regular event. When she developed a serious heart condition the impact on both of them was considerable; it restricted their ability to travel, everyday life and also relationships:

Cause the worst part about that was she was the fittest lady there was. Then all of a sudden she's got this in her now. She's had 50 years. So life's on hold for a bit because like well you can't fly with that. We used to go to Australia every 12 months you know.

Larry's network was reduced due to his involvement in his wife's treatment and care. Normal life for them both took a considerable time to establish.

Factors which influence the structure of networks change; some factors become more important at a particular stage in life or for a specific reason; others recede and new factors emerge. Medical conditions changed relationships and the number of health professionals involved in a network increases. In contrast, men who were fit and healthy or had an easy-to-manage illness had a reduced number of health-related nodes. These men would only communicate with a GP for routine tests or medication and so had little involvement with medical personnel. Networks of these healthy men included a greater proportion of family, friends and others.

#### ***4.1.1.2 Groups as Nodes in the Networks***

Two groups which have a significant presence in men's networks are immediate family and special-interest or hobby groups but one group which was absent were health-related support groups. All three group nodes are discussed in the following section.

Immediate family have a considerable influence on the structure of men's networks. A strong existing network of immediate family members such as children, siblings, brothers or sisters-in-law characterised this later stage of life. Geographical proximity to family was important for nearly all the men. Some nodes, individuals or family units, lived within a few kilometres of each other, often in the same community or town. Adult children who lived in close proximity constituted a significant part of men's networks, more so than children who lived further away. Geographical closeness tended to promote more frequent communication and many men had closer relationships with their children who lived in close proximity as face-to-face contact was easier for the men.

Michael, who had four children, introduced them according to proximity rather than in descending order of age; the closest was mentioned first and the child who lived furthest away in Christchurch mentioned last. Many comments indicated Michael was in more frequent contact with the child in closest proximity; in this case the youngest. "Yeah the youngest one he's just putting on three garages for his boys cause they're car mad. I ring him every day." Another man, Donald, had three children only one of whom lived nearby. "The other daughter lives handy,

only about three kilometres away so probably we see her reasonably all the time.” Due to the close proximity of this daughter he also had regular contact with her two children.

Family members who were medical professionals had a prominent role in the men’s networks. Several men disclosed they had a medical professional in the immediate family with whom they discussed prostate issues. If a sibling or other family member was a medical professional, nurse or doctor, a closer relationship was created as a result of sharing prostate issues and receiving support. Several men commented on the importance of regular contact with these family members. John’s son who lived elsewhere in New Zealand exemplified the relationship: “my son’s actually a doctor and I have told him about it. He checks [on me] as if I were a patient. Not every day, every couple of days or something.” While Edward, in pondering who to tell about the biopsy considered sharing with his sister who was a nurse and her husband a doctor:

I have a sister who’s a qualified nurse, or was, she’s married to a paediatrician and they’re semi-retired but he does stints overseas and they’re in Germany. They’re coming back in about ten days. So I didn’t know whether to pop in and see them. But if he’d been here I think I would have.

David had family nearby and used opportunities to keep his brother-in-law updated with his medical progress, “I’ve been quite fortunate because my brother-in-law’s a doctor too. He’s in city B and he’s been talking to me about all this stuff.” Immediate family who are medical professionals fulfil one of two roles within the men’s networks; as a supplier of credible information and as overseer of prostate management. Men are encouraged to be part of the decision-making process for treatment options and usually want to be well informed. They used the relationship with the medical family member as a significant node in the network even if the prior relationship with them was not a strong one.

Special-interest groups, usually based around a hobby, were also significant nodes in men’s networks. A variety of clubs were represented: bowls, golf, dance or the Cosmopolitan Club. Charles, the bowling champion, found the bowling club provided him with an extensive network of friends with whom he could discuss almost anything and his network is illustrated overleaf in figure 5:

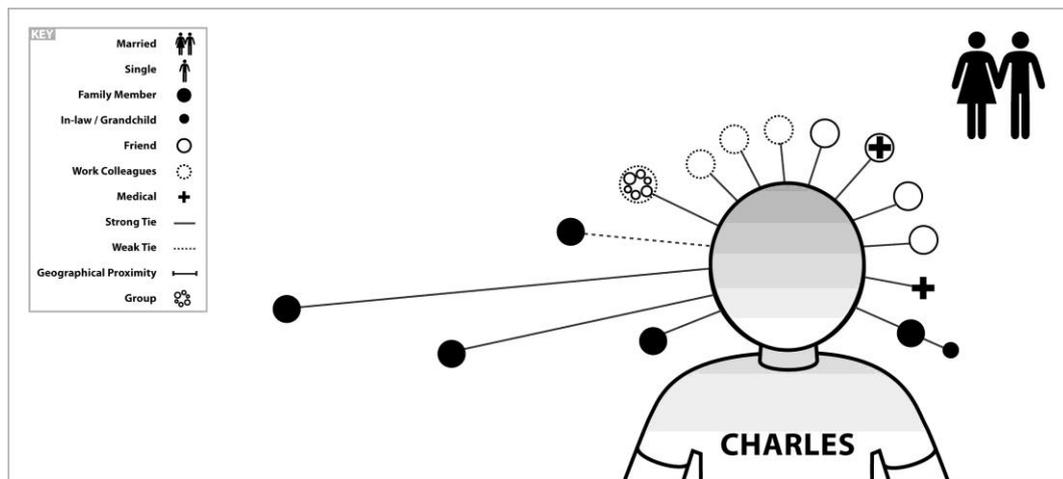


Figure 5: Charles' network

Charles' perspective on conversation with his bowling friends is given in the following example:

Well just a lot about bowls and just general business really of being pensioners. You know. Talk about sometimes finances or you know general business. Talk about things going up and how do we manage. It's not easy out there. Yeah. We're just talking about general business. Oh yeah.

At this time he was waiting for a referral from his GP to the urologist but discovered his referral had gone missing through a friend in the bowling club:

So he (GP) said I think we better do something about it [suspicious prostate examination]. So anyway I left it at that. Eighteen months went by and hadn't heard. I hadn't heard, hadn't heard. So I was talking to a woman that I play bowls with, outdoor bowls. And she said I'll look into it. And anyway I think she's in that sort of department.

Robert was well-connected though the dance club he regularly attended:

And I know a lot of people from the dance club too. I can go to the clubs on Friday or Saturday night look around and say I know that lady, know that lady, cause I belonged to the dance club. I've done dancing over the years.



The absence of a potentially significant resource of health-related support groups in the men's networks could be due, in part, to the ego's networks providing all the necessary support. It may have been some time since the men were treated for another medical condition which was well-managed and did not necessitate contacting a support group. Being involved in support organisations could be perceived as a weakness or inability to manage the illness. Alternatively, support groups have a very low public profile resulting in patients who could benefit from them being unaware of their existence or capabilities. This perspective is endorsed by the local branch of the Cancer Society which admitted that only 30% of all patients recently diagnosed with cancer in the Waikato region are aware of their existence (G. Harbutt, personal communication, May 3, 2013).

#### **4.1.2 Ties in Men's Communication Networks**

Nodes are not isolated in networks but joined by ties, both of which determine the structure of networks. Features of ties include frequency, proximity, stability, strength, reciprocity and homophily. Frequency describes how often communication occurs between individuals. Frequency is increased with regular participation in interest-based groups and also with family who lived nearby. Frequency is highly correlated with proximity and several men were up-to-date with the lives of their children and grandchildren and could recount recent events and future plans due to living close by. Stability is the existence of the ties over time with longer ties contributing to stable relationships and networks. Stable relationships ensure nodes remain in changeable networks. For example, Richard's group of networks was comprised of local friendships from the past 30 years, the nodes being very stable.

Strength is also an important feature of ties, shaping the structure of networks. In order for a strong tie to exist the relationship needed to demonstrate a sense of the relationship being special, an interest in being together and a sense of mutuality (Wellman & Wortley, 1990). Strong ties existed with the wife or partner but strong ties also occurred with the men's other family members. Richard, a full-time and busy manager, made time for developing strong ties within his family unit:

Actually we have one of our nieces come and visit us this past weekend. And she used to stay with us when she went to university as well and she's been going through some relationship problems. And she decided, because we're like her second mum and dad, so she came and sat down with us, spent the weekend with us. And we had a good chat.

For many men strong ties existed with a few close male friends. Richard would only tell his closest friends about his prostate issues: "I wouldn't tell every Tom, Dick and Harry. I'd just tell probably about three or four and that's all." While thinking of who he would and would not disclose to, William named his three best friends amongst a group of others:

I'm not as confident as I appear to be. Like there's a whole circle of friends out there like Steve and Colin and Chris and all those. They don't know that I've prostate cancer at all. I've never even mentioned to them.

Reciprocity of ties also contributed to network structure. A relationship in which both individuals devote equal time and energy is a reciprocal one. Relationships with the ego's children demonstrated reciprocity, with the men communicating regularly and taking initiative to connect with some if not all the children. Frank had close family living overseas and being quite immobile relied on skype to communicate with them. He noted the effort to communicate was reciprocal and regular amongst all the family, with others initiating contact with him as often as he initiated it. Frank's strong and reciprocal ties with his family overseas are shown in his network figure overleaf:



### **4.1.3 Summary of Research Question 1**

The first section of this chapter on network characteristics addressed the first research question: What factors shape the structure of men's communication networks prior to being diagnosed with prostate cancer?

Factors that shape men's communication networks included the relationship and employment arrangements of the men, proximity to others and the presence of medical professionals and the medical conditions of others. In addition, immediate family and special-interest groups had a significant presence in men's networks. Each of these components had an impact on how networks were structured although networking through health-related support groups was not a priority. Some features of ties were also explained, features which included proximity, strength and homophily. The next section addresses the second research question and explains the implications of nodes and ties in men's networks in more detail.

## **4.2 Research Question 2**

For men who are faced with a diagnosis of prostate cancer, what are their perspectives about disclosing their health status and receiving social support?

This research question is focused on the content of networks; the relationships and communication between the ego and others in his networks. Men who are faced with a possible diagnosis of cancer have a difficult decision to make about whether to tell others about what they are going through. If they do choose to share consideration needs to be given as to whom to tell, what information is involved and when is the best time (Gray et al., 2000). All men chose to share with a significant other, usually their wife or partner. Some other men chose to ignore the potential diagnosis and regarded the biopsy as just another appointment in their week; some were quite open with everyone while others would disclose only to a small group of core friends. Four important factors were found to contribute to the men's motivation for being open or closed about their current prostate situation: the context of disclosure, benefits of disclosure, barriers to disclosure and resolving the tension between the benefits and barriers. It is these points that will now be considered.

### **4.2.1 Context for Disclosure**

Given a choice people will not disclose to individuals they perceive as unsafe or in an unsafe context. Safety requires an element of trust in relationships where both parties value the words spoken and feelings expressed to a similar degree. Mutual respect and understanding also helped foster safe relationships which in turn provided a safe context. Many men with prostate issues were embarrassed by the nature of these issues, the physical body parts, symptoms and treatment complications as well as the sexual connotation and threat to their manhood. The need to have safe relationships and contexts in which to disclose was of the utmost importance, both of which are discussed in the next two sections: within and beyond safe environments.

#### ***4.2.1.1 Within Safe Environments***

After talking with their wives some men stated they preferred disclosing their own health on a one-to-one and face-to-face basis with individuals with whom they felt safe enough to talk freely. In everyday conversation John reinforced his basis for communicating about his health “but we would only talk about health things perhaps on a one-to-one basis.” More specifically, Richard chose not to tell one particular friend until they met face-to-face: “oh I’ve got one mate in town A that I would probably talk to about it cause he’s had a prostate operation. I haven’t talked to him yet cause I haven’t seen him.” This relationship was long standing due to stability and shared experience but only existed when they met face-to-face with there being no communication between meetings.

Other men who felt reasonably safe and confident disclosed to a small group of established friends with whom they had strong ties; mates in a small group who met regularly in an established context, such as playing bowls or over a drink in the pub. Larry (figure 1, page 59) was married and had a very extensive network of friends and acquaintances which included people he met through his work. He chose to only tell a few of his long-standing friends in one of his weekly pub visits:

Well I told them that I’ve been through for you know like a prostate thing. And you know like and I’ll be having a few drinks down at the bar, there’s a big group of acquaintances but I’ve got three you know all the same, very close friends.”

In all cases, except one, the men only disclosed to people within their networks. Uniquely, David openly discussed his prostate issues with one man, unknown to him, in a waiting room:

Cause I'm sitting in a clinic and I told the guy "oh what are you here for mate?" You know the way it goes. I'm talking to a stranger so I mean. I'm not a blabbermouth but I'm a very outward-going person so you know when I see someone that's suffering or someone: "oh how are you? What's happened?" I'll talk to them you know. You know so yeah I'd talk to anybody.

However, for most of the men a level of trust, mutual respect and understanding in significant relationships had been formed over many years with their wives or core groups in their networks. Gary, in talking about his openness and willingness to share about prostate issues with his work mates postulated "I just think it's the good friendship and trust between the people that I work with you know." Likewise, John (figure 6, page 68) had built up confidence in his urologist: "Well you have to trust somebody so I trust the urologist." Safe disclosure, whether sharing with one other person, a small group or a wider community, was carefully considered by the men. Men who shared with a significant other and a few friends felt safe, and none of the men stated they regretted their choice to share with either a particular individual or in a specific context. The desire to be in control of the release of personal information is a natural inclination; however, unspoken rules of communication change dramatically with cancer.

#### ***4.2.1.2 Beyond Safe Environments: Gossip***

A cancer diagnosis is a life changing event of magnitude for almost everybody in the men's networks, not just for the individual. In reality, gossip can be the backbone of how this information is dispersed. Gossip is defined as two or more people talking about someone else who is absent (White, 2013). It can be innocuous but also as White (2013) noted have a morally suspect nature too; the unhelpful motivation of the originator of gossip. Many men were aware of the existence of gossip; William, who was well-travelled and well-connected, aptly described the potential downfall of disclosing as "a little percolating gossip chain." David, while discussing his network of friends demonstrated a reserved attitude to gossip:

You know so that's how all the conversation happens. You know cause we all, we got friends everywhere. Someone talks to so and so or they may have caught up with someone and they've shared something with them. You know what I mean?

Both William and David worked fulltime, had an extensive circle of colleagues and friends and lived in the same city for many years. They perceived gossip to form a significant barrier in choosing whether to disclose. Several other men felt similarly; John postulated that because he had chosen not to disclose he might be the subject of gossip in the running club:

I live in [town B] I don't go to their weekly meetings on a Sunday morning and this week they have a special run. So they are probably talking amongst themselves [about him] and they have no idea what's going on.

Richard's natural preference was to be an onlooker in social occasions with his friends. A quiet, introverted man, gossip made him even more reluctant to disclose: "I'd just tell probably about three or four and that's all. Although once you tell one, they'll tell the whole lot anyway."

Several men were the recipients of gossip about others. They were exposed to similar medical stories and needed to make a decision on how to manage hearing about the situation of others. In most circumstances the men chose not to follow-up on gossip they had acquired. William knew of several individuals who were going through prostate treatment but chose not to talk about it directly with them: "I know of people. Like I know for example of a principal whose husband has just finished having an operation but I've never spoken to him about it." John was in a similar situation through his extensive network of IT friends: "I've heard of a friend who's had prostate troubles but I know people who've sort of been through it." Gossip can be seen and accepted as a functioning part of everyday life as David illustrated:

I've got a friend now who's also got prostate cancer over in Australia and he wasn't looking too good the last time a friend of mine came back from Aussie. They would go there and visited him. And they said "boy he looks terrible."

Several men did share despite knowing the potential of gossip, partly because they relied on gossip to manage their decision of whether to talk or not; that is, they knew if they told one person in their network, they could count on others finding out too without having to make an active decision about who to tell. Gossip ensured they did not have to make an active decision about disclosure which in many instances is an easier decision as the entire situation can be overwhelming. Some men displayed a philosophical attitude to gossip, a sense that it is inevitable and will always exist so is not worth fighting against. Some men like Robert felt safe being the centre of gossip; others such as William felt unsafe and may have responded by being measured in disclosing or intentionally choosing to withdraw socially. Feeling insecure and knowing there is gossip men may also become isolated as others alienate them not knowing how to react (Spiegel et al., 1981). Gossip can directly or indirectly lead to social withdrawal or isolation, both of which are significant problems for those diagnosed with cancer.

Gossip or news-sharing is a significant factor in how networks function. Individuals often know each other and can be well-connected with a multitude of others feeling vulnerable. In order to receive any support the men needed to feel safe about disclosing. The context in which they shared and the person or group with whom they shared had to be of their choosing and at the right time and place. Having established a safe context in which to disclose men were then able to receive and give benefits from disclosing. The next section identifies potential benefits to the men themselves and to others.

## **4.2.2 Benefits of Disclosure**

Within a context of safety men could understand some of the benefits of sharing their issues with others in their network. Talking about issues in life rather than being closed is usually seen as a preferential way to manage them. By disclosing about prostate issues men stand to gain significantly, not only the men themselves, other people can also benefit.

### ***4.2.2.1 Benefit for Self: Received Support***

Social support is one of the most important benefits derived from functioning networks. It is the practical working out of relationships without which individuals quickly become isolated. Social support can be provided in the forms of emotional aid, information, instrumental aid or companionship.

Emotional support is an expression of empathy, love, trust and caring (Heaney & Israel, 2002). Men's need for emotional support was often implied rather than clearly stated but many men gave the impression of physical and emotional independence. A few of them admitted to being concerned about the diagnosis and prognosis. David told of his underlying panic about the current situation in the face of a possible diagnosis of cancer. His first wife died unexpectedly and despite having remarried he felt quite insecure about the future:

You know. I've got to cope with it. So you know some days I panic. Oh the other day I was stupid. But I was thinking should I write her [wife] a note and just let her know how much I appreciate her and really love her heaps but those are some of the things that come through my mind sometimes. Cause I'm thinking "ooh I'm finding it kind of hard to breathe at the moment".

David received significant support from his wife who had also had cancer; this resulted in reciprocal and valued emotional support between he and his wife. Wives were the most significant other for men to turn to for emotional support (Gray et al., 2000). Gary discussed with his wife about how and when to tell their children about the biopsy:

Like my kids over in Australia. They come back for Christmas because my wife and I, we spoke about it. About not telling them over the phone you know that. The first time telling them you know it was pretty hard but yeah we waited for them to come back at Christmas.

Wives provided significant levels of support, but so too did siblings. Dennis enjoyed a long-standing relationship with his sister:

I got a sister who often just checks in in Melbourne who checks us to see whether, how I'm going and with it so. It's sort of my sister and that's the main one and mum and the friend in Tauranga that we've got.

The support between siblings was often mutual. George's brother was recently diagnosed with cancer and so George was offering him support within a close relationship:

But he's [brother] 75 I think and he's getting on a bit. No, I have quite a bit to do with my brother. Go around and see him quite often. In our young days we used to be out pig hunting and deer stalking and all sorts of things. Chasing pigs around a bush and yeah.

He also received emotional support from his sister in a recently renewed relationship "I got a sister in town B but yeah, have a lot to do with her. She comes quite often and sees me and I go down there and see her too. Pretty close to my sister now." Siblings provided significant emotional support. A long history with siblings resulted in relationships that were already emotionally close, despite there being a considerable geographical distance between them for some men. Siblings also provided support and for men who lived alone these ties were even more significant.

Workmates provided emotional support and encouraged David to share about his prostate issues and to communicate about his current situation. He owned his own business and worked fulltime: "you know I'm very independent so I don't want anything else from them [work mates] you know. But it's just good to be able to talk to them about it." Charles (figure 5, page 67) echoed a similar attitude to sharing at work:

Oh um well my work mates and that. I've got the boss and the apprentice boy and the other chap there. The same thing happened. I was about to go to the toilet quite a bit and they were saying you crook Charles? I say oh just one of those bad days. And then since I been on these injections, they said "oh you're pretty good. You don't go as much as you used to." And we just talk a little bit about it. Not a lot.

He also received support and understanding from a friend in the bowling club. Charles had only known his good friend for six years but felt a significant loss when this mate, the only one he really shared with, passed away recently:

I had a mate that we played [bowls] together a lot and he had cancer of the stomach and he went into remission and poor devil just after a couple of years it came back at him. I was always ringing up or went on the bowling green asking how we going yeah and yeah he died a few months ago. And you know we; actually that's the really the only

one that I really talked about myself to you know and all that sort of stuff. Making enquiries about him and he was asking about my problem and that and we were you know, pretty good mates really.

Wives, siblings and workmates were a source of emotional support for the men at this time and each had a distinctive part to play in the men's network. Another benefit the men experienced from disclosing was receiving information support.

#### ***4.6.1.3 Informational Support***

Men needed to be informed about the possible diagnosis, treatments and side effects of prostate cancer as they were expected to be part of the decision-making process for the treatment. They obtained information in the first instance from their GP, nurse or urologist. All were given verbal information and in some cases written literature. Some men actively obtained further information from credible sources such as medical family members and supplemented this by accessing online information themselves. Edward (figure 3, page 63) attended meetings organised by his GP practice to understand more about prostate cancer and "went to a couple of men's meetings. Went about once and my brother said to me "what the hell are you doing that for?" and I said "it's interesting." Edward understood that his doctor was aware of misinformation around prostate issues and had organised an information evening. Men sought credible sources of information and actively dismissed information from non-reputable sources.

Most of the men were aware they needed to be fully informed. John (figure 6, page 68) said: "so he's [urologist] kind of sitting on the fence and he's giving me the information so it's my decision. I'm aware of that" and William commented: "I'll be probably quite selfish about it [getting information] because I just want information because I'm picking on I'll have to make a decision on whether I have to have radiation or surgery." Both these men had actively sought information from a range of sources and were well equipped to be part of the decision-making process in their own treatment. All the men relied on the medical profession for information. Larry (figure 1, page 59) talked with the urologist:

All I'm saying is like when we went in there he [urologist] just said to me, basically explained to me the whole thing about prostate and how it works and all that. Oh I wouldn't say it was a conversation, he told me what it was.

Robert (figure 2, page 60) took the initiative to find information online but relied on the doctors for credible information:

I might look up like Google prostate cancer and just get a general picture of it. But I don't take it for the gospel truth, no, I rely on the doctor for that.

Primary and secondary health providers helped by offering written material at the time of consultation but James discovered the right information was not always available at the most helpful time:

There's been no communication. Only one letter to say you're not supposed to have the biopsy but I can feel something's not right. And it's only come. It's only beginning to get like this since I went to them. You know. Like three months ago, three and a half months ago, there was nothing. I had no idea at all what I was even going for.

Men wanted information support and in many instances they proved adept at locating information about prostate cancer and treatment for themselves; whether it was on the internet or through other written material such as brochures at their GPs practice or in books. They tended to rely on medical professionals for verification. Information support was particularly important at this stage in the medical journey. Instrumental support, on the other hand, was a part of everyday life for the men, especially with immediate family who lived locally.

#### ***4.6.1.4 Instrumental Support***

Instrumental support is the provision of tangible aid such as transport, meals and finances. The men received some instrumental support as part of their everyday lives usually unrelated to health issues and mostly provided by their sons. Charles (figure 5, page 67) was in the process of making a transition from full-time to part-time work which resulted in a decrease in income so his son provided instrumental help by selling his father's car:

Yeah my son came over from Australia and helped to sell the car to try and get down to one car. We had both cars when I was working. I was working three or four days a week and earning a lot more money and we could afford to run these two cars and my wife was housekeeping and that, but she had a stroke about 12 months ago.

Michael also maintained a good relationship with the youngest of his sons, benefiting from his instrumental support when he “just came down and we had the oak tree chopped down and he just came down with a chainsaw and cut it all up.” In the health context the most common form of instrumental support was transport to the appointment for the biopsy. This was provided by a family member, usually the wife, but in some cases a daughter. Despite children offering to provide transport this was rarely taken up by the men. Donald (figure 4, page 64) spoke for virtually all the men who were fortunate enough to be independent:

You know just look after myself and not worry about using other people if I can avoid it. Like today both my son and my daughter you know, wanted to bring me up and I said “ah I’ll be right. I’ll be good as gold you know.”

Donald, despite being married, wanted to maintain his independence by not inconveniencing his children and pursue his routines at this stage. A more common scenario was for men to be the providers rather than the recipient of instrumental support, often undertaking practical home maintenance. Michael was a retired chair-frame maker and so was willing and able to do practical jobs for his son who lived locally:

My son and daughter in-law are living here [in the same town] too. And the son’s just got two twin boys. Well we go around there; it’s just up the road, number 95. We can walk up there. And grandma looks after the twins during the day so that their mum can work and that so we wander up there sometimes and see them. Oh do jobs for them if they want jobs done or something like that. Daughter-in-law bought some chairs at the auction and she wanted me to go fix them. Well I put a leg on one. Anyway I’ve fixed them and she wanted me to build a little bit of a wine-rack and I’m sort of building that now.

Michael was quite involved in the lives of his local family and the instrumental support he provided was a regular and committed part of how the both families worked. It was expected Michael would come round to fix or make something because the children lived locally. He provided support when it was needed and not just when his wife was babysitting. David provided instrumental support by gifting his house to his children. He had moved from Wellington to be nearer his children after his first wife died as he moved on in his bereavement he was able to create a win-win solution for everybody in his family by giving the house to his children:

Two of my kids, and they, one of them got married and they've decided to move to Aussie and then so I gave them the house and says "you have the house and ah, just to help you guys out." And then I thought well I can't hang around their coat-tails for the rest of my life. I've gotta move on aye.

Instrumental support was valued as a resource which naturally flowed through networks between families, generations and friends in everyday life. At this juncture most men preferred to give instrumental support rather than receiving it. They wanted to remain independent, demonstrated by their resistance to the offer of transport to the biopsy appointment. Several of the men were dependent on others, were not in good health or were frail and elderly and instrumental support for this group was not a choice. Companionship, another benefit, was evidenced between friends in networks.

#### ***4.6.1.5 Companionship***

Companionship is getting alongside another and being together. Companionship in the health arena can be demonstrated as the willingness of others to come forward and provide a friendship when many would find the issues with cancer too hard and keep away. Many men had regular meetings with mates in the usual context but did not actively seek it out as something special. James worked fulltime and found companionship in the local pub:

And I've got a whole lot of mates. Well I frequent the bar quite a bit I'll go and have a beer every night and I've got a whole heap of mates that I've known for years and years. You know, all been at work but there are other people, you know.

Robert's (figure 2, page 60) long standing fishing friends provided him with companionship. "I'm not religious, none of my family goes to church and I don't think any of my mates go to church. No, not really, we don't talk about that [health issues]. We do a lot of fishing together." On the other hand, David had friendships which made light of the health issues they faced and his relationships give the impression of companionship rather than emotional support:

We're a bunch of hypochondriacs and we all talk about our health problems and we're all crackin' up. I've shared a bit, my family know about it. I've shared it with a couple of mates and I says "yeah yeah I've got a...Cause I asked him how he was "yeah good, good, good, good" and as we were talking away there and you know. "It's just life mate. I've got this too. Don't worry about. It's just part of life."

William had an extensive network with various groups of friends associated with particular hobbies. Happy companionship featured in all his groups:

Then there was another group of friends who are into food and wine. And so we chat about that and quite often meet. Some of us got together with a good bottle of red. And some will meet up and have a few tickles trying a couple of bottles of red or something like that.

For many men the contexts of their companionship were well-established; they met regularly as part of the bowling or fishing group. Companionship proved useful to the men as it promoted a relatively normal life and there was a readily available opportunity to talk in depth if required. Companionship also provided a sense that others in the network were getting alongside them at this time.

Receiving support was not the only motivation for the men wishing to share their medical journey; they also wanted others to benefit and so they could also provide support. In order to achieve this some men's focus was on promoting discussion and action motivating other men to be responsible for their own prostate health.

#### ***4.2.2.2 Benefits for Others***

Many men perceived potential benefits for others in their networks if they disclosed and they were keen to 'put their experience to good use.' By doing so they achieved a sense of satisfaction knowing they had promoted discussion amongst and action in individuals.

Men perceived that sharing their own experience could be beneficial to others by promoting openness, discussion and action. Many men were mindful of the stigma associated with cancer in general and prostate issues in particular and made a concerted effort to counteract the stigma. Jerry wanted to promote discussion at a men's group in the church he attended regularly for the benefit of others who may be in a similar situation: "I'll probably make a comment or two and that'll set something rolling. That might help some with the same problems." Men who attended this group were aged 45 or older and Jerry felt this was a suitable age range and forum for discussion. Gary also initiated discussion with work mates and facilitated talk by making others aware of his situation:

It's more or less just been at work between some of my friends cause some of them. Since I've told them about my prostate cancer, they've been talking to me about some of their friends that have prostate cancer you know and some have passed on and talking about the operation and all that you know.

Several men also actively promoted prostate cancer with the men in their family, siblings or children. Donald (figure 4, page 64) assumed responsibility for telling his family in the belief the knowledge would help his son-in-laws: "I tend to speak to them as well about my health issues. Well mainly prostate problems probably because it's the issue that relates to them more than anything else probably." The men saw themselves as a catalyst and trailblazer; even the quiet and introverted men were prepared to talk at times about their experience to promote discussion. However, all the men were careful about who they chose to speak to. They were more likely to choose men in the older age group as the higher risk age bracket for acquiring prostate cancer; particularly work colleagues or men with whom they share hobbies.

Men were encouraged to share by hearing open discussion on the radio and television about prostate cancer by prominent and respected individuals. Richard had seen many adverts and heard discussion on television:

I don't see it as a big secret or taboo cause as I say as soon as one knows, the lot will know anyway. It's a sort of thing that seems to be discussed now. It's not sort of a like a secrecy around it. Might have been years ago but I don't think there is now.

Several men actively promoted discussion and they were empowered to do this by the openness in the media about prostate issues. This has been the result of a dominant political theme of individuals taking personal responsibility for their health, particularly in the case of prostate cancer. Men have been encouraged by politicians to be assertive in seeking medical assessments but also in the promotion that it is desirable behaviour to do so. Most men who promoted discussion carefully chose who they talked with, choosing those in the high-risk group i.e. those over 45 years of age.

Furthermore, seven men strongly advocated for other men to act and be responsible for their own health by going to their GP to get a blood (PSA) test. Larry (figure 1, page 59) told his work mates “all I’ve told everybody like ah like I had to think geez, I’m no bloody, what is it, flag bearer but I have told everybody to start getting their arse in and start getting checked all over.”

Kenneth was explaining his impending absence for the biopsy to his colleague:

“Oh yeah I won’t be around for two or three days.” [Work mate replied] “Oh why’s that?” “Oh I’m going into hospital to have a prostate check”. He said “Oh bugger” he said “I don’t know whether I should do it or whether I shouldn’t”. I said “Well, if it’s not working for you properly you go in and have a check, mate. It’s better that you do it now rather than wait another 10 years. Cause, ” I said “you wait another 10 years, you got a problem”. I says “easier picked up now.”

Michael was waiting to tell his sons when he had a diagnosis and would then promote action. As a result of being interviewed for this research he had a sense of urgency to tell them as his wife (who also attended the interview) pointed out the familial link of prostate cancer:

Michael: Bearing in mind I think we should tell them [sons]. I’ve gotta go up there tonight when he comes back. Gordon comes home and I should tell them and we can get them checked out. I should tell him so he can do it.

Wife: Yeah cause Michael’s father died of prostate cancer.

Michael: Right. So that makes it much more important then is it really?

The motivation for disclosure, discussion and action was different to the need for emotional support. The men chose to encourage their sons, work colleagues or a few friends to be aware of prostate cancer. In contrast, other men were more reticent to speak up, choosing only to talk with their wives and not to promote any discussion or action. This distinction depended on the men's perception of the "social conditions (e.g. others' criticism, denial withdrawal) that lead individuals to feel unsupported, misunderstood or otherwise alienated from their social network" (Lepore & Revenson, 2007, p. 315). Some men felt free to promote discussion, others felt constrained.

In summary, an assumption is made that individuals with cancer are only the recipients of social support. In the case of emotional and informational support they are beneficiaries but on many occasions men gave support to others and they continued to maintain these roles. Choosing to disclose can bring benefits both to the man himself and to others in his networks. Potential benefits included a range of social support strategies which would not be available had he not disclosed. Others can also gain by being part of discussions on prostate issues and encouraged to visit their GP proactively for a routine check-up. However, the question of disclosure is not always so clear cut; benefits can be counteracted by barriers.

### **4.2.3 Barriers to Disclosure**

Whilst some men actively promoted discussion and action, others were more reluctant to disclose personal and medical information. Three perspectives of barriers to sharing are presented in the following section: the uncertainty of diagnosis, men's perception of themselves, and their perceptions of others.

#### ***4.2.3.1 Uncertainty of Diagnosis***

Uncertainty of diagnosis coloured the first interview for this research as the men were interviewed immediately prior to the biopsy. Most of the men felt there was little to be achieved by discussing vague possibilities and situations that may not eventuate. The uncertainty motivated some men to actively avoid having conversations, considering options, or making plans until they had more clarity around the diagnosis. Edward (figure 3, page 63) in reflecting on a recent conversation with his wife, noted "frankly I'm quite at peace with it, I'm not

really you know, I'm not really that concerned at this stage and to be honest, sounds awful, I should be I suppose. I don't know."

Tensions existed between keeping the family informed of the latest developments and having nothing of importance to tell them. David illustrated this well:

Yeah the kids are always saying, "Well hey, how'd you go on your last visit to the doctor?" You know so I gotta give them an update and say "Oh don't worry about it, I'm fine. Good as gold. No, come on dad, tell us now. Oh he just did the usual thing you know. There's nothing new yet. Unless something comes up that's worthwhile telling you, I'll tell you". Yeah I'll let them know what's happening cause they worry about me.

The men gave the appearance of not wanting to discuss possibilities at this stage but had been primed by the medical profession for a worst-case scenario of cancer. In the event of a diagnosis of cancer the men would choose to adopt an open approach to communication as evidenced by Donald (figure 4, page 64): "if it's positive and I've got cancer in the end then I'll probably tell people that I have got some cancer there. I won't try and hide it." George had considered options in the event of a positive diagnosis but had not yet told his daughter of his proposal:

Oh, if the worst comes to worst, I'd probably just go down and stay with my daughter at Coromandel. She's got a big house and plenty of rooms and beds and things. I'd just go down there. Put my house on the market I suppose until. It depends what happens.

The current medical uncertainty had considerable implications for the men about how seriously to take the biopsy. Some men stated they had a lack of concern at this juncture but this approach was challenged by the concern of family members. The men managed the tensions by delaying tactics, assuring others they would be informed when the situation was more certain. A few men had thought through the implications of a diagnosis of cancer, the impact on themselves, their wives, and the decisions which would need to be made and created solutions to potential problems.

#### *4.2.3.2 Perception of Self*

Another factor which was a barrier to disclosure was the men's perception of themselves. How they perceived themselves in relation to others partly determined their attitude to sharing and two factors were of significance: their perceived reliance on others or being perceived as needy or ill. Some men did not want to be perceived as relying on others. They preferred to be independent and so went to considerable lengths to ensure they were not seen as relying on other people. Michael, in referring to the help he could receive from his youngest son, commented:

Oh I think he could take time if he wanted to but I wouldn't sort of really ask him to take time off. And the third one, I wouldn't dare ask. He hasn't got any transport anyway so. So you have to look after him really.

John (figure 6, page 68) echoed a similar sentiment of independence:

So in a way I'm strong and committed and will get through. My partner's family, she has family in city A. Cause they're both working and busy people. So I'm fairly independent sort of person. Don't like to depend on other people too much.

Men were genuinely concerned not to involve others when they considered themselves fit and healthy and capable of doing what was required. Some men did not want to be perceived as being needy or ill and requiring additional help. A few men stated they were perfectly fit and able, emphasising their good health throughout life. James claimed "I've never been sick in my life. I never get the flu. Never get a cold. Never been to hospital. I've got blood pressure I take tablets for and I get gout." They were proud of their record and did not want to be perceived by others as being ill when they did not feel ill. They just wanted to get on with normal everyday life without interruption. Healthy lifestyles were what they knew and were familiar with. John (figure 6, page 68), in referring to his daughter who also had cancer stated "but she's like me. She just sort of ignores it and keeps going" and later reiterated "I don't want everybody to know. I don't want people fussing around." Both Robert (figure 2, page 60) and Donald (figure 4, page 64) emphasised their desire for normality:

Robert: Oh got a lot of support from them [son and his wife] of course and another friend who can do blah blah but I don't think I really need that. I think I'd rather just be treated like a normal person, yeah.

Donald: I was thinking I would be pretty open. I'd probably disclose it to anyone that really needed to know about it. You know. I feel as if it's better off to let people know when you've got these problems than try and hide it and helps people understand that they don't have to sort of do anything special for you or anything like that.

The image some men wanted to project was being normal and to be perceived as being stronger and therefore coping better. Edward (figure 3, page 63) reflected a similar sentiment "My God, my memory's not very good either just at this stage or something and you're trying to cover up and be strong." The ability to ignore the current situation is a coping strategy particularly at this point in time.

Portraying an image in public appeases the men's expectations around health and being ill; they expect to carry on as normal, to be seen as being strong in the face of adversity and behave as the archetypal strong, independent Kiwi.

#### ***4.2.3.3 Perception of Others***

In addition to how they perceived themselves, most men showed insight into how others could perceive them when they talked about their prostate issues and a number of men were more reserved about disclosing. Influential factors to affect disclosure to others included not wanting to worry others or be a nuisance; the men were more concerned about the health of others who were perceived as being too busy to help.

The majority of men claimed they did not want to worry others, due in part to the uncertainty of this early stage in the medical process. If the diagnosis was negative or benign some men indicated they would choose not to talk about it at all, this being a matter of timing and seriousness. Edward (figure 3, page 63) offered a response typical of the majority of men when explaining his stance:

I don't want to worry people about it. And frankly I'm quite at peace with it, I'm not really you know, I'm not really that concerned at this stage and to be honest, sounds awful, I should be I suppose. I don't know.

Several men did not want to be perceived as a nuisance; they did not want to get in the way of the other's lives by requesting time or attention. George, identifying his lack of willingness to talk about himself, suggested who he could share with: "nobody else. Only my family. Keep to myself. Cause they got problems themselves and I don't want to bother them too much. Unless I really have to." Paul was an exception and had no problem being assertive with his GP, whom he believed was performing inadequately:

I first went and got this, the read-out from the doctor. When I got down there, the stuff that I wanted done was not. So I went back to him and I said, "sort it out. I want these things personally done." He says "why?" I said, "because I'm the patient and you're the one with all the knowledge. You've got the authority to get it done. That's why." So he says "okay." So he wrote it down.

Paul had a medical background and so was confident in his medical knowledge. He demonstrated that not all men were concerned about how they were perceived or worried about being a nuisance.

Another barrier preventing disclosure was that several men were more worried about the medical situation and health of others, particularly their wives. When it was considered to be detrimental to the health of others then a choice was made not to tell of their own prostate issues as they did not want to compound existing problems. In several cases the partners were in poorer health than their men or in an acute phase of ill health which required significant resources from their husbands. This resulted in their prostate issues being marginalised while concentrating on the health issues of others. Charles (figure 5, page 67) was quite honest about where his concerns lay and therefore how to manage his own health: "the less I know the better. I'm feeling good. I worry more about her [wife's] health than my own." John (figure 6, page 68) came from a close family who were used to sharing with each other and offering support but he considered his sister not well enough to be told about his prostate issues:

My family knows. And my two brothers know. My sister doesn't know. She's a year older and she has a bit of early stage dementia. She's at a rest home. And she's had a lot of stress and depression so we don't want to upset her.

Finally, the men perceived others to be too busy with with their own lives, bringing up children or working to be worried about them. George, who lived by himself but had close relationships with his two daughters and son, reinforced his perceptions about his children being too busy on several occasions “I don’t talk about my health problems too much because they got problems themselves and I don’t wanna burden with my problems” and again later:

So they worried about anything I did so I just sort of keep it to myself by choice. Unless it’s a tumour and I’ve got to really tell them something which is going to be pretty hard so hope not. They got enough problems themselves bringing up families and everything and just life.

George was intentional in his choice not to disclose to family but often these men had chosen to talk with significant others prior to choosing not to share more widely. By doing so, they had satisfied their own need for support and care. Despite the benefits associated with disclosure, men also experienced barriers to talking. An important barrier was the uncertainty of the diagnosis at this point. Not knowing how serious the result of the biopsy would be, some men chose not to talk about it other than to their wives, waiting for more conclusive information before telling others. A further barrier was the perception of self; not wanting to rely on others or being seen as needy or ill. Finally, their perception of others was a potential barrier; not wanting to worry others or be a nuisance, the health of significant others was more important than their own and they perceived others to be too busy.

#### **4.2.4 Summary of Research Question 2**

The second part of this chapter addressed the second research question: For men who are faced with a diagnosis of prostate cancer, what are their perspectives about disclosing their health status and receiving social support?

Context proved to be an important factor the men took into account when choosing whether to disclose; some contexts were perceived as safe and others were not. Given the right context they were aware of the potential benefits of disclosing but were also mindful that barriers to disclosure could stop them sharing. The men realized they had the potential to benefit from disclosing their prostate issues; they received social support as emotional aid provided in the first

instance by their wives or significant other. They also received information to help them be part of the decision-making process. Furthermore, instrumental aid and companionship were also received as support. Benefits also accrued for others which included promotion of discussion and action around getting annual checks ups, both important facets of prostate management for some of the men.

Uncertainty surrounding the biopsy was considered as the most significant barrier for the men in choosing whether to disclose to others about their own medical situation. Many men felt they could not or did not want to share as they were concerned about how others would perceive them. Compounding the issue of disclosure was the men's perception of others and not wanting to be a burden to them. For men the benefits of disclosure and the barriers to disclosing proved to be a considerable tension; benefits and barriers form a two-edged sword. At times men demonstrated a willingness and even keenness to share and yet in other contexts would not do so. The following section identifies factors which contribute to resolving this tension by answering the third research question.

### **4.3 Research Question 3**

How do men resolve the tension between the benefits of disclosure and the barriers to disclosure?

A few men appeared not to have any tension between the benefits of and barriers to disclosure; they either did not talk to anybody other than their partner about their prostate issues or they talked to everybody about everything. For the majority of men, however, tensions in communication arose throughout the early stages of diagnosis. They had a choice about whether to share and if so with whom, when and how. Network structure can contribute to resolving the tensions as their decision about disclosing was based on assessing four dominant factors in their relationships with others: homophily, proximity, strength of ties and an alter's professional or personal experience of cancer.

#### **4.3.1 Homophily**

In the first instance, married men shared with their wives. They were then likely to disclose to others who were similar to themselves. Homophily, connections with others who are similar, is well-established in literature (McPherson, Smith-Lovin, & Cook, 2001; Prell, 2012). Individuals can be similar in age, socio-economic status or professional status for example and homophily is often found

in interest-based groups. Homophily was a very dominant feature in the men's networks. With the exception of two men all the men chose to share with others beyond their wives and immediate family demonstrating homophily. One man, Robert (figure 2, page 60) who was single, shared equally with women and men. Jerry shared in a church group which was comprised of men of all ages. They met like-minded friends, mostly male, with whom they created meaningful ties which provided various forms of support such as companionship or information.

#### **4.3.2 Close Proximity**

When the men had a choice about disclosing, a single individual or core group of people in the networks were privileged to be informed of the men's prostate issues by them. Geographical proximity was the most significant factor, those in closest proximity were their partners and all the men disclosed to their partners. Others who were in close physical proximity were children who lived locally and a few long-standing male friends or work colleagues. Donald (figure 4, page 64) noted the impact of proximity on his networks when the main office for his job was moved from the town where he lived to a city over one hour's drive away. His main relationships "changed from being sort of local people to people at work basically." James recounted those he would tell and all of them lived locally: "Oh my best mates. I'd tell the boss at work." Many had daily contact with a small group of male colleagues and it was often one of this group who was a party to disclosure. Larry (figure 1, page 59) had a busy fulltime job with responsibility for over 60 staff and would disclose "at me workplace to the people like my immediate boss or close acquaintances there."

The face-to-face component of communication is very important to men and so proximity in networks is a key factor in men's decision whether to disclose. Their first preference is for face-to-face communication and they would only use a phone to talk with family who lived further away or overseas if they had no choice. Larry (figure 1, page 59) was not keen on using a phone but talked with his daughter who lived in another city:

I'm not a very big telephone person. But I like to say what it is. It's like being around last Sunday for father's day and she's [daughter] one of those ones: just loves talk.

Furthermore, a few men preferred their wives or partners to communicate with those who lived further away using communication technology such as emails and mobile phones. This job-sharing reinforced the importance of close proximity for men.

### **4.3.3 Strong Ties**

The strength of the ego's ties with others was another factor which contributed to men resolving the tension between the benefits of and barriers to disclosing. Individuals, with whom the men had strong ties, were likely to be told by the men themselves. Kenneth already had a strong and supportive relationship with his sister who rang about the prostate biopsy:

Then my sister in city C she rang up last night and she's "oh I wish you the best for tomorrow." And I said "Oh" I said "thanks very much" and I said "I thought you might have forgotten." "Oh no no no" she said."

Strong ties tend to have been established either over a long time or through a significant or traumatic event. Turning to someone with whom there is a strong tie is a natural response to challenging events in life. The context of illness may be new to the individuals but similar situations may have been encountered in the past and so previous experience can be useful to the man in the current situation. People with strong ties are safe to share with as the other is already well-known.

### **4.3.4 Alter's Professional or Personal Experience of Cancer**

When an alter has had professional medical experience or had cancer themselves the men are more likely to talk as the perceived risk of sharing is minimised. The risk is that others may not value what they have shared, may dismiss it or give it too much importance. Knowing others have a helpful or similar experience facilitates common ground and therefore sharing. Ronald, in seeking informational support commented "I wouldn't ask anyone who didn't have constructive input. I'd be looking for knowledgeable people." Men value sharing with others who have had any form of cancer but specifically prostate cancer. William was very intentional about who he would chose to speak to:

I wouldn't talk to the nurse about it. I don't want to be bothered talking to people who haven't got it or had it. You know. I'd rather just talk to someone who's been there, done that. Been down the journey; had the journey.

William, the professional IT consultant, had a previous prostate biopsy resulting in a diagnosis of cancer. He was therefore familiar with the health system and appreciated the need for support and finding contacts online:

And I've spoken to a lot of people. I went on to this prostate cancer website. I went on to that and found a couple of people locally. One of whom has had the operation and one of whom has had radiation. And so I've sort of made myself known to them and had a chat to them about it.

William searched online for men with the same diagnosis and who were more advanced in their treatment and then chose to make contact with those men who lived nearby. He was one of only two men who sought to disclose to another who was outside of any of his existing communication networks.

The knowledge that others had been through a similar experience stimulated the desire for the men to share and so provided a considerable level of bonding. Men desired understanding, insight and a legitimate opportunity to express themselves through their current experience and to have someone known to them who have been through a similar journey proved a significant factor in their willingness to disclose. Of the 22 men two chose not to tell anyone other than their wives about their prostate issues. The other 20 demonstrated either proximity or strong ties in disclosing to others. Assuming homophily was a given factor for all men, 11 (50%) of the men who disclosed talked with others each of whom demonstrated two of three factors (proximity, strong ties or others medical conditions).

#### **4.3.5 Summary of Research Question 3**

The final section of this chapter answered the third research question: How do men resolve the tension between the benefits of disclosure and the barriers to disclosure? Most men experienced a tension between the benefits of disclosure and the barriers to it and four important factors were identified which contributed to resolving the tension by helping the man make a decision about whether to

disclose or not: homophily, close geographical proximity, strong ties and others who had a professional or personal experience of cancer. This set of factors is one of the major findings from this research and will now be discussed in more detail.

In order to make a prediction about disclosing two assumptions are made. First, all married men communicated with and received support from their wives. Second, that homophily exists; men communicate with and reveal personal health information to men who are similar to themselves. All men demonstrated both features. Then, if any one of the remaining three factors; proximity, tie strength or experience is present in one individual, the man is likely to consider disclosing. Twenty men (91%) in the study demonstrated either proximity or strong ties in disclosing to others. Men are more likely to talk with someone who lives nearby than another who lives elsewhere for example. If two factors are present then he is highly likely to share. Eleven (50%) of the men who disclosed talked with others, each of whom demonstrated two factors.

Common permutations of two out of three factors within the group of men were shown in partners who were in close proximity and also were their strongest tie but may not have had previous experience of cancer. Siblings who were a strong tie and a medical professional but who lived elsewhere in New Zealand or overseas; work colleagues who were in close proximity and had prostate cancer themselves but were only a weak tie. Larry (figure 1, page 59) was quite open discussing his own and other's health with his regular drinking mates who were his strongest ties. One of his mates also demonstrated the other two factors necessary for disclosure, proximity and the experience of cancer:

Well I told them that I've been through for you know like a prostate thing. And you know like and I'll be having a few drinks down at the bar and he's just had his jaw. He's just had cancer taken off his jaw so we do have a talk you know like. He's been through radiation and chemo and all that.

In several instances the strength of the tie was questionable but if the men had been in the same workplace for a number of years the tie was considered to be strong. Kenneth disclosed to his wife and three individuals two of whom demonstrated two of the above factors each and one had one factor. He disclosed to his manager at work with whom he had long-standing relationship and to a

local work colleague who also had prostate cancer. Kenneth also disclosed to his sister who was a strong tie but did not live locally or have experience of cancer.

If all three factors are present and the man had a strong tie with an informal knowledgeable other who also lives nearby, he will almost certainly disclose his prostate issues. A family member, work colleague or long-standing friend could fulfill all three factors as illustrated by David whose second wife had cancer herself. “So you know I was there for her and she wants to understand what’s happening to me. She’s been to all my appointments with the hospital.” David recorded the interview for this research so she could listen to it later that day.

#### **4.4 Summary of Findings**

The findings have been addressed according to the three research questions. The first question concerning the structure of men’s networks identified the nodes and ties in the networks and highlighted important factors which explained the presence of individuals and groups who were in the men’s networks. These factors included men’s relationship and employment status and previous medical experience. Family and special interest groups formed the dominant group nodes in the networks. The nature of ties, such as frequency, proximity and homophily was discussed in the context of relevance to network structure. This research question also highlighted the diversity of networks between the men in the study; some had family-based local networks while others had networks which were more extensive and geographically dispersed.

The second question concerned the content of networks and the men’s response to disclosing their prostate issues and receiving social support and three important aspects were relevant. The first was the importance of the context in which the men disclosed; they perceived some contexts as being safe and others unsafe. Second with regard to disclosure, he and others gained some benefits from his disclosure but third, significant barriers existed which ensured he was more reserved or even closed about disclosing. Most men held the benefits and barriers in tension and this difficulty was addressed in the final research question.

The third research question developed the discussion on the men’s management of the tension they experienced between the benefits of and barriers to disclosing their prostate issues. The men tended to evaluate their disclosure to others in their networks based on four factors: homophily, close proximity, strong ties and the

professional or personal experience of others. The presence of these factors as individual factors or combinations in the nodes and ties within the network would encourage the men to disclose. The next chapter offers further consideration of these findings.

## **Chapter 5: Discussion**

The purpose of this research was to identify the communication networks of men recently diagnosed with prostate cancer and also to distinguish some of the factors men take into account whether or not to disclose their prostate issues to others in their networks. The following chapter addresses the structure and content of men's networks, together with the features which helped to shape them.

Throughout this chapter the point of reference for the patient is the biopsy; they did not have a definitive diagnosis at this stage but the possibility of cancer is a major threat. This chapter is in three sections. The first section summarises the arguments for and contributing factors to each of the three research questions and relates these findings to the extant literature. The theoretical, research and practical implications of this research are described in the second section and the final section explains the limitations of this research together with future directions this research could take.

### **5.1 Research Question One**

The first research question was: What factors shape the structure of men's communication networks prior to being diagnosed with prostate cancer? This question considered the structure of networks; the factors which contribute to why the network consists of the ties and nodes it does. The findings revealed two different types of networks, general and health and it is these types that are discussed next.

#### **5.1.1 General Communication Networks**

General communication networks are those in existence in everyday life and three factors have been found to contribute to their structure: relationship status, employment status and the proximity of the individual's immediate family.

##### ***5.1.1.1 Relationship status***

This study revealed that for men with a partner these significant others were very important in their networks. In the event of a possible diagnosis of cancer the role of the partner becomes even more crucial, both to the effectiveness of the treatment and the wellbeing of the marriage. Identifying the significant others of single men was not as conclusive; they tended to have close relationships with

their children or siblings and an extensive network of friends but rarely one significant other. Married men's networks also comprised of their children and a few friends.

Literature abounds with the importance of the wife to the man's ability to cope with prostate cancer (Bloch et al., 2007; Harden et al., 2008; Wellman & Wortley, 1990). The findings from this study are consistent with this literature. Implicated in this relationship is the strong correlation between effective spousal communication and wellbeing for both partners (Song et al., 2012). However, most of the literature on networking fails to differentiate the status of those who are married with those who are single. Single men do not have the same status as married men, they tend to be referred to in passing as demonstrated by Harden et al. (2008) who claimed *partners* in the title of their research, but overtly interpreted partners as spouses. Lepore and Revenson (2007) had a similar but more concealed approach by illustrating important points on social constraints with two real-life examples using married couples. Single men were also compared to married men as a minor group following a discussion of married men. Lin et al. (1985) noted the disruption to the social environment on those who suffered marital disengagement as a "serendipitous finding" (p.260). Single men are largely absent in the literature (Gray et al., 2000; Song et al., 2012); the marginalisation of single men exposes the magnitude of difficulty in understanding this group of men.

This study found the difference in networks between married and single men to be highly significant. Single men often had strong ties with friends and children. Men who lived by themselves had different network structures to those of married men having more extensive networks with a larger group of friends, as illustrated by Robert's network (figure 2, page 60). In contrast, married men such as Edward (figure 3, page 63) had networks comprised predominantly of family who lived elsewhere and one close friend. Donald (figure 4, page 64) or John (figure 6, page 68) both had networks containing a number of family members and few friends.

The difference in networks between men who are married and those who are single is rarely differentiated in literature. An exception which investigated the difference between the networks of single and married men was that of Helgason et al. (2001) which assessed men's ability to share emotional concerns with a

partner or with someone other than a partner. They concluded: “among the patients living with a partner the spouse was the only source of support for 90% of men. Approximately 80% of patients not living with a partner had no one to confide in.” (p.100). A few studies noted single people in the demographics but failed to identify any results for this group (Poole et al., 2001) and did not note the difference in networks. Relationship status is one facet of network structure, another is employment status; the extent to which men’s networks involved their work colleagues.

#### ***5.1.1.2 Employment Status***

In the current study, men who were working fulltime had little spare time and so their networks tended to be comprised only of work colleagues and immediate family as with Edward (figure 3, page 63) who had several family members but only one friend. Semi-retired men included family and friends from interest-based groups in their networks but rarely involved work colleagues. Several men in this group worked in new part-time jobs for income generation, but did not have meaningful relationships with their colleagues. Retired men had the time and inclination to be involved in various groups but also created significant friendships with individuals in interest-based groups. In several instances, the men’s networks changed significantly to include new friends from new activities in this stage of life. Some of these findings are consistent with the literature. Employment status tends to determine network structure and the proportion of colleagues and friends in networks. According to Stephens et al. (2011) networks change with age and even across a small age band from 55 (still working) to 70 (mainly retired). During working years ties with colleagues can become strong due to factors such as physical proximity (Monge & Contractor, 2001) as individuals working in close physical contact increases the potential for strong ties (Martin & Yeung, 2006 ).

Furthermore, the frequency of contact also contributes to tie strength (Martin & Yeung, 2006 ). Everyday life is easily shared at work and when health issues arise networks already exist in which support can be offered, requested and received. Work colleagues can provide support and the men showed they confided in two or three close colleagues. The literature appears to be divided on the networks of older or retired people. Stephens et al. (2011) noted the networks of retired people comprised more community ties and closer relationships with local family, friends

and neighbours than younger men who were still at work. The findings from the current study on the men in full-time and part-time employment are consistent with the literature. These findings showed networks changed considerably for those who were retired and as literature is divided on the networks of older and retired people these findings are consistent with a section of the literature.

#### ***5.1.1.3 Proximity of Immediate Family***

The findings also showed the importance of the proximity of immediate family in the ego's networks. Several men had children and grandchildren who lived in the same town and siblings who lived within 20 kilometres. Face-to-face communication with these family members was important to the men. For men with immediate family who lived locally the individuals in the family formed significant nodes in the men's network. Immediate family who lived elsewhere, particularly siblings, were also included in the men's networks and these people were more likely to have weaker ties. Robert (figure 2, page 60) had only local networks which included family with whom he had strong ties. Men with immediate family who lived further away had strong ties such as with Charles (figure 5, page 67) and Edward (figure 3, page 63) but these ties could also be weak as shown by Donald (figure 4, page 64).

This finding is consistent with the literature on family ties, that the core of networks consist of immediate kin and there is more contact and stronger ties with individuals and family who live nearby than with those who live further away (Wellman et al., 1997; Wellman & Wortley, 1990). Wenger and Tucker (2002) classified support networks into five types of which two are 'local family dependent' and 'locally integrated support' networks and both network types feature close family ties. The local 'self-contained' and 'private restricted' networks were characterised by the absence of local relatives but the remaining support network 'wider community focused', contained active relationships with distant relatives. Wellman (2007a) noted that kin dominate personal networks in Iran and Germany but in North America and France networks contain a broader range of ties, friends, neighbours and workmates. Therefore, the findings on immediate family from this study are consistent with the literature but cannot be generalised since they only apply in New Zealand.

## **5.1.2 Health Communication Networks**

In addition to general networks the findings showed that health communication networks existed, with their nodes and ties structured around health issues. The first part of this section identifies gaps in the literature on health communication networks and describes features of these networks in more detail as demonstrated by the men in this study. The second part highlights two factors which were important in the construction of the men's health networks – if the man had previous medical experience and if there was a medical professional in the immediate family.

### ***5.1.2.1 Features of Health Communication Networks***

A health communication network structure serves to help men manage their illness, in this case, prostate cancer. At times health communication networks evolve; partly derived from the general communication network, partly created from new. At other times the network changes from being a general network to being health-related very quickly as the individual becomes so consumed with managing the illness that many of the people in the existing network become health focused or are exchanged for others who are health related.

This discussion on the nature of health communication networks has identified two significant gaps in the literature. First, networks in the health arena have been almost exclusively applied on a population level of analysis and particularly in epidemiology which assesses the spread of disease in populations (Berkman et al., 2000). Health networks have rarely been analysed in the health field from an individual level of analysis such as from an egocentric point of view. Also, in the network literature there is no differentiation between general and health communication networks. When networks are referred to in literature they are assumed to be general networks. The relationship between population networks and health is covered in the literature (Abbott, 2009) but the descriptive detail of the structure of health networks is largely absent.

Health communication networks evolve in various ways. They can include partners, children and the GP who may already exist as part of the general communication network. For those men who had little involvement with the medical system their health networks were relatively undeveloped beyond these people. For other men, people known in another capacity may then become health

related such as a medical professional in the family who was not previously in the man's health network and may be included by virtue of their health qualification. Friends and colleagues may also add this health dimension to their existing relationship depending on their enthusiasm to be involved and the man's willingness to let them or invite them.

Others who were previously unknown become part of a health network; specialist physicians such as the urologist, nurses and urotherapists (specialist physiotherapists who advise on bladder and continence issues). These are often, but not always, new relationships. A few men, who had a previous biopsy which returned as negative, may present for a routine annual check at a later time and the prostate may then give cause for suspicion. They will usually be referred back to the same urologist for another biopsy on a subsequent occasion and so the urologist will already exist in the health network.

Not only does network structure change when health issues arise, but so too the characteristics of individual ties such as the strength, frequency and reciprocity. The nature of the tie with a urologist is not a strong tie. Strength as already mentioned is determined by a sense of the relationship being special, an interest in being together and a sense of mutuality (Wellman & Wortley, 1990). This is not demonstrated in the relationship with a urologist even though there is a sense of it being special, the latter two features do not apply; neither is it a weak tie as in most cases the relationship is a new one. This aligns with Granovetter's (1973) theory on weak ties providing access to resources which would otherwise be unavailable to the individual.

Frequency is also a factor in this relationship as the men meet the urologist more frequently than previously. However, reciprocity is non-existent as the relationship only functions for one reason, for the urologist to manage the illness and so the tie is more of a dependant tie than strong or weak. Dependent ties do not feature as a specific category in the network analysis literature in which ties were defined in a multitude of other ways. Feld et al. (2007) considered school/work support and general support ties in changes to personal networks; Wellman (2007b) referred to socially close ties; kin, friends, neighbours and also role types (Wellman & Wortley, 1989). The literature on networks classifies ties

based on role types such as professional ties but these are not included in the social science framework.

Organisations can become an important part of the men's health networks. Health-related support organisations did not feature in the health networks in this study despite most of the men having previous or concurrent medical conditions. One man, Edward, suggested he had intended to get back in contact with a support organisation for a head injury and John, who had a previous positive prostate biopsy, contacted an online prostate support group. These findings suggest that support organisations appear to be insignificant in men's networks at this juncture. Rather than the face-to-face support of health-related organisations it appears from the literature that men with prostate cancer are turning to the internet for information and support and have done so increasingly over the past 10 years (Mo et al., 2009; Seale et al., 2006; Thaxton et al., 2008) particularly since 2009 (McHugh et al., 2011). They pursued their own internet searches in an attempt to complement the information they had been given by their urologist or GP. One man, John, who had an existing diagnosis of prostate cancer, was starting to get involved in an overseas online prostate cancer support group.

In the case of the men in this study, the lack of organisational impact is related to timing being in the early stage in the management of the disease. As the treatment and disease progresses, these organisations may have an increased presence in the networks by providing practical help in the form of nursing or financial support. However, support organisations do not feature in the responses of men who had comorbid chronic conditions. Health-related support organisations have a specific role for patients, but their absence in networks at the early juncture in prostate cancer and throughout in other conditions appeared to have been superseded by the internet to fulfil patient's information and support needs.

#### ***5.1.2.2 Factors which Influence Men's Health Communication Networks***

Two factors, relatively unimportant in general networks were more significant in health networks. First, health networks were determined, in part, if the man had previous medical experience and second, if he had medical professionals in his immediate family. Most of the men in this study had a previous medical condition, had a current condition, or their wives or partners had a medical condition. The networks of these men had a greater proportion of health-related people and the

men had some degree of health literacy and medical knowledge. Only two men were healthy or had a well-managed comorbid condition which had a minimal impact on their quality of life. These men had a relatively small number of health-related nodes in their networks. Several men in this study had a family member, sibling or brother/sister-in-law, who were medical professionals and therefore held a unique position in the men's networks. The other individuals, usually a doctor or nurse, became instrumental in the on-going management of their prostate cancer and formed a highly significant node which became a strong tie often with frequent contact. Networks in the literature do not acknowledge the value of an individual's previous medical experience, and the place of family members who were medical professionals in the structure of men's networks. This study extends the current literature.

The health literacy gained by an individual from previous or other medical conditions is transferable to other medical situations and networks can be resurrected or translated in the event of a new context of prostate cancer. A degree of health literacy, therefore, gives the man a significant advantage in creating and utilising his networks. This finding is entirely consistent with the literature on health literacy such as Davis et al. (2002) and Manafo and Wong (2012) who identified the positive relationship between health literacy and health outcomes. A man will also be able to benefit from his wife's health networks if she has a medical condition. Their health network may be well established enabling him to easily access what he requires, in which case his ability to manage the prostate cancer happens more effectively.

The literature assumes the man offers his wife support and not constraints and therefore he will acquire, be involved in and benefit from her health network. Should unresolved tensions arise in the marriage resulting in constraints, these individuals and resources will not be freely available to him and the potential benefits to his health network derived from being involved in his wife's medical conditions will be negated. Networks will contain fewer health-related nodes and therefore function less effectively, if at all, to help the men or their wives.

It appears that no literature identifies the contribution of family members in an individual's networks to the psychosocial aspect of prostate cancer. Authors acknowledged the need for recently diagnosed men to talk with others who could

provide valuable information (Gray et al., 2000; Poole et al., 2001; Shim et al., 2011) but all the authors concentrated solely on other specific groups of cancer patients who provided information, disregarding the potential contribution of family members. Family members who are medical professionals also fit Granovetter's (1973) theory of weak ties as they can provide access to another network - the health system.

## **5.2 Research Question Two**

The second question addressed the content of networks: For men who are faced with a diagnosis of prostate cancer, what are their perspectives about disclosing their health status and receiving social support? For those men who chose to disclose they selected a safe environment and safe people with perceived benefits to themselves and to others. A safe environment and person was one in which others, partners, and a few (up to three) close male friends could be trusted with the information. Perceived benefits to the man himself included receiving social support; particularly emotional and information aid. Men perceived the benefits to others as the openness to discuss prostate issues and the encouragement to get a regular check-up at the GP. For those men who chose not to disclose it was their perception of an unsafe environment and people with barriers who prevented them from disclosing. An unsafe environment contained gossip and more than three friends were considered unnecessary. Significant barriers proved to be the uncertainty of the diagnosis, and a negative perception of themselves or others in their networks. Some men chose at times to disclose to wider family members such as children and siblings while others chose not to disclose at all.

This question is once again answered in two parts. It addresses specific characteristics of disclosure, men's desire for normality at this time, person- and context-related disclosure followed by disclosure and cancer. Then a brief discussion follows on the role of social support in networks.

### **5.2.1 Disclosure**

The context in which this research took place was immediately prior to biopsy and is a unique time in the medical journey for the patient. It poses a distinctive set of stressors and is a key time for men, heralding the possible transition from good health to illness and significant adjustments. It remains a crucial time for the man and his family with particularly challenging decisions to be made about disclosing

his prostate issues. Of over-riding importance to the men in this study was the pursuit of normality. However, being symptom-free at an annual check-up can cause a multitude of complications. In most illnesses individuals would usually present to a GP with symptoms, but prostate cancer is one of few medical conditions which is prophylactically screened and men can be symptom-free on presentation. To then be referred for a biopsy while feeling well can result in a shock for the patient as they may have had several years of routine check-ups with no indication for further investigations. Between the initial urological consultation and the biopsy, up to three months duration, the men have had time to adjust to the shock of referral and possibly with cancer, hence the desire for normality. Disclosure during this period was held in tension with a desire to carry on the routines of life with minimum disruption.

Another reason for the need for normality was that many men, not being particularly health literate, did not fully understand the reasons for the biopsy and so were not aware of the implications of the result. For these men, their 'default setting' in life was to carry on as normal. This finding is consistent with the literature which notes the desire of men to pursue normality as much as possible (Coon et al., 2007; Gray et al., 2000).

The issue of disclosure arose for all the men in this study. For a few disclosure was intuitive and spontaneous; they just talked about their prostate issues without prior consideration. Most men, however, indicated they carefully thought about disclosure. They assessed the balance between the benefits of and barriers to disclosing; sometimes they chose to talk and at other times not. If they wanted to talk they had to consider when, where and to whom. For some men, the decision about whether to disclose was person-based and for others context-based and this distinction between person- and context-related disclosures was not evident in the literature. Men disclosed to a specific individual because of who they were and the relationship between them. At other times disclosure was context related; it occurred because they were, for example, in the pub and the specific individuals were not important all being mates.

In taking account of person-related disclosure, the men chose to disclose in a well-recognised order; first to medical professionals, then to wives and family and finally to friends. This is consistent with prior research such as that of Lepore and

Revenson (2007) and Halbert et al. (2010). Helgason et al. (2001) claimed as much as 90% of men confided only in their wife and no one else. Findings from this current study estimate that 29% (5) of the men with partners told only their significant other. Most men in this research gave the impression of effective communication with and strong support from their wives and these findings indicated some inconsistency with the literature.

Communication within marriage has been well researched in the cancer field; how men and their wives communicate at diagnosis (Halbert et al., 2010) and at various stages throughout the cancer journey (Boehmer & Clark, 2001; Coon et al., 2007; Song et al., 2012). But assumptions were made in the literature that by the nature of marriage, the wife would be supportive when in fact she could be constraining the husband. Bloch et al. (2007) observed that men were likely to feel more constrained due to the wife being the main, if not only, form of support and so spousal constraints on talking about cancer contributed to more distress in the patient than family or friend constraints (Lepore & Revenson, 2007). Two men in this study, Kenneth and Dennis, whose wives were present in the interview appeared to be subject to spousal constraints as the men were either undermined or contradicted throughout the interviews. The findings of the men's relationships with their wives are consistent with the literature in part.

Men in this study also gave consideration to the context of disclosure, one in which the family or others were placed. Children were perceived as too busy with young grandchildren or they lived overseas and so the men failed to disclose at this time. These findings are consistent with the literature but again only in part. Research shows the strong correlation between the nature of the tie and disclosure; for example, disclosure will happen just because the recipient is a family member (Wellman & Gulia, 1999; Wellman & Wortley, 1990). Men certainly demonstrated a willingness to talk to wives and children if it was deemed appropriate and the timing was right. This failed to take into account the context in which disclosure occurs. Contrary to assumptions made in the literature, the men in this study sometimes considered context a more important factor than the nature of the tie.

In the health context the literature on disclosure in the communication and cancer care fields is overwhelmingly focused on the doctors' communication with and disclosure to the patients (Ong et al., 1995; Stewart, 1995), often about imparting bad news of the diagnosis (Wright et al., 2008) or communication with other medical professionals such as nurses. Little literature discussed disclosure from the patient's point-of-view and therefore this study extends the literature.

Men in this study, in sharing about their prostate issues, revealed a cautious approach to the possibility of cancer which is entirely consistent with the literature (Gray et al., 2000; Lepore & Revenson, 2007). None of the men talked with others about two concerns of medical importance. They did not consider the possibilities of a diagnosis other than cancer giving the impression they did not understand about benign disease. They had been informed by the urologist of the worst-case scenario of cancer and the men's mental processing continued with this approach. Also, despite family history being a strong predisposing factor for prostate cancer (Peyromaure & Bodon-Gibod, 2007), none of the men talked with their sons about this genetic component, even though two men, William and Michael, disclosed that their fathers had died of prostate cancer. Michael indicated that this knowledge encouraged him to talk with his son sooner rather than later. The men chose to disclose because they considered their sons would soon be in the high risk age bracket for prostate cancer and would therefore need to take responsibility for their prostate health by getting regular check-ups.

### **5.2.2 Social Support**

Social support is a vital function of networks and this research demonstrated the value of networks in the provision of social support for the men (Berkman et al., 2000; Heaney & Israel, 2002; Stephens et al., 2011; Wellman & Gulia, 1999). All men who needed it received some degree of emotional support from someone in their networks; from their partners, family, friends or work colleagues. All the men except two stated they had received helpful information from medical professionals in a timely manner. Instrumental support and companionship tended to be reciprocal in nature with the men giving and receiving from others in their networks equally. All these findings on the strong relationship between networks and the support functions they provide and the provision of support by specific individuals within the networks are consistent with the literature (Boberg et al., 2003; Wellman & Wortley, 1990; Zhou, Penedo, Lewis, et al., 2010). These

findings suggest that family ties were positive and helpful. There is, however, some inconsistency of the findings with the literature where negative relationships exist; living in close proximity does not necessarily equate to positive relationships (Boehmer & Clark, 2001; Wright et al., 2008). Research is starting to emerge on the negative aspects of relationships, those of social constraints, isolation and undermining (Brooks & Dunkel Schetter, 2011; Lepore & Revenson, 2007; Oetzel et al., 2007; Stephens et al., 2011). The findings of this current study did not suggest evidence of negative ties in networks, but this is possible by virtue of self-reporting, the networks only consist of positive relationships.

At the time of pre-biopsy the most significant problem or challenge for men was the one of disclosing their new prostate issues. This question on the content of networks has discussed the issues of timing and disclosure with particular relevance to New Zealand. The third and final research question addresses disclosure in more detail.

### **5.3 Research Question Three**

This section addresses the third research question: How do men resolve the tension between the benefits of disclosure and the barriers to disclosure? This research revealed that all the men lived with a tension between the benefits associated with telling others about their prostate issues and the barriers to doing so. Men assess, intuitively or otherwise, the other person or context in order to make their decision about whether or not to disclose. This tends to be on a case-by-case basis. They used a combination of four characteristics of ties or nodes: homophily, geographical proximity, tie strength and the other's professional or personal experience of cancer. The following section contains a discussion of relational dialectical theory as a useful perspective for analysing the tensions and a discussion on disclosure with relevance to the four predictive factors.

Men need to resolve the dilemma of disclosure; whether or not to disclose to a particular individual or in a given context; and if they choose to disclose, who they disclose to. Relational dialectical theory is a useful theory to explain some of the contradictions in relationships. Dialectic is defined by Baxter and Braithwaite (2007) as "the dynamic interplay of unified opposites" (p.276), where each facet interacts with and depends on the other, in juxtaposition at any point in time. Relational dialectical theory is appropriate in this study and is useful in

understanding significant points of change in life (Baxter, 2004) such as the diagnosis of cancer. Furthermore, as Baxter and Braithwaite (2007) claimed: “relationships, not individuals, hold contradictions” (p.288) and relationships or ties are the essence of network analysis. Four types of contradictions are relevant to this study: expression/non-expression, binary/multivocal, internal/external and stability/change and the relevance of each one is briefly described below.

The most relevant aspect of this theory is the contradiction between expression and non-expression, demonstrated as open or closed states of disclosure. The men in this study considered who would benefit by their willingness to disclose - the benefits to others could outweigh the barriers for them. Furthermore, one facet of the expression / non-expression dialectic is the protection of others from hurt and at the same time protection of self (Baxter & Braithwaite, 2007). This study concurs with this literature but these findings also showed that disclosure was not only avoiding the negative outcome of hurt but rather the provision of positive outcomes. This provided potential benefits to both the individual and others at the same time.

Resolution of the tension for the men who chose to disclose was the decision who to disclose to. Current literature suggests the decision around disclosure is most likely to be based on the type of tie men have with others (Gray et al., 2000; Lepore & Revenson, 2007). The findings from this current study would suggest factors other than typology of ties are more significant for men to take into account when deciding about disclosure of their prostate issues. The four predictive factors: homophily, geographical proximity, tie strength and other’s professional or personal experience of cancer when combined, is a new contribution to the literature. The first three concurred with the literature, the fourth, other’s professional or personal experience of cancer, did not.

Homophily in social networks is well established in literature (McPherson et al., 2001; Monge & Contractor, 2001), the extent of which has been evaluated in one study as the “homogeneity of age in close and very close friends in networks is 33% and sex homogeneity is 86%” (Blieszner, 2006, p. 213). These findings also concurred with Wellman (2007b) who observed that “the more voluntary the focus (e.g. friends as compared to kin) the more homophilous the tie” (p. 353). Proximity, family members who live close by are more likely to hear than those

who live far away and so geographical proximity also influenced disclosure. Those who live or work in closer proximity were more likely to hear than others who were further afield. Thus, while family members are important recipients of disclosure, local friends are more likely to hear than distant family members. In some contexts, for example with work colleagues, proximity is a stronger indicator of disclosure than tie strength. Tie strength is a foundational concept of networks analysis in literature (Granovetter, 1973; Lin, Ensel, & Vaughn, 1981) and these three factors are consistent with literature. The final factor of the set in these findings, the value of other's professional or personal experience of cancer is not referred to in the literature and so this finding provides an extension.

Some decisions about disclosure were based on context rather the person. The men would choose to disclose at the pub or bowls and not because of the individuals who were there at the time. Baxter and Braithwaite (2007) identified this as the internal/external contradiction, the importance being the network in which the dyad was embedded. This finding is also consistent with literature.

Another relevant aspect of this theory is the contradiction of stability and change; this is needed to provide balance in life and the interplay between these two is important at times of major transitions in life. This research adds to the current literature as the period around a biopsy is the period between stability and change; signalling a period of transition for the man, his family and his networks. The biopsy and subsequent diagnosis have the potential to be a very significant change and the time is filled with uncertainty. The uncertain period can be lengthy; between the initial consultation when the man is referred for a biopsy to having it can be as long as three months. This is followed by a period of approximately three weeks before he receives the diagnosis. It is part of the spectrum between the two opposites of stability and change.

By choosing to disclose benefits would be accrued for both the man and for others; his position was not a simple polarised view as in relational dialectical theory. Tensions are not dialectical with two simple binary options to resolve; rather both tensions and their resolutions constitute a spectrum which Baxter and Braithwaite (2007) referred to as multivocal contradictions. All four factors contributing to disclosure individually increased the likelihood of disclosure; as each factor is

added to another, the likelihood increased to a point at which one other person may exhibit all factors. The men would be very likely to disclose in this instance.

Baxter and Braithwaite (2007) noted partial disclosure as one resolution of this tension; revealing some things but not others. This current research extends the concept of partial disclosure by proposing variable disclosure which could be considered another type of resolution. Variable disclosure is where the man does not disclose initially but chooses to later and this may be due to many reasons: internal processing of the situation, provision of a suitable context or person or reaction to stress. Relational dialectical theory has been used to explain some of the tensions men face with regard to disclosure. Many of the findings concurred with the literature on this theory and a number of them from this study have implications for future research.

## **5.4 Implications**

Some of the findings have created new perspectives on networks and disclosure. Viewing networks from both structural and content perspectives has enabled a fresh approach to health care of the individual and will lead to better health outcomes. The following section offers implications on the theoretical, research and practical aspects of this research.

### **5.4.1 Theoretical Implications**

Two significant theoretical contributions are considered in this section; the existence of health communication networks and the four factor influence of disclosure. The concept of health communication networks is relatively new (Kreps et al., 2003) with little clarification on how health communication networks are defined and perceived as an entity in their own right. This current research adds more clarity to health communication networks by discussing how health networks are created and their evolution when a health issue arises. Some health networks are already in existence and well established with medical professionals being part of an individual's network due to their previous medical history. Other health networks emerge from general networks with a few individuals in the general networks acquiring a health-related role who then provide a foundation as the network acquires other medical professionals.

The value of disclosure is well known with the emphasis in literature on it being positive and helpful (Lepore & Revenson, 2007), leading to increased well-being (Stephens et al., 2011; Zhou, Penedo, Bustillo, et al., 2010) and helping reduce anxiety and depression (Edwards & Clarke, 2004). Disclosure to individuals in networks has traditionally been assessed on the nature of the tie; either kin, friend, work colleague. This research has identified an alternative perspective on disclosure by taking into account four factors which exist regardless of the nature of the tie: homophily, geographical proximity, tie strength and another's professional or personal experience of cancer. The potential of these features in other people creates opportunities for disclosure within new areas of networks; new nodes and ties are possible in the utilisation of this formula. New areas of existing networks can be intentionally created around these factors to maximise the benefits for everyone while creating a good health outcome. To consider the implications of these four factors enables egocentric networks to be viewed in greater depth, with more accuracy and realising more potential.

#### **5.4.2 Research Implications**

A number of significant areas for research have emerged from this study. Consideration is given first to networks in this section. New opportunities to research networks can be considered at an individual level in the health field and then in the structure of networks; nodes of single men and siblings are then examined. Also the potential for assessing the dynamic nature of networks over time using the pre-biopsy time as a baseline for network theory is considered. Finally, there is a discussion on disclosure and its context in New Zealand men.

Network analysis is a very flexible tool which can be applied to many different contexts. Using network analysis to evaluate health communication is a new and novel amalgamation in two emerging fields of research. In the health field network analysis has been used primarily in public health at a population level; its application on an individual level is relatively new. In the network field illness rarely constitutes a significant life event as defined in the literature, yet it can have a considerable impact on communication networks (Bidart & Lavenu, 2005; Feld et al., 2007; Stephens et al., 2011).

This research has implications for other research into the gaps in networks; such as how men who are living by themselves are supported in coping with cancer. Combining being single with the New Zealand 'make-do' attitude and single men become in danger of 'falling between the gaps' in the medical and psychosocial management of the disease. The medical profession tends to assume men are married and have the positive support of their wives. It is not clear from these findings or in the literature who single men disclose to but one study highlighted the magnitude of the problem. Helgason et al. (2001) claimed 67% of single men could not share their emotional feelings with anyone else and 80% had no one to confide in. Compared to married men, single people have less of a voice and different needs and in addition older bereaved men may be more dependent on others.

Another group of people, who were under-researched in their role in networks, is siblings. Several siblings of men in this study were medical professionals and proved to be crucial in providing on-going support. However, many researchers refer to siblings in passing who are not given sufficient importance as they can be a significant and strong tie for single men (Borgatti, Mehra, Brass, & Labianca, 2009; Burt, 1984; Haythornthwaite, 1996). There is a lack of research about the value of the sibling relationship in men with prostate cancer. Extending the concept of reduced efficacy of treatment, further research could be conducted as an evaluation of which other groups of prostate patients may be at a higher risk of not receiving the best treatment possible for them.

This study has highlighted the potential changeable nature of networks over time (Monge & Contractor, 2001). Recognising the uncertainty around the biopsy and a possible significant life event that could precipitate rapid network change, a longitudinal study of communication networks could establish network stability or instability. A suitable baseline could be the point of pre-biopsy and not the point of diagnosis. Extensive communication research over the past 10 years has been conducted in the context of the period immediately following diagnosis with a particular emphasis on doctors' communication of bad news. This is especially pertinent with patients receiving a diagnosis of cancer; very little, if any, research has been conducted from a communication perspective at the pre-biopsy stage in the men's medical journey.

Although most of the men had pre-existing conditions there was little involvement with support organisations in networks. Support organisations seemed to have minimum impact amongst the people they are trying to help; yet some run highly-effective but little known programmes to help patients. A longitudinal study would also provide on-going evidence of the uptake of prostate cancer support groups over the course of treatment. Involvement in New Zealand support groups, either face-to-face or online, has been very slow and yet other countries such as Canada have a vast number of these groups. Their role in relation to online support groups in networks could also be identified.

Significant opportunities for research lie in the area of disclosure about health and the context in which it occurs. This research has identified the difficult decision faced by men at the pre-biopsy juncture. The symptoms, treatment and long-term side effects of prostate cancer have serious social implications and using network analysis has identified the support available in networks to counter these difficult situations. One area of interest to arise from this study is the disclosure around a stigmatising disease.

Disclosure in the context of New Zealand male stereotypes proves to be a considerable tension between being invincible, macho and self-sufficient while being vulnerable in the face of a potential diagnosis of cancer. This research has identified that single men with prostate cancer is a significantly under-researched area; who they disclose to and how they utilise their networks. Their networks are structured differently to those of married men and the functionality of their networks is not well understood.

### **5.4.3 Practical Implications**

This research also has practical value. This next section is a discussion about health communication networks and their implications on the four factors of disclosure. Network utilisation is a misunderstood and underrated opportunity for individuals and organisations to embrace health care. Benefits for harnessing networks are numerous and on an individual level include better mental health, quality of life and prognosis. Health organisations can reduce costs, increase the efficacy of treatment and offer better health outcomes among a multitude of benefits.

As the dominant theme in health in this country is one of personal responsibility an increasing emphasis needs to be on the holistic approach to the management of prostate cancer. The psychosocial care of prostate cancer patients needs to complement medical care with a more balanced perspective than has been in the past. Most men are able to be strategic in managing their psychosocial needs by harnessing their networks but in order to be effective they need to be educated and encouraged in how best to connect with people in them. Utilising networks is a solution which can be of benefit for everyone involved: the men, their families, friends, others and the medical system. As Lepore and Revenson (2007) so succinctly noted “coping with cancer involves the mutual influence of cancer survivors and members of their social network as they cognitively and behaviourally engage the stressors posed by the illness” (p.317). Coping with prostate cancer is about the networks functioning as a whole.

Networks are affected by men choosing whether or not to disclose their prostate issues; new individuals and organisations are brought into the networks which result in a changing structure. Some existing relationships are deepened or strengthened as a result of disclosure about prostate issues; other relationships are lessened or weakened due to reasons such as men not having the confidence to talk about cancer, or the mental and physical strain potential illness imposes on relationships. Understanding the dynamics of networks under these circumstances will help men cope better and manage their own treatment more effectively.

Inclusion of peer support groups in the men’s networks can be encouraged. The concept of peer support is not a new one and yet prostate cancer support groups have been very slow to take off in this country. There is little literature on prostate cancer support groups in New Zealand and the findings from this study are consistent with both the literature and the practice. Networks can comprise support groups which are both online and face-to-face. Not-for-profit organisations such as the Prostate Cancer Foundation and the Cancer Society run some local groups around the country but with varying degrees of success. Online support groups have proved very successful overseas; the lack of support groups in New Zealand is a major concern but also a significant opportunity. Men can be involved or even start a group but support groups do not suit everybody; prostate

cancer will always be a very private disease for some men. Individuals who choose to include support groups as part of their health networks can potentially gain considerable health benefits.

By understanding the four dominant factors of disclosure men can be encouraged to be aware of the value of actively searching out individuals in their networks who exhibit these characteristics. Health care professionals can encourage the men to seek help for themselves, actively manage their own health and make resources in their own networks as effective as possible. Conversely, educating the men on the negative impact of social constraints could ensure issues are addressed early on in the management and lead to improved wellbeing (Lepore & Revenson, 2007).

Disclosure is responsive to the changing nature of society as disclosure has been strongly linked to stigmatisation in the literature. Less stigmatisation and more publicity about men's health and prostate cancer has encouraged more openness and discussion in men with prostate cancer. The last five years have seen significant changes in this country with more openness to talk about prostate cancer, as demonstrated by the willingness of men to participate in this study. Research needs to be up-to-date and New Zealand-based and take into account the significant movement in society away from stigmatisation and towards acceptability. The usual emphasis of the medical system is on the physical management of prostate cancer. Men's psychological and social needs are as significant and often more debilitating than the physical aspect of prostate cancer and are of particular importance in the early stages of the disease.

Wellman and Wortley (1990) observed that gender is the "only personal characteristic that is directly associated with support" (p. 582). Men struggle to receive social support in a meaningful way and New Zealand men are particularly vulnerable to the male stereotype (Cupples et al., 2007). Men in this study gave the impression of being perceived as strong, infallible and self-sufficient. They had a 'make-do' attitude to whatever came their way; they will find a way to resolve any practical issues. New Zealand men, particularly farmers, are very proud of their ability to use the number 8 gauge wire, a cultural icon, which is used to fix anything. Issues that are not practical but rather emotional or mental tend to be resolved in much the same way, ignore it or find a one-stop solution.

These typical male stereotypes influence the nature of disclosure by inhibiting men's ability to disclose.

Searching for help or emotional support is also subject to the Kiwi male stereotype. The attitude of men tends to be one of "help was something to be endured for the benefit of the helper" (Gray et al., 2000, p. 276) and so not be received in the same generous spirit with which it was offered. They considered themselves vulnerable among their wider network of friends and reverted to the stereotype of being strong by choosing not to share. The limitations of this study and opportunities for further research are addressed now.

## **5.5 Limitations**

A number of limitations existed in the study and the following points will be discussed briefly in this section. Only men in the public health system were included in this study, only interviews of men with a positive diagnosis were used and various ethnic groups were underrepresented.

Only men being treated in the public health system participated in the research, no private patients were included; this was due to a system failure. The progress of referral through the health system was so rapid for private patients it proved impossible to contact the men between the urological consultation and biopsy; at times this was less than a week or two at the most. In addition, the urologists would refer men to this study by copying me into their letter to the GP and inevitably this was too late for their inclusion into the study. It is of concern the network structure and content of these two groups of men may be completely different.

Due to constraints on the men's availability and possible mental state a decision was made to interview all men prior to a biopsy. The study, however, was only concerned with men diagnosed with cancer. Therefore, as half the men were diagnosed with cancer, only their half of the interviews was used and the rest remain unused at this stage. A significant amount of time was therefore 'wasted' interviewing non-cancer men. This was carefully considered when formulating the methodology and it was considered to be in the men's best interests to be interviewed at this time. A further limitation was that the interviews could not be verified as they represented only one opinion, that of the man himself. Alters in networks who the man talked about were not interviewed.

Maoris were represented in this study by two men which is a fair sample of the general population in New Zealand but they have a very different network structure centred on the whanau, the extended family. Whanau naturally comprises a network. Maori culture has little concept of individuality preferring instead a group identity approach to life and healthcare in particular (Cram, Smith, & Johnstone, 2003; Durie, 1985). All other ethnic groups present in the community such as Chinese, Indian or Somali were absent in this study. Significant differences exist in health care between Asian and Western styles of assessment and treatment which contribute to barriers for Asian people accessing Western health systems. This results in a low level of health care utilisation (Ho, Au, Bedford, & Cooper, 2003; Lawrence & Kearns, 2005; North, Trlin, & Henderson, 2004; Rasanathan, Ameratunga, & Tse, 2006). It is well established that Asian people in New Zealand use both Western and traditional health practices simultaneously (Ho et al., 2003). This study did not represent a proportion from ethnic groups relative to the national demographics of the population.

Additionally, men from lower socio-economic classes and the less well educated were represented by seven men (46%) and so the whole group tended to characterise a relatively homogenous layer of New Zealand society that of white, middle class, educated men. As this study was specifically concerned about men with prostate cancer, it is unclear how generalizable the results could be. They may or may not represent the networks of men with other forms of cancer or diseases.

## **5.6 Future Directions**

The primary aim of further research into the communication networks of men with prostate cancer would be the development of a psychosocial risk assessment scale which could be used in the clinical setting by social workers and medical staff. Scales which are simple, effective and easy to use are proving to be invaluable in health care at present as they provide objective insight into the men's own assessments of their issues and offer some form of standardisation. Many scales are currently being used in clinical situations, such as in the assessment of pain or depression and the risk of bed sores; as a consequence using them results in superior care for men. Scales are particularly helpful for situations where the issues are difficult or laborious to identify or measure. Individual's

communication networks are eminently suitable for this tool, being both difficult to understand and time consuming to assess yet the knowledge they yield can provide inestimable benefits to many. A network-based psychosocial risk assessment scale is not being used at present and so there is a significant need to develop a relevant and effective one.

In order to develop a scale there would be a need to identify, prior to being treated for prostate cancer, which men are at risk of psychosocial complications because their networks do not contain helpful or even essential nodes and ties. These nodes and ties would provide encouragement for the men to disclose and social support in the form of aid but in their absence the risk of psychosocial complications increases. The following four studies would contribute to identifying the at-risk men.

First, a longitudinal study would identify the changes in health networks as the men progress through treatment and onto medical maintenance. This knowledge will aid in establishing the impact of health issues on an egocentric network level. This would comprise men in the current study who would be followed on an annual basis. A second study would be based around interviewing alters, others in the networks of men in the current study which would provide a comprehensive picture of networks and verify network structures and content from various perspectives.

In order to identify how the networks of men with cancer can differ from those of men who are in good health a comparison study could compare the networks of those men with a positive biopsy i.e. those who comprised the present study, to a control group with a negative biopsy - those who were interviewed but did not progress in the current study.

Finally, a preliminary psychosocial scale could be developed to assess the likely risk of individuals receiving little understanding or support from their networks throughout their treatment for prostate cancer. Various psychosocial aspects would be included such as the four factors of disclosure from this study and other potential factors from the previous studies. This scale would then be trialled in a clinical setting. The value of this scale is that it is not specific; it can be used across multiple applications such as gender, age or disease in health care.

## **5.7 Conclusion**

This research aimed to consider how men with prostate cancer communicated about their health to others in their networks. The purpose was, first, to identify the general and health communication networks of men recently diagnosed with prostate cancer and second, to identify some of the factors men take into account when choosing whether to or not disclose about their prostate issues to others in their networks.

Communication networks consider individuals as nodes and the relationships between them as ties. This research is based on an ego-centric level analysis of networks where an individual, the man with prostate cancer, is at the centre of their network and evaluation is made on the communication and relationships they have with others around them. For the purpose of this research network functions were separated into structure and content where structure comprises the individuals or groups and content is the relationships and communication between them.

The first research question was, what factors shape the structure of men's communication networks prior to being diagnosed with prostate cancer and considered the structure of networks, the nodes and ties? The second research question was: for men who are faced with a diagnosis of prostate cancer, what are their perspectives about disclosing their health status and receiving social support? The final research question focused on the content of networks: how do men resolve the tension between the benefits of disclosure and the barriers to disclosure?

A background to prostate cancer was provided in the literature review which included a medical overview and discussion on PSA testing. Men's health and communication in New Zealand was considered and finally networks for understanding men's communication in this country. Qualitative research was undertaken using semi-structured interviews with the men between the time of their initial consultation with a urologist and the scheduled biopsy.

Findings demonstrated how men's general and health communication networks were comprised. Significant findings were the presence of medical others in the close family and the existence of previous medical conditions in the men; these factors helped shape how networks were comprised. The focus was on the

willingness or otherwise of the men to disclose their prostate issues. Considerable benefits were gained for the men themselves by disclosing; benefits such as informational support and companionship. On the other hand, the men experienced barriers to disclosing such as the uncertainty of diagnosis and perception of themselves and others.

The three most significant findings from this research on the communication networks of men with prostate cancer were the invaluable role of others who had some experience of cancer, either personal or as a medical professional. The context in which disclosure occurs is another important finding and is assessed either intuitively or otherwise and finally, the presence of four factors - homophily, close proximity, strong tie and experience of cancer - perceived in others, the combination of which would encourage men to disclose about their prostate issues. Networks form an underrated but potentially highly effective tool for men with cancer. This research has uncovered a small part of what they are and how they work and provided clear direction for future study for the benefit of men with prostate cancer.

## References

- 5+ A Day Charitable Trust. (2013). What is 5+ A Day? Retrieved March 13, 2013, from [www.5aday.co.nz](http://www.5aday.co.nz)
- Abbott, S. (2009). Social capital and health: The problematic roles of social networks and social surveys. *Health Sociology Review, 18*(3), 297-306.
- Allen, F. (2010). *Health psychology and behaviour in Australia*. North Ryde, NSW, Australia: McGraw-Hill.
- Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report, 2*(1), 1-3.
- Arrington, M. I., Grant, C. H., & Vanderford, M. L. (2006). Man to man and side by side, they cope with prostate cancer. *Journal of Psychosocial Oncology, 23*(4), 81-102. doi: 10.1300/J077v23n04\_05
- Balderson, N., & Towell, T. (2003). The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology, 8*(2), 125-134.
- Bauman, A., McLean, G., Hurdle, D., Walker, S., Boyd, J., van Aalst, I., & Carr, H. (2003). Evaluation of the national 'Push Play' campaign in New Zealand—creating population awareness of physical activity. *Journal of the New Zealand Medical Association, 116*(1179), 1-11.
- Baxter, L. (2004). Relationships as dialogues. *Personal Relationships, 11*, 1-22.
- Baxter, L., & Braithwaite, D. (2007). Social dialectics: The contradictions of relating. *Explaining Communication: Contemporary Theories and Exemplars, 275-292*.
- 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.
- Bidart, C., & Lavenu, D. (2005). Evolutions of personal networks and life events. *Social Networks, 27*(4), 359-376.
- Blakely, T., Shaw, C., Atkinson, J., Cunningham, R., & Sarfati, D. (2011). Social inequalities or inequities in cancer incidence? Repeated census-cancer cohort studies, New Zealand 1981–1986 to 2001–2004. *Cancer Causes and Control, 22*(9), 1307-1318. doi: 10.1007/s10552-011-9804-x

- Blieszner, R. (2006). Close relationships in middle and late adulthood. In A. Vangelisti & D. Perlman (Eds.), *The Cambridge handbook of personal relationships* (pp. 211-227). New York, NY: Cambridge University Press.
- Bloch, S., Love, A., Macvean, M., Duchesne, G., Couper, J., & Kissane, D. (2007). Psychological adjustment of men with prostate cancer: A review of the literature. *BioPsychoSocial Medicine*, *1*(2), 1-14. doi: 10.1186/1751-0759-1-2
- Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Offord, K. P., Koch, C., Wen, K. Y., . . . Salner, A. (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counseling*, *49*(3), 233-242.
- Boehmer, U., & Clark, J. (2001). Communication about prostate cancer between men and their wives. *The Journal of Family Practice*, *50*(3), 226-231.
- Borgatti, S., & Cross, R. (2003). A relational view of information seeking and learning in social networks. *Management Science*, *49*(4), 432-445.
- Borgatti, S., & Halgin, D. (2011). On network theory. *Organisation Science*, *22*(5), 1168-1181.
- Borgatti, S., Jones, C., & Everett, M. (1998). Network measures of social capital. *Connections*, *21*(2), 27-36.
- Borgatti, S., Mehra, A., Brass, D. J., & Labianca, G. (2009). Network analysis in the social sciences. *Science*, *323*(5916), 892-895.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.
- Briton, N., & Hall, J. (1995). Beliefs about female and male non-verbal communication. *Sex Roles*, *32*(1/2), 79-90.
- Britten, N. (1995). Qualitative research: Qualitative interviews in medical research. *British Medical Journal*, *311*(6999), 251-253.
- Brooks, K. P., & Dunkel Schetter, C. (2011). Social negativity and health: Conceptual and measurement issues. *Social and Personality Psychology Compass*, *5*(11), 904-918.
- Burleson, B. R. (2008). What counts as effective emotional support? In M. T. Motley (Ed.), *Studies in applied interpersonal communication* (pp. 207-227). Los Angeles, CA: Sage.

- Burleson, B. R., & Mortenson, S. R. (2003). Explaining cultural differences in evaluations of emotional support behaviors exploring the mediating influences of value systems and interaction goals. *Communication Research, 30*(2), 113-146.
- Burt, R. S. (1984). Network items and the general social survey. *Social Networks, 6*(4), 293-339.
- Cavill, N., & Bauman, A. (2004). Changing the way people think about health-enhancing physical activity: Do mass media campaigns have a role? *Journal of Sports Sciences, 22*(8), 771-790.
- Center, M. M., Jemal, A., Lortet-Tieulent, J., Ward, E., Ferlay, J., Brawley, O., & Bray, F. (2012). International variation in prostate cancer incidence and mortality rates. *European Urology, 61*(6), 1079–1092. doi: 10.1016/j.eururo.2012.02.054
- Chambers, S., Newton, R., Girgis, A., Nielsen, L., Lepore, S., Mihalopoulos, C., . . . Occhipinti, S. (2011). Living with prostate cancer: Randomised controlled trial of a multimodal supportive care intervention for men with prostate cancer. *BioMed Central Cancer, 11*(1), 317-324. doi: 10.1186/1471-2407-11-317
- Chapple, A., & Ziebland, S. (2002). Prostate cancer: Embodied experience and perceptions of masculinity. *Sociology of Health and Illness, 24*(6), 820-841.
- Clarke, J. N. (1999). Prostate cancer's hegemonic masculinity in select print mass media depictions (1974-1995). *Health Communication, 11*(1), 59-74.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310-357.
- Coleman, J. S. (1988). Social capital in the creation of human capital. *American Journal of Sociology, 94*(S1), 95-120.
- Consedine, N. (2011). Are we worrying about the right men and are the right men feeling worried? Conscious but not unconscious prostate anxiety predicts screening among men from three ethnic groups. *American Journal of Men's Health, 10*(5), 1-14. doi: 10.1177/1557988311415513
- Coon, S. K., McBride-Wilson, J., & Coleman, E. A. (2007). Back to basics: Assessment, communication, caring, and follow-up. A lesson from a couple's journey with multiple myeloma. *Clinical Journal of Oncology Nursing, 11*(6), 825-829.
- Cram, F., Smith, L., & Johnstone, W. (2003). Mapping the themes of Maori talk about health. *The New Zealand Medical Journal, 116*(1170), 1-7.

- Cupples, J., Guyatt, V., & Pearce, J. (2007). "Put on a jacket, you wuss": Cultural identities, home heating, and air pollution in Christchurch, New Zealand. *Environment and Planning* 39(12), 2883-2898.
- Dale, W., Sartor, O., Davis, T., & Bennett, C. L. (1999). Understanding barriers to the early detection of prostate cancer among men of lower socioeconomic status. *The Prostate Journal*, 1(4), 179-184.
- Davis, T., Williams, A., Marin, E., Parker, R., & Glass, J. (2002). Health literacy and cancer communication. *A Cancer Journal for Clinicians*, 52(3), 134-149.
- Denscombe, M. (2008). *The good research guide*. Milton Keynes, UK: Open University.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314-321.
- Duffy, M. K., Ganster, D. C., & Pagon, M. (2002). Social undermining in the workplace. *Academy of Management Journal*, 45(2), 331-351.
- Durant, K. T., McCray, A. T., & Safran, C. (2012). Identifying gender-preferred communication styles within online cancer communities: A retrospective, longitudinal analysis. *PLoS ONE*, 7(11), e49169.
- Durham, J., Low, M., & McLeod, D. (2003). Screening for prostate cancer: A survey of New Zealand general practitioners. *Journal of the New Zealand Medical Association*, 116(1176), U476. Retrieved from <http://journal.nzma.org.nz/journal/116-1176/476/content.pdf>
- Durie, M. (1985). A Maori perspective of health. *Social Science and Medicine*, 20(5), 483-486.
- Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology*, 13, 562-576.
- Else-Quest, N. M., LoConte, N. K., Schiller, J. H., & Hyde, J. S. (2009). Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology and Health*, 24(8), 949-964.
- Ereaut, G., & Whiting, R. (2008). What do we mean by 'wellbeing'? And why might it matter?
- Eton, D. T., & Lepore, S. J. (2002). Prostate cancer and health-related quality of life: A review of the literature. *Psycho-Oncology*, 11(4), 307-326.

- Etzioni, R., Cha, R., Feuer, E., & Davidov, O. (1998). Asymptomatic incidence and duration of prostate cancer. *American Journal of Epidemiology*, *148*(8), 775-785.
- Etzioni, R., Penson, D., Legler, J., Di Tommaso, D., Boer, R., Gann, P., & Feuer, E. (2002). Overdiagnosis due to prostate-specific antigen screening: Lessons from U.S. prostate cancer incidence trends. *Journal of the National Cancer Institute*, *94*(13), 981-990.
- Feld, S., Suitor, J., & Hoegh, J. (2007). Describing changes in personal networks over time. *Field Methods*, *19*(2), 218-236. doi: 10.1177/1525822X06299134
- Ferlay, J., Shin, H. R., Bray, F., Forman, D., Mathers, C., & Parkin, D. M. (2010). Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *International Journal of Cancer*, *127*(12), 2893-2917.
- Forster, P. M. (2004). Psychological sense of community in groups on the internet. *Behaviour Change*, *21*(2), 141.
- Gaglio, B., Glasgow, R. E., & Bull, S. S. (2012). Do patient preferences for health information vary by health literacy or numeracy? A qualitative assessment. *Journal of Health Communication*, *17*(3), 109-121.
- Granovetter, M. (1973). The strength of weak ties. *American Journal of Sociology*, *78*(6), 1360-1380.
- Granovetter, M. (2003). The strength of weak ties. In E. Ostrom & T. K. Ahn (Eds.), *Foundations of social capital*. Cheltenham, UK: Edward Elgar. (Originally published 1973 in *American Journal of Sociology*, *78*(6) pp. 1360-1380).
- Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). To tell or not to tell: Patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, *9*(4), 273-282.
- Grunfeld, E., Drudge-Coates, L., Rixon, L., Eaton, E., & Cooper, A. (2013). "The only way I know how to live is to work": A qualitative study of work following treatment for prostate cancer. *Health Psychology*, *32*(1), 75-82.
- Haber, M. G., Cohen, J. L., Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology*, *39*(1), 133-144.
- Haines, V., Beggs, J., & Hurlbert, J. (2008). Contextualising health outcomes: Do effects of network structure differ for women and men? *Sex Roles*, *59*(3), 164-175. doi: 10.1007/s11199-008-0441-3

- Halbert, C., Wrenn, G., Weathers, B., Delmoor, E., Ten Have, T., & Coyne, J. C. (2010). Sociocultural determinants of men's reactions to prostate cancer diagnosis. *Psycho-Oncology*, *19*(5), 553-560.
- Harden, J., Northouse, L., Cimprich, B., Pohl, J., Liang, J., & Kershaw, T. (2008). The influence of developmental life stage on quality of life in survivors of prostate cancer and their partners. *Journal of Cancer Survivors*, *2*(2), 84-94. doi: 10.1007/s11764-008-0048-z
- Hawkins, J. L., Weisberg, C., & Ray, D. W. (1980). Spouse differences in communication style: Preference, perception, behavior. *Journal of Marriage and Family*, *42*(3), 585-593.
- Haythornthwaite, C. (1996). Social network analysis: An approach and technique for the study of information exchange. *Library and Information Science Research*, *18*(4), 323-342.
- Health Committee. (2011). Inquiry into early detection and treatment of prostate cancer (pp. 1-50). Wellington, New Zealand: New Zealand Parliament.
- Heaney, C., & Israel, B. (2002). Social networks and social support. In K. Glanz, B. Rimer & F. Lewis (Eds.), *Health behavior and health education* (3rd ed., pp. 185-209). San Francisco, CA: Jossey-Bass.
- Helgason, Á. R., Dickman, P. W., Adolfsson, J., & Steineck, G. (2001). Emotional isolation: Prevalence and the effect on well-being among 50-80 year-old prostate cancer patients. *Scandinavian Journal of Urology and Nephrology*, *35*(2), 97-101.
- Ho, E., Au, C., Bedford, C., & Cooper, J. (2003). Mental health issues for Asians in New Zealand: A literature review (M. R. Group, Trans.) (pp. 1-79). Migration Research Group, University of Waikato: Mental Health Commission.
- Hsing, A. W., Tsao, L., & Devesa, S. S. (2000). International trends and patterns of prostate cancer incidence and mortality. *International Journal of Cancer*, *85*(1), 60-67.
- Jagers, J., & Walgrave, S. (2007). Populism as political communication style: An empirical study of political parties' discourse in Belgium. *European Journal of Political Science*, *46*(3), 319-345. doi: 10.1111/j.1475-6765.2006.00690.x
- Jenkins, C., Hurst, M., & Rose, R. (1979). Life changes: Do people really remember? *Archives of General Psychiatry*, *36*, 379-384.

- Kampf, A. (2010). "The risk of age"? Early detection test, prostate cancer and practices of self. *Journal of Aging Studies*, 24, 325-334. doi: 10.1016/j.jaging.2010.08.002
- Kassan, E. C., Williams, R. M., Kelly, S. P., Barry, S. A., Penek, S., Fishman, M. B., . . . Taylor, K. L. (2012). Men's use of an internet-based decision aid for prostate cancer screening. *Journal of Health Communication*, 17(6), 677-697.
- Klemm, P., Hurst, M., Dearholt, S. L., & Trone, S. R. (1999). Cyber solace: Gender differences on internet cancer support groups. *Computers in Nursing*, 17, 65-72.
- Knoke, D., & Yang, S. (2008). *Social network analysis* (2nd ed.). Los Angeles, CA: Sage.
- Koopman-Boyden, P., & Waldegrave, C. (2009). *Enhancing wellbeing in an aging society*. Hamilton, New Zealand: Population Studies Centre and Family Centre Social Policy Research Unit, University of Waikato.
- Kreps, G. L., Bonaguro, E. W., & Query Jr, J. L. (2003). The history and development of the field of health communication. *Russian Journal of Communication*, 10, 12-20.
- Kunkel, E. J., Bakker, J. R., Myers, R. E., Oyesanmi, O., & Gomella, L. G. (2000). Biopsychosocial aspects of prostate cancer. *Psychosomatics*, 41(2), 85-94.
- Lawrence, J., & Kearns, R. (2005). Exploring the 'fit' between people and providers: Refugee health needs and health care services in Mt Roskill, Auckland, New Zealand. *Health and Social Care in the Community*, 13(5), 451-461.
- Leana, C. R., & Pil, F. K. (2006). Social capital and organizational performance: Evidence from urban public schools. *Organization Science*, 17(3), 353-366.
- Leik, R., & Chalkley, M. (1997). On the stability of network relations under stress. *Social Networks*, 19, 63-74.
- Lepore, S., & Helgeson, V. (1998). Social constraints, intrusive thoughts, and mental health after prostate cancer. *Journal of Social and Clinical Psychology*, 17(1), 89-106.
- Lepore, S., & Revenson, T. (2007). Social constraints on disclosure and adjustment to cancer. *Social and Personality Psychology Compass*, 1(1), 313-333.

- Lin, N., Ensel, W., & Vaughn, J. (1981). Social resources and strength of ties: Structural factors in occupational status attainment. *American Sociological Review*, 46 (4), 393-405.
- Lin, N., Ensel, W. M., Simeone, R. S., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and an empirical test. *Journal of Health and Social Behavior*, 20(2), 108-119.
- Lin, N., Woelfel, M., & Light, S. (1985). The buffering effect of social support subsequent to an important life event. *Journal of Health and Social Behavior*, 26(3), 247-263.
- Llorente, M. D., Burke, M., Gregory, G. R., Bosworth, H. B., Grambow, S. C., Horner, R. D., . . . Olsen, E. J. (2005). Prostate cancer: A significant risk factor for late-life suicide. *American Journal of Geriatric Psychology*, 13(3), 195-201.
- Lopes, P. N., Brackett, M. A., Nezlek, J. B., Schütz, A., Sellin, I., & Salovey, P. (2004). Emotional intelligence and social interaction. *Personality and Social Psychology Bulletin*, 30(8), 1018-1034.
- Luke, D., & Harris, J. (2007). Network analysis in public health: History, methods, and applications. *The Annual Review of Public Health*, 28, 69-93. doi: 10.1146/annurev.publhealth.28.021406.144132
- MacGeorge, E., Feng, B., & Burlison, B. (2011). Supportive communication. In M. L. Knapp & J. A. Daly (Eds.), *The Sage handbook of interpersonal communication* (4th ed., pp. 317-343). Thousand Oaks, CA: Sage.
- Manafó, E., & Wong, S. (2012). Health literacy programs for older adults: A systematic literature review. *Health Education Research*, 27(6), 947-960.
- Marsden, P. (1988). Homogeneity in confiding relations. *Social Networks*, 10(1), 57-76.
- Martin, J., & Yeung, K. (2006). Persistence of close ties over a 12-year period. *Social Networks*, 28, 331-362.
- McHugh, S. M., Corrigan, M., Morney, N., Sheikh, A., Lehane, E., & Hill, A. D. (2011). A quantitative assessment of changing trends in internet usage for cancer information. *World Journal of Surgery*, 35(2), 253-257.
- McLaughlin, D., Vagenas, D., Pachana, N. A., Begum, N., & Dobson, A. (2010). Gender differences in social network size and satisfaction in adults in their 70s. *Journal of Health Psychology*, 15(5), 671-679.
- McPherson, M., Smith-Lovin, L., & Cook, J. (2001). Birds of a feather: Homophily in social networks. *Annual Review of Sociology*, 27, 415-444.

- Menshealthweek. (2013). A history of men's health week Retrieved March 12, 2013
- Midland Cancer Network. (2009). The Psycho-Social Assessment Tool Project Report. Hamilton, New Zealand: Author.
- Ministry of Health. (2008). A portrait of health. Key results of the 2006/07 New Zealand health survey. Wellington, New Zealand: Ministry of Health.
- Mo, P. K. H., Malik, S. H., & Coulson, N. S. (2009). Gender differences in computer-mediated communication: A systematic literature review of online health-related support groups. *Patient Education and Counseling*, 75(1), 16-24.
- Monge, P., & Contractor, N. (2001). Emergence of communication networks. In L. Putnam & F. Jablin (Eds.), *New handbook of organizational communication* (pp. 440-494). Thousand Oaks, CA: Sage.
- Morgan, D., Neal, M., & Carder, P. (1996). The stability of core and peripheral networks over time. *Social Networks*, 19, 9-25.
- Mulac, A., & Lundell, T. L. (1986). Linguistic contributors to the gender-linked language effect. *Journal of Language and Social Psychology*, 5(2), 81-101.
- North, N., Trlin, A., & Henderson, A. (2004). *Asian and other skilled immigrants self-reported illnesses in the first four years of settlement in New Zealand*. Paper presented at the International Asian Health Conference: Asian health and wellbeing, now and into the future, New Zealand: The University of Auckland, School of Population Health.
- Oetzel, J. (in press). Social support and social undermining as explanatory factors for health-related quality of life in people living with HIV/AIDS.
- Oetzel, J., Duran, B., Jiang, Y., & Lucero, J. (2007). Social support and social undermining as correlates for alcohol, drug and mental disorders in American Indian women presenting for primary care at an Indian health service hospital. *Journal of Health Communication*, 12, 187-206.
- Ong, L. M. L., De Haes, J. C. J. M., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: A review of the literature. *Social Science and Medicine*, 40(7), 903-918.
- Owen, W. (1984). Interpretive themes in relational communication. *Quarterly Journal of Speech*, 70, 274-287.
- Parks, M. (2011). Social networks and the life of relationships. In M. L. Knapp & J. A. Daly (Eds.), *The Sage handbook of interpersonal communication* (4th ed., pp. 355-388). Thousand Oaks, CA: Sage.

- Perry, B. L., & Pescosolido, B. A. (2012). Social network dynamics and biographical disruption: The case of "First-Timers" with mental illness. *American Journal of Sociology*, 118(1), 134-175.
- Peyromaure, M., & Bodon-Gibod, L. (2007). The genitourinary system. In B. Lunefeld, L. Gooren, A. Morales & J. Morley (Eds.), *Textbook of men's health and aging* (2nd ed., pp. 131-146). London, UK: Parthenon.
- Poole, G., Poon, C., Achille, M., White, K., Franz, N., Jittler, S., . . . Doll, R. (2001). Social support for patients with prostate cancer: The effect of support groups. *Journal of Psychosocial Oncology*, 19(2), 1-16.
- Powell, W. (1990). Neither market nor hierarchy: Network forms of organisation. *Research in Organisational Behaviour*, 12, 295-336.
- Prell, C. (2012). *Social network analysis: History, theory and methodology*. Los Angeles, CA: Sage.
- Prorok, P. C., Miller, A. B., & Kramer, B. S. (2012). Prostate cancer screening in the randomized prostate, lung, colorectal, and ovarian cancer screening trial: Mortality results after 13 years of follow-up. *Journal of the National Cancer Institute*, 104(10), 793-794.
- Prostate Cancer Foundation of New Zealand. (2010). Prostate Cancer Foundation of New Zealand Retrieved December 14, 2012, from [www.prostate.org.nz](http://www.prostate.org.nz)
- Rasanathan, K., Ameratunga, S., & Tse, S. (2006). Asian health in New Zealand: Progress and challenges. *The New Zealand Medical Journal*, 119(1244).
- Ray, M. (1994). The richness of phenomenology: Philosophic, theoretic and methodologic concerns. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 117-133). Thousand Oaks, CA: Sage.
- Reinard, J. (2001). *Introduction to communication research*. New York: NY: McGraw-Hill Higher Education.
- Ridgeway, C., & Smith-Lovin, L. (1999). The gender system and interaction. *Annual Review of Sociology*, 25, 191-121.
- Roesch, S. C., Adams, L., Hines, A., Palmores, A., Vyas, P., Tran, C., . . . Vaughn, A. A. (2005). Coping with prostate cancer: A meta-analytic review. *Journal of Behavioral Medicine*, 28(3), 281-293.
- Roth, A., Weinberger, M., & Nelson, C. (2008). Prostate cancer: Quality of life, psychosocial implications and treatment choices. *Future Oncology*, 4(4), 561-568. doi: 10.2217/14796694.4.4.561

- Ryan, G., & Bernard, H. (2003). Techniques to identify themes. *Field Methods*, 15(1), 85-109. doi: 10.1177/1525822X02239569
- Scrignaro, M., Barni, S., & Magrin, M. E. (2011). The combined contribution of social support and coping strategies in predicting post-traumatic growth: A longitudinal study on cancer patients. *Psycho-Oncology*, 20(8), 823-831.
- 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 and Medicine*, 62, 2577-2590
- Seeman, T. E. (1996). Social ties and health: The benefits of social integration. *Annals of Epidemiology*, 6(5), 442-451.
- Seibert, S. E., Kraimer, M. L., & Liden, R. C. (2001). A social capital theory of career success. *Academy of Management Journal*, 14(2), 219-237.
- Shim, M., Cappella, J. N., & Han, J. Y. (2011). How does insightful and emotional disclosure bring potential health benefits? Study based on online support groups for women with breast cancer. *Journal of Communication*, 61(3), 432-454.
- Shuy, R. (2002). In-person versus telephone interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research* (pp. 537-555). Thousand Oaks: CA: Sage.
- Silverman, D. (1993). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London, UK: Sage.
- Silverman, D. (2011). *Interpreting qualitative data*. London, UK: Sage.
- Sloan, C., Gough, B., & Conner, M. (2010). Healthy masculinities? How ostensibly healthy men talk about lifestyle, health and gender. *Psychology and Health*, 25(7), 783-803.
- Smart, R. (2008). PSA testing and DRE, TRUS scanning with sector biopsy, improved histology, curative treatments, and active surveillance for prostate cancer: A success story for men's health. *The New Zealand Medical Journal*, 121(1287), 57-68.
- Sneyd, M., Cox, B., Paul, C., & Skegg, D. (2007). PSA testing and digital rectal examination in New Zealand. *Australian and New Zealand Journal of Public Health*, 27(5), 502-506.
- Song, L., Northouse, L. L., Zhang, L., Braun, T. M., Cimprich, B., Ronis, D. L., & Mood, D. W. (2012). Study of dyadic communication in couples managing prostate cancer: A longitudinal perspective. *Psycho-Oncology*, 21(1), 72-81.

- Spiegel, D., Bloom, J., & Yalom, I. (1981). Group support for patients with metastatic cancer: A randomised prospective outcome study. *Archives of General Psychiatry*, 38(5), 527-533.
- Sport New Zealand. (2013). Push Play Retrieved March 13, 2013, from [www.sportnz.org.nz](http://www.sportnz.org.nz)
- Statistics New Zealand. (2011). New Zealand in profile: 2012, from [www.statisticsnz.govt.nz](http://www.statisticsnz.govt.nz)
- Stephens, C., Alpass, F., Towers, A., & Stevenson, B. (2011). The effects of types of social networks, perceived social support, and loneliness on the health of older people. *Journal of Aging and Health*, 23(6), 887-911.
- Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: A review. *Canadian Medical Association Journal*, 152(9), 1423-1433.
- Stohl, C. (1993). European managers' interpretations of participation. A semantic network analysis. *Human Communication Research*, 20(1), 97-117.
- Stohl, C. (1995). *Organisational communication: Connectedness in action*. Thousand Oaks, CA: Sage.
- Stohl, C., & Stohl, M. (2007). Networks of terror: Theoretical assumptions and pragmatic consequences. *Communication Theory*, 17, 93-124. . doi: 10.1111/j.1468-2885.2007.00289.x
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Thousand Oaks, CA: Sage.
- Tagg, B. (2008). Imagine, a man playing netball! Masculinities and sport in New Zealand. *International Review for the Sociology of Sport*, 43(4), 409-430.
- Thaxton, L., Emshoff, J., & Guessous, O. (2008). Prostate cancer support groups. *Journal of Psychosocial Oncology*, 23(1), 25-40. doi: 10.1300/J077v23n01\_02
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
- Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse*, 19(1-2), 75-87.
- Van Der Gaag, M., & Snijders, T. (2005). The resource generator: Social capital quantification with concrete items. *Social Networks*, 27, 1-29.

- Van Tilburg, T. (1992). Support networks before and after retirement. *Journal of Social and Personal Relationships*, 9(3), 433-445.
- Vaughan, & Hansen, E. (2004). Like minds, like mine. *Australasian Psychiatry*, 12, 113-117.
- Vickers, A. J., Roobol, M. J., & Lilja, H. (2012). Screening for prostate cancer: Early detection or over-detection? *Annual Review of Medicine*, 63, 161. doi: 10.1146/annurev-med-050710-134421
- Visser, A., & Van Andel, G. (2003). Psychosocial and educational aspects in prostate cancer patients. *Patient Education and Counseling*, 49(3), 203-206.
- Wallston, B. S., Wallston, K. A., Kaplan, G. D., & Maides, S. A. (1976). Development and validation of the health locus of control (HLC) scale. *Journal of Consulting and Clinical Psychology*, 44(4), 580.
- Warren, C. A. B. (2002). Qualitative interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research* (pp. 83-102). Thousand Oaks, CA: Sage.
- Wellman, B. (1997). Structural analysis: From method and metaphor to theory and substance. In B. Wellman & S. D. Berkowitz (Eds.), *Social structures: A network approach* (pp. 19-61). Greenwich, CT: JAI Press.
- Wellman, B. (2007a). Challenges in collecting personal network data: The nature of personal network analysis. *Field Methods*, 19(2), 111-115.
- Wellman, B. (2007b). The network is personal: Introduction to a special issue of Social Networks. *Social Networks*, 29(3), 349-356. doi: 10.1016/j.socnet.2007.01.006
- Wellman, B., & Gulia, M. (1999). The network basis of social support. In S. Wellman (Ed.), *Networks in the global village* (pp. 147-184). Boulder, CO: Westview Press.
- Wellman, B., Wong, R., Tindall, D., & Nazer, N. (1997). A decade of network change: Turnover, persistence and stability in personal communities. *Social Networks*, 19, 27-50.
- Wellman, B., & Wortley, S. (1989). Brothers' keepers: Situating kinship relations in broader networks of social support. *Sociological Perspectives*, 32(3), 273-306.
- Wellman, B., & Wortley, S. (1990). Different strokes from different folks: Community ties and social support. *American Journal of Sociology*, 96(3), 558-588.

- Wenger, G. (2002). Interviewing older people. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 259-278). Thousand Oaks, CA: Sage.
- Wenger, G., & Tucker, I. (2002). Using network variation in practice: Identification of support network type. *Health and Social Care in the Community, 10*(1), 28-35.
- Wengraf, T. (2001). *Qualitative research interviewing: Biographic narrative and semi-structured method*. Thousand Oaks: CA: Sage.
- White, P. (2013). *A philosophical look at gossip. Can democratic institutions of higher education do without it?* Paper presented at the Annual Conference, Philosophy of Education Society of Great Britain, New College: Oxford.
- Williams, K. C., & Spiro, R. L. (1985). Communication style in the salesperson-customer dyad. *Journal of Marketing Research, XXII*, 434-442.
- Worchel, F. F., Prevatt, B. C., Miner, J., Allen, M., Wagner, L., & Nation, P. (1995). Pediatrician's communication style: Relationship to parent's perceptions and behaviors. *Journal of Paediatric Psychology, 20*(5), 633-644.
- Wright, K., Sparks, L., & O'Hair, H. (2008). *Health communication in the 21st century*. Malden, MA: Blackwell.
- Zhou, E., Penedo, F., Bustillo, N., Benedict, C., Rasheed, M., Lechner, S., . . . Antoni, M. (2010). Longitudinal effects of social support and adaptive coping on the emotional wellbeing of survivors of localised prostate cancer. *Journal of Support Oncology, 8*(5), 196-201.
- Zhou, E., Penedo, F., Lewis, J., Rasheed, M., Traeger, L., Lechner, S., . . . Antoni, M. (2010). Perceived stress mediates the effects of social support on health-related quality of life among men treated for localised prostate cancer. *Journal of Psychosomatic Research, 69*(6), 587-590. doi: 10.1016/j.jpsychores.2010.04.019
- Zorn, T., Roper, J., Broadfoot, K., & Weaver, C. K. (2006). Focus groups as sites of influential interaction: Building communicative self-efficacy and effecting attitudinal change in discussing controversial topics. *Journal of Applied Communication Research, 34*(2), 115-140. doi: 10.1080/00909880600573965

## **Appendix A: Glossary**

### **Medical**

Accident Compensation Corporation (ACC): Government department responsible for managing accident-related injuries.

Benign: Of a mild type that does not threaten health or life.

Biopsy: The removal and examination of tissue, cells or fluids

Brachytherapy: The implantation of radioactive seeds into the prostate

Digital rectal examination: Examination of the anus, lower rectum and prostate with the index finger.

District Health Board (DHB): organisations responsible for ensuring the provision of health and disability services to populations within a defined geographical area.

Dysuria: Obstruction of the flow of urine.

Health-related quality of life: A multi-dimensional construct that includes physical, mental and social domains to affect the health of an individual.

Malignant: Tending to produce death or deterioration.

Metastasise: The spread by metastases.

Ministry of Health: Government department which oversees national health care.

Polyuria: Excessive secretion of urine.

Prostatic hyperplasia: Increase in cells in the prostate leading to enlargement.

Prostatectomy: Surgical removal of the prostate.

Prostate Specific Antigen (PSA): A protease that is secreted by the prostate and is used in the diagnosis of prostate cancer, since its concentration in the blood serum tends to be proportional to the clinical stage of the disease.

Trans Rectal Ultrasound biopsy: A procedure in which a probe is inserted into the rectum which emits high-energy sound waves to produce a sonogram and is used to guide a biopsy.

Urethra: The canal that carries urine from the bladder and in the male is a passageway for semen.

Urotherapist: Specialist physiotherapist who advises on bladder and continence issues.

## **Communication**

Alters: Others in a network known to the ego. The individual whose network is being analysed is the ego and others to whom the ego is directly connected are known as alters.

Communication network: Patterns of contact between communication partners.

Ego: The individual in the centre of the network.

Egocentric network: A type of network analysis in which one individual is in the centre of a network and the direct and indirect links to others are traced.

General communication network: Network of everyday relationships with whom an individual has some level of communication.

Health communication: A primary tool to seek, process and share health information.

Health communication network: Networks of individuals or organisations with whom the individual communicates about health.

Homophily: Social situation of actors preferring to have social relations with others who are similar to themselves.

Node: The individuals or groups in a network.

Tie: The relationships between individuals or groups in a network.

## **Appendix B: Interview Questions**

1. Tell me the story of how you came to be here today.
2. I would like to hear about your circle of other people and organisations.
3. What kind of topics do you talk about in your social circle?
4. What kind of topics do you not talk about with this social circle?
5. What communication technology do you feel comfortable with if you can't talk face-to-face?
6. How important do you consider your own health?
7. Tell me about positive or negative experiences of communication you have had in dealing with individuals or organisations about your health.
8. When discussing men's health topics, who are the people you would normally talk to?
9. Who are the people in your social circle you would not talk to about your own health?
10. To what extent do you think the people in your networks would help you as you go through the medical process?
11. What kind of support do you think you might need?
12. Do you use electronic communication to help you manage your health?
13. Are there any other comments you want to make about your own social circle and health?
14. Finally may I follow-up with you any additional questions that come to mind later?