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**Understanding the cancer-related distress and coping of men
from provincial New Zealand:
'Bullet proof' meets radical prostatectomy.**

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requirements for the degree of

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ABSTRACT

Men suffer inequities regarding their health which may largely be attributed to masculine culture. The present study sought to better meet men's needs for psycho-oncological care by describing men's cancer-related distress and coping, and deriving from that knowledge suggestions for intervening more effectively to address their distress.

The study used participant action research methodology. Twenty-one Pākehā and six Māori men from rural provinces of New Zealand with lower socio-economic statistics, were interviewed in depth about their cancer-related distress and coping using a semi-structured format. Interviews were recorded, transcribed, and thematically analysed, producing preliminary descriptions of distress, coping, and a distress processing metaphor. These were discussed with small teams drawn from the original participants for verification and adjustment. Suggestions for intervention consistent with the findings were also discussed with these men.

The description of distress summarises a wide range of matters under superordinate themes of: distress featuring a lack of control; anxiety or despondency at anticipated or actual loss; 'black' feelings (degradation, anger, self-pity, guilt and regret); and empathic distress. It includes the reporting of 'no distress' and ambiguous reporting. Dynamics associated with each of these groupings is discussed, notably the association of traditional masculine norms with 'no distress' reporting and with more sources of distress, and the wide range of distress associated with sexual dysfunction as a side-effect of cancer treatment.

The description of coping lists four widely used coping strengths, namely: a positive attitude; an active and practical orientation; rationality and control; and social support/helping others. Use of social support varied with ethnicity and allegiance to traditional masculine norms.

The processing metaphor describes a trajectory of suddenly losing and then gradually regaining control, which is likened to being overwhelmed by a rogue wave while paddling at the beach.

Common to both descriptions and highlighted by the metaphor is the significance of control, which is underpinned by information. Accordingly, a new paradigm regarding the provision of information as part of standard treatment pathways is suggested. This features relevant, timely, and accessible information orienting men to the disease, its treatment and side-effects, the medical system, and social services.

DEDICATION AND ACKNOWLEDGEMENTS

Dedicated to the men who participated in this study, with deepest thanks for their generosity and courage in sharing their hearts in the service of others.

Particularly to those who knew, at the time of their interview, that they had not long to live, yet still gave of their precious time and energy.

I hope that the survivors among you, and the families of those of you who have passed on, will be satisfied that the contribution you made has been respected and will be put to good practical use.

Nga mihi nui. Arohanui.

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regarding what a privilege it is to do PhD study, sealed the deal. By this time I knew she would be right. And so she was. But I am acutely aware that the joy of the creative experience is almost entirely dependent upon the support of all the other people and organisations involved. And, what can I say? There cannot be many students who are so fortunate as I have been with the participants in, and many other supporters of, their research. Once again, nga mihi nui. Kia ora kotou katoa.

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1. THE TROUBLE WITH MEN

Of deficits and contradictions

Men and women experience cancer differently. More men than women get cancer, more men than women die from cancer, and men usually adapt less well than women after a cancer diagnosis. (Nicholas, 2000, p.27.)

New Zealanders used to talk about Māori failing in education: Māori were said not to value education and to have various other short-comings leading to the failure of Māori students. Since the deficit was perceived to be with Māori, the focus of remedial attention (or, simply, blame) was on Māori. These days we talk about the education system failing Māori, and we focus on trying to improve the education system. We Pākehā (New Zealanders of European descent) have begun to learn that racial deficit thinking is unjustified, insulting and unproductive. We have begun to realise that our worlds and ways of seeing life are different, and that we need to find ways of seeing education through brown eyes, recognising the white assumptions that have been built into the system, and modifying it – or encouraging a whole new system to grow up – so that Māori children can achieve too: 'Māori succeeding as Māori'.

Could similar 'cultural blindness' and 'deficit thinking' explain the disadvantage of men in the context of health outcomes, and society's failure to address these inequities? The statistics around cancer – indeed, physical and mental health generally – may be taken to suggest that many men live in a different world from the one the health system was designed to serve. Something of the breadth of the inequality will be described below, but health behaviours, utilisation of services, and incidence and mortality from serious illness (including cancer), all feature. In New Zealand, many health services are free or subsidised, so why don't men use them as effectively as women? Do we ascribe deficit to men, saying, 'Men don't care about their health', just as we used to say, 'Māori don't value education'? Again, as will be seen below, workers in the health system have been inclined to do this. But is this notion sensible? Could cultural factors relating to masculine norms, and their mismatch with the health system, explain part of the gender inequality in health outcomes? Is it time for 'the system' to start to look to its own deficits in serving men, by starting to examine services through masculine eyes? Indeed, does the system 'care' about men's health?

It could be argued that analogising men and the health system with Māori and the education system is fundamentally flawed in that men are a socially, politically and economically powerful group, who have been instrumental in designing the system at issue, whereas the opposite has been the case for Māori in relation to the education system. But on examining Anglo-western literature on the intersection of masculinity and health (see Chapter 4), a significant vulnerability is seen: In short, 'real men' do not display, or concern themselves with, their own physical or mental vulnerability. This being the case, the needs of many men are rendered invisible, and a contradiction arises: the needs of this otherwise powerful demographic group have been as invisible as those of a socio-political minority. Indeed, recent literature suggests that the hegemonic masculine position of power is actually constructed *against* healthy practices, which are seen as feminine, notwithstanding that such denial of health needs is ultimately undermining of that privileged position. The present research steps into this context of deficit thinking, contradiction, and inequality, in an attempt to make a contribution in a growing movement to bring the health needs of men into clearer visibility and to address them in ways that men find relevant and useful.

In the introductory chapters of this thesis, I background those factors that are known to contribute to men's experience and expression of cancer-related distress and how they cope with it. I begin, in this chapter, with material regarding men's physical and mental health status, and utilisation of services, including psycho-oncological services. In the following chapter I discuss how patients make psychosocial adjustments to cancer, with a particular focus on men and their more limited social support resource. Then I overview the main academic conceptualisations of masculinity in the context of health, and unpack some issues of particular relevance to the present research – issues around what 'doing health' means to men, and the particular challenges men face in adapting to the losses associated with chronic illness. I close the introductory chapters by explaining the rationale for this research.

Male disadvantage in health

In the remainder of this chapter I discuss men's physical and mental health and use of services, with a particular focus on cancer, noting the significance of socio-economic factors, and elaborating on the particular nature of depression in men. This material

draws a picture of inequality disadvantaging men, which begs the explanation forthcoming in later chapters.

Physical health

Both in New Zealand and worldwide, men have long had worse mortality rates than women, and worse incidence of cancer, specifically (Bray & Atkin, 2004; Callister & Didham, 2009; McKinley, 2005). Cancer is now New Zealand's leading cause of mortality, contributing to one in three deaths (N.Z.H.I.S., 2007), and worldwide the disease has a mortality rate of approximately one in two of those diagnosed (Holland, 2002). Environmental factors are estimated to be responsible for 80-90% of cancers, and men are considerably more at risk of cancers associated with smoking and drinking (head and neck, bladder, lung, oral cavity, and liver) and poor diet (stomach, kidney and colon)(Bray & Atkin, 2004). While social deprivation (Salmond & Crampton, 2000) and poor education (Callister & Didham, 2009) are also strong predictors of poor health and higher mortality, the gender effect remains robust after such factors are accounted for. Although the gender gap has been steadily narrowing since its peak in 1976 (Sandiford, 2009), 2005-2007 data for New Zealand still showed a gap of four years for life expectancy at birth (78.1 years for men, and 82.2 for women)(Jones & McCreanor, 2009), and men had higher mortality for all 15 leading causes of death (McKinley, 2005).

The slight biological disadvantage that men have explains little of the mortality differential (Courtenay, 2002, 2003; McKinley, 2005) and masculinity is implicated as a unique contributor to men's health (Stanton & Courtenay, 2004). Gendered roles, behaviours, and expectations are socialised from childhood, affecting attitudes and behaviours and modifying the environment, so that men and women both behave differently and are treated differently (Baum & Grunberg, 1991). Reviewing the literature from a New Zealand perspective, McKinley (2005) theorises the critical factors disadvantaging men to be: structural inequalities in society (e.g. no co-ordinated men's health policy in New Zealand); different health-related behaviour and lifestyles; and differences at the interface between men or women and the health system.

Courtenay (2002) argues that differences in lifestyle are the biggest contributor to men's poorer health outcomes. From the American literature, the behaviours he identifies of particular relevance to cancer incidence or prognosis include: lower utilisation of health

services and poorer treatment compliance; unhealthy diet and weight, and poorer fitness; greater tobacco and alcohol use; lack of social support; and greater exposure to toxic substances and to sunlight, with less use of sun protection. McKinley's (2005) New Zealand literature review draws a similar picture, except finding that men here are less likely to be overweight and more likely to be physically active than women. McKinley suggests that socialisation is explanatory of men's poorer health behaviours. Men are brought up with less understanding of personal health (including the identification of illness symptoms) and the health system, and are less aware of their vulnerability, and so think themselves more healthy and at less health risk than they are, under-report symptoms, underestimate risks associated with dangerous activities, and tend towards a reactive rather than a proactive approach to illness. Furthermore, she notes that men may deliberately undertake risky behaviour in order to prove their manhood, sensitive to social pressure to appear invulnerable and fearless.

Differences at the interface with the health system encompass differences in help seeking behaviour including access to, and utilisation of, health services, and differences in the care that health professionals provide to men and women. McKinley's (2005) review and a large study of the utilisation of GP services in New Zealand (Jatrana & Crampton, 2009) both show adverse comparisons for men, with even worse trends for ethnic minorities. Overseas literature confirms the gender disparity, and includes findings that men are less likely to have a regular doctor and more likely to believe that it is difficult to obtain health care (Stanton & Courtenay, 2004). Again, men's disadvantage may be largely attributed to gender socialisation, including discomfort with seeking help (Addis & Mahalik, 2003), disadvantageous perceptions and interpretations of threat (socialisation to ignore pain and 'be tough') and stress coping strategies (Courtenay, 2002; Stanton & Courtenay, 2004), and ignorance of health matters and services (McKinley, 2005). But men are disadvantaged by the way services are delivered as well, in that they are not optimally convenient and comfortable for them (McKinley, 2005) and because health professionals have negative misconceptions about their natural longevity and their willingness or ability to cooperate with health professionals and generally look after their health (McKinlay et al., 2005). Thus gendered attitudes, biases and expectations impact men both directly and through health providers.

Male disadvantage is exacerbated by ethnic difference and socio-economic deprivation (McKinley, 2005). This is for reasons related to the cultural competence of services and their accessibility and affordability to people of limited education and/or income, and also for reasons that may be less apparent such as an ethnic group's fatalistic views associated with intergenerational experience of shorter lifespan, which can prevent the taking of timely action (McKinlay, et al., 2005).

Social isolation may also have particular relevance in explaining the health vulnerability of men (Callister & Didham, 2009), since it is a particularly strong predictor of mortality (Holt-Lunstad, Smith, & Layton, 2010) and men are more dependant upon their spouse/intimate partner for emotional support (Goldzweig et al., 2009; Helgason, Dickman, Adolfsson, & Steineck, 2001). To some extent, the health effects of lifestyle factors such as diet, exercise, and medical help-seeking may be mediated by social support (Courtenay, 2002, 2003), but it is also theorised that the alleviation of emotional distress as a direct effect of social support may lower mortality (Holt-Lunstad, et al., 2010). The effects of lack of formal education, social isolation, and low income may be overlapping on mortality rate, at least for men (Callister & Didham, 2009).

The clustering of demographics which predict poor health is particularly felt by men who belong to ethnic minorities, notably, in New Zealand, Māori and Pacifica men. Māori have poor all-cause and cancer mortality statistics, dying from cancer at a rate *nearly double* that for European/other men (Callister & Didham, 2009, using 2001-2004 data). A large part of the cancer incidence and mortality disparity is not attributable to greater deprivation amongst Māori men, however (Robson, Purdie, & Cormack, 2010), and being Māori has been calculated as an independent predictor of poor prognosis (Gill & Martin, 2002). In the New Zealand context it is possible that lack of education is a most – perhaps *the* most – important driver behind ethnic inequalities in health (McKinley, 2005) not only impacting occupation and wealth, but also the ability to navigate the health system in times of need.

Although a great range of socio-economic and access factors influence health outcomes, gender remains the most consistent predictor of health and longevity (Courtenay, 2002, 2003). But it must be remembered that within-gender differences tend to be greater than between-gender differences, and that causes of the gender effect

are likely to be multifaceted, combining biological, behavioural, and environmental influences (Courtenay, 2003). The latter two broad factors are not immutable, but are socio-cultural, institutional, and political, and amenable to change and manipulation. They hinge upon societal understandings of masculinity, and so it is important to consider theoretical understandings of masculinity and male socialisation, and I return to these later.

Mental health

In New Zealand, socio-economic, gender, and physical health status all contribute to differential distribution of the incidence and nature of mental health problems. The New Zealand Mental Health Survey, 2006 (*Te rau hinengaro*, Ministry of Health, 2006b) found that women had higher prevalence of anxiety disorder, major depression and eating disorders, but men had substantially higher prevalence of alcohol and substance use disorders. New Zealand men are also known to have more than three times the rate of completed suicide than women, although women attempt suicide and are hospitalised for self-harm more often than men (Ministry of Health, 2007, 2010). These differences are consistent with those of industrialised countries, where it is frequently found that women suffer depression at about twice the rate of men (Nolen-Hoeksema, 1990). However, the female depression rate drops away dramatically post-menopause (55 years), leaving the male rate relatively stable and so considerably higher than the female rate in older age (Bebbington et al., 1998), which is the age when cancer is most prevalent. The New Zealand Mental Health Survey, 2006, also found that people with chronic physical conditions were more likely to experience mental disorders. Thus older men with cancer could be particularly vulnerable.

It is not known why the rate of depression for women is generally substantially higher than for men, and a long list of biological, social and psychological influences, together with interactions between them, could play a part (see Bebbington, 1998). However, the finding itself has been challenged. Cochran and Rabinowitz (2000) point out that affect in men is difficult to measure because men forget or under-report symptoms. These authors ask whether, given the considerable co-morbidity of mood disorders with alcoholism and substance abuse, the latter should be considered self-medication for a form of depression that is 'masked'. Crediting Pollack (1998), they say that if this is done, and comparison is made between the prevalence of alcohol abuse, depression and

anti-social personality disorder in men on the one hand, and the prevalence of depression and anxiety disorders in women on the other, then rates are very comparable. If this line of argument is accepted, then overall it appears that men suffer a greater prevalence of serious mental illness than women. Further, they are more likely to take destructive action to address their psychic pain (violence and suicide, perhaps influenced by alcohol or other substance abuse) and are less likely to seek treatment. Men were seen by secondary mental health services in New Zealand in the 2009-2010 year at 1.3 times the rate of women (Ministry of Health, 2012b).

New Zealand data relating mental disorder with cancer prevalence, specifically, do not appear to be available, and a wide range of rates are reported in the international literature. However, most estimates agree that cancer patients suffer mental disorder at rates above general population norms (Stanton, 2006) and it is known that most of these disorders are affective in nature and adjustment related (Derogatis et al., 1983). A very large representative American household survey found affective distress (i.e. anxiety, depressed mood, and substance abuse) manifesting in a significantly increased likelihood of major depression, drug dependence, simple phobia, and agoraphobia in cancer patients (Honda & Goodwin, 2004). Furthermore, having cancer predicted a striking increase in depression differentially by gender. It was found that the rate of male cancer patients with depression was 533% – i.e. more than five times – that of non-patients, whereas there was only an 81% higher rate among females. It was suggested that differences in perceived personal control and social support may be the cause of this gender differential. Andersen (1992) has suggested that cancer-related distress is a function of loss and social support, and these factors could also be hypothesised to effect men more: traditional masculine norms emphasise physical strength, invulnerability and virility, so a man's sense of masculinity can suffer loss from cancer treatments (e.g. loss of sexual potency from prostate cancer treatment) and, as already noted, men may have less social support available to help buffer against negative emotions arising from such loss.

What little literature exists (and it is foreign) tends to confirm the intuitive expectations that economic deprivation increases cancer-related distress (Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001) and that higher education associates with better mental functioning in cancer patients (Eton, Lepore, & Helgeson, 2001). It is difficult

to predict how these factors might interact with ethnicity, however. Ethnicity is associated not only with particular levels of education and deprivation, but also with cultural and spiritual factors which may significantly aid coping with the pressures of cancer (Sawyer, Ayers, & Field, 2010). So, for Māori cancer patients, some of the additional emotional burden arising from deprivation might be offset by social and spiritual strengths arising from cultural emphases on whānau (extended family), collectivity, and wairua (spirituality).

Men's experience of depression.

Since affective disorder, especially depression, is the psychopathology of most concern with cancer patients, I pause to discuss its nature and effect on men further. The psychosocial risk factors for depression in late life – the stage of life when most cancer is diagnosed – which have the strongest evidence in the literature are: the onset or worsening of severe or life threatening illness; disability and decline in ability to function; lack of social contact; the loss of a spouse or loved one; and other negatively perceived life events or chronic issues (Bruce, 2002). Clearly cancer diagnosis, treatment side-effects, and symptoms, fall squarely within these. For men, age-related losses may compound the risk. A man may have already lost his wife and only confidant, and suffered severe blows to his identity and sense of purpose associated with retiring from work.

Men experience a similar course of depression to women (Simpson, Nee, & Endicott, 1997) and may experience similar feelings, but tend to express their depression differently, 'masking' their psychic pain by somatising or externalising it (Cochran & Rabinowitz, 2000). Somatising (e.g. overeating, chronic back pain, high blood pressure, excessive sleeping, difficulty concentrating) may function to displace psychic pain onto something physical thereby avoiding self-blame and consequent loss of control and shame; acting out aggression may be a cathartic expression of sadness, but can ultimately worsen a man's self-criticism since the target is usually an intimate; and altering mood with the use of alcohol or illicit substances may be an attempt to calm feelings of impotence, anger and self-reproach. Over-work, gambling, and sex (including infidelity) can be used as more socially acceptable addictions or distractions which can also substitute feelings of impotence with the illusion of power, diverting thoughts from painful inner conflicts, but they also tend to exacerbate problems in the

long term (Cochran & Rabinowitz, 2000). Attempts to avoid or escape psychic pain by short term strategies that are ultimately ineffective and, in fact, counterproductive, are a feature of the male experience of depression as found in recent qualitative studies by (Brownhill, Wilhelm, Barclay, & Schmied, 2005; Chuick et al., 2009).

Men participating in the Chuick et al. (2009) study saw the role of masculinity in their experience as only negative, i.e. creating restrictions to options for coping, and pressuring men to hide their negative affect and so keep resorting to maladaptive coping strategies. Another qualitative study of men's depression, by Heifner (1997), concluded that men's experience was defined by their masculinity: "Beliefs about being male are challenged by the illness, and challenge the process of treatment and recovery" (Heifner, 1997, html p.11/12). Men experienced social isolation, fearing that to express their true fears and vulnerabilities would be to indicate weakness and deficiency. They experienced depression as losing control to a crushing force, and nearly all of the participants considered suicide as a means of retaking control. They also feared losing control at therapy, and described accessing treatment through means that shielded their masculine self image (e.g. being 'forced' to go after a suicide attempt or by police or family members). Thus issues of strength and control were central. Men may also find loss and grieving – salient in the context of cancer, and a common root of depression – problematic to process in accordance with masculine norms. Cochran and Rabinowitz (2000) suggest that men wish to avoid the victim role associated with grieving, considering it shameful, and so avoid seeking help and instead may strive to retake control, even if through means which are ultimately self-defeating, including suicide.

In summary, New Zealand data show that people with chronic physical conditions such as cancer suffer more mental disorder, and older men suffer more depression, leading to the assumption that male cancer patients, who are generally in the older age group, may be particularly vulnerable to psychological distress. Overseas literature concurs that cancer patients suffer psychological distress more commonly and there is quality research indicating that the increase is far greater among men. The course of depression amongst men is similar to that experienced by women, but it's expression may be 'masked', and under-diagnosed. Because of factors relating to masculinity, such as a fear of losing control or showing weakness (which will be discussed further), men may

find processing depression problematic, and may attempt to escape or avoid it in ways that are ultimately self-defeating.

Health service utilisation

Despite their poorer health statistics, men tend to make less use of health services than women. The finding that men seek professional help less frequently than women is strikingly consistent in research covering medical, mental health, and substance abuse contexts, and regarding different ages, nationalities and ethnic and racial backgrounds, according to a review by Addis and Mahalik (2003). This reluctance manifests as delay and failing to report symptoms.

In New Zealand specifically, McKinley's (2005) work based on the 2002/2003 New Zealand Health Survey concluded that men are reluctant users of primary health care. Consistent with overseas findings (Stanton & Courtenay, 2004), men are less likely to have a regular doctor and more likely to believe that it is difficult to obtain health care. Men are less likely to have a GP, underutilise GP services, report fewer issues (particularly mental health issues), have shorter consultations, take less sick leave from work, and are less aware of when they should attend screening. The large New Zealand study of utilisation of GPs by Jatrana and Crampton (2009) found that women were more likely to report life-threatening problems, whereas a higher proportion of men utilised GPs for administrative purposes or for problems restricting their ability to function, but not for life-threatening medical or surgical reasons. Clearly this has serious implications for men in relation to the early diagnosis of cancer, consequent treatment options and prognosis, and the mental health implications that can accompany these. McKinley noted that Asian, Māori and Pacifica men show even greater primary service under-utilisation.

A recent review of the literature on whether, how and why men delay seeking help (Galdas, Cheater, & Marshall, 2005) found mounting evidence indicating that traditional masculine beliefs are significant in influencing the health risk appraisal and help-seeking behaviour of men when they are ill, such that men are not permitted to express the weakness considered inherent in illness. Men ignored symptoms; hoped that symptoms would go away or cure themselves (like a cold); hoped that they could fight symptoms off; did not consider symptoms sufficiently serious to warrant seeing a doctor (who should be consulted only when one is 'really ill'); rationalised or attempted

to normalise symptoms (even despite severe chest pain); had a 'wait and see' attitude; felt that seeking help was not an obvious solution / regarded seeking expert advice as strange; felt discomfort and unfamiliarity with confiding in a GP; had feelings of vulnerability / embarrassment; had reluctance to / fear of appearing foolish, weak or not masculine, because it was considered important to be controlled and silent about one's emotional life; and had feelings of 'invincibility' which militated against seeking help. Galdas and colleagues noted that several authors suggest these findings are linked to traditional norms of masculinity, and associate more awareness and health concern with femininity.

In New Zealand, men also appear to reach out for assistance with their mental health (defining services broadly, to include those provided by non-health care professionals) less than women (Ministry of Health, 2006b). However, men appear to use *secondary* mental health services at a higher rate (Ministry of Health, 2012b) and, when they have mental disorder, to use mental or health professional services at a higher rate than women (Ministry of Health, 2006b). These findings suggest that men less readily seek help, and prefer mental health service providers to hold recognised specialist credentials when they do.

In the context of psychotherapy, Addis and Mahalik's (2003) review found that most men enter treatment as a last resort at the urging or direction of loved ones, doctors, employers or legal authorities, seeing themselves as having no other option. Reluctance to utilise psychotherapy may be because of stereotypes that male psychotherapy clients are weak, conflicts between the male role and the client role, a traditional male sense that there is a collusion among women and therapists against men, and a lack of recognition of men's particular needs in therapy (Good & Brooks, 2005). Assumptions underlying one-on-one psychotherapy may be seen as inherently at odds with traditional masculine norms of concealing weakness. Therapy can be perceived as inherently humiliating, shaming and unfamiliar as it relies on skills foreign to the traditional man, primarily, the ability and willingness to disclose intimate feelings (Shay & Maltas, 1998). It also requires an inherent admission that help is needed and the willingness to depend on another for it, both of which run counter to traditional masculine norms (Shay, 1996).

Thus men are seen to be more 'reluctant' users of both primary health and mental health services generally. Causes may include ignorance as to the availability of services and how to access them, as well as inconvenience, but a notable deterrent to use is the clash between the dependent and 'weak' status of the patient or psychotherapy client, and the masculine norms of invulnerability and self-reliance. As will be elaborated further below, in this respect and others it is problematic for men to 'do health'.

Psycho-oncological services.

In recent years, there has been more development of psychosocial services specifically for cancer patients, but it appears that men also generally make less use of these. I now briefly discuss the services local to the present research since their work is important to the way the participants experienced cancer-related distress, and will also be important to the generation and implementation of practical outcomes to improve the experience of men.

Here, the Cancer Society of New Zealand (CSNZ) has long provided information, emotional and practical support programmes, and field worker assistance to cancer patients and their families, while hospitals have provided support through social workers, mental health specialists, and chaplains, to all patients. Recently, more specialist cancer services have been emerging, and there has been more recognition of particularly vulnerable demographic groups within the cancer patient population. CSNZ has sought to encourage recognition of the need for specialist cancer psychologists by funding a team of health psychologists in Auckland. Then in February 2006 the first cancer-dedicated psychology service contracted by a DHB began. The Cancer Psychology Service (CPS), staffed by clinical psychologists, is run jointly by the MidCentral Health DHB and the Massey University Psychology Clinic at Palmerston North, and remains the only such service to date. The service has been negotiating with adjacent DHBs to extend the service to some of their cancer patients and now provides it to cancer patients under Whanganui DHB also. CSNZ has recently recognised the importance of promoting men's health and, at time of writing, has a relationship with Movember to fund men's research (including the present study) and a draft Men's Health Strategy. The importance of providing services specific to the needs of Māori has also received some attention, with the establishment of services such as Māori Cancer Coordinators (employed by Māori tribal authorities under contract to DHBs) and Māori

āwhina (social workers employed by hospitals). Cancer patients also have the support of hospital social workers, some of whom specialise in oncology patients, together with community based nurses, including hospice and Primary Health Organisation (PHO) nurses. While the nursing services may be primarily concerned with physical needs, they also provide significant personal encouragement and support.

As there are no relevant statistics available, I have gathered some local data as a sketch of men's use of psycho-social services provided for cancer patients. This was intended simply to confirm or challenge the suggestion that men generally use these services less than women, and to give some sense of the size of any disparity. Table 1-1 (below) provides data from a selection of the services provided by CSNZ nationally and in its regions, and from services local to the regions from which participants in the present research were drawn, namely the CPS in Palmerston North, the oncology social workers at Palmerston North hospital (base for the Regional Cancer Treatment Service), and two Māori Cancer Coordinator services. The data show the proportion of service users who are men ('Men %').

Table 1-1. *Psycho-social services for cancer patients: utilisation by gender*

Organisation	Service and dates	Men <i>n</i>	Women <i>n</i>	Men %	
Canterbury/West Coast Division CSNZ ^b	Active client ^a list at 7 October 2010	357	889	28.7%	
	Cancer Information Service users 1 October 2009 – 7 October 2012	534	1681	24.1%	
Auckland Division CSNZ ^d	Counselling and Psychology Service referrals ^c	Patients	156	454	25.6%
		Supporters	6	7	46.2%
	Relaxation and Stress Management Course ^c	Monthly figures, range:		0-25%	
	Support for Supporters Course ^c	Monthly figures, range:		11-25%	
	'Moving Forward' Course ^c	Monthly figures, range:		0-17%	
	One-on-one Relaxation Sessions, February – September 2010			28%	
Canterbury/West Coast Division and Wellington Division CSNZ ^e	Aggregated Helpline data 2008-2009, callers	Patients	721	2762	20.8%
		Supporters	413	1768	19%
Nationwide service CSNZ ^f	'Cancer Connect' (peer support service) June 2008 – July 2009, callers	50	105	32.3%	
Waikato/ Bay of Plenty Division CSNZ ^g	Liason Nursing Service, 1 October 2009 – 8 October 2010, clients	200	368	35.2%	
Wellington Division CSNZ ^h	Cancer Information Service, October 2009 – September 2010, callers	243	1007	19.4%	
	Support and information, 10 October 2009 - 10 October 2010, referrals	238	598	28.5%	
Te Runanga O Raukawa, Levin ⁱ	Māori Cancer Coordinator Caseload as at 12 September 2012	7	17	29.2%	
Te Waka Huia a Manawatu, Palmerston North ^j	Māori Cancer Coordinator Caseload as at 12 September 2012	3	12	20%	
Social Workers, MidCentral DHB, Palmerston North ^k	Haematology and oncology patient contacts, 1 April 2011 – 31 August 2012 14	1235	628	66.3%	

Cancer Psychology Service, Massey University/MidCentral DHB, Palmerston North ¹	First time referrals, February 2006 to 20 September 2012 (72% for patients, remainder family/ whānau)	549	954	36.5%
<p>a. 'Client' means support service user registered on data base, and excludes one-off enquiries and Helpline callers.</p> <p>b. Data from E. Horn, Manager cancer information and support, Canterbury West Coast Division, CSNZ, pers.com. 7 October 2010</p> <p>c. Period October 2009 - September 2010</p> <p>d. Data from F. Kenny, Manager supportive care, Auckland Division, CSNZ, pers.com. 8 October 2010 and 12 September 2012</p> <p>e. Data from Murphy, H., Harre Hindmarsh, J., & Bright, N. (2010) An Evaluation of the 0900CANCER Information Helpline Service: Final Report, CSNZ, Wellington</p> <p>f. Data from Noble-Adams, R., Horn, E., & Biggs, B. (2010) Cancer Connect NZ – Peer support service for people living with cancer. Power-point presentation given to Psycho-social Oncology New Zealand Conference, CSNZ, Wellington</p> <p>g. Data from G. Harbutt, Support Services Manager, Waikato / Bay of Plenty Division, CSNZ, pers.com. 20 October 2010</p> <p>h. Data from F. Pearson, Manager Information and Support, Wellington Division, CSNZ, pers.com. 11 October 2010</p> <p>i. Data from P. Masters, Māori Cancer Coordinator, Te Runanga O Raukawa, Levin, pers.com. 12 September 2012</p> <p>j. Data from C. Paul, Māori Cancer Coordinator, Te Waka Huia a Manawatu Trust, Palmerston North, pers.com. 13 September 2012</p> <p>k. Data from L. Sheehan, Health information officer, MidCentral DHB, Palmerston North, pers.com. 16 September 2012.</p> <p>l. Data from G. Shirley, Service Administration, Cancer Psychology & Health Conditions Psychology Services, School of Psychology, Massey University, Palmerston North, pers. com. 21 September 2012.</p>				

With the notable exception of hospital social workers (66.3% of contacts were with men), the data show that male cancer patients and male supporters use available services less than women, and in many cases at about half the rate. This trend is consistent with the proportion of men who used support groups in an Australian study (Pascoe, Edelman, & Kidman, 2000), with the observation of the authors of a Canadian study regarding the use of psychosocial services provided by Ottawa Hospital Cancer Centre (Manii & Ammerman, 2008), and with the general finding in the literature that men use health services less than women. The exceptional data for the hospital social worker service may be explained by the uniqueness of the service in that it does not require initiative from men or other referral sources to make contact. Social workers attempt to contact all cancer inpatients during their hospital stay, as well as patients referred to them (L. Sheehan, Health information officer, MidCentral DHB, Palmerston North, pers. com. 16 September 2012), and thus have a 'captive' clientele. Since men suffer a higher incidence of cancer, and present later so are more likely to become hospital inpatients, a service which tries to achieve comprehensive inpatient coverage like this will naturally connect with more men. A further interesting aspect of the social work data are that 212 of the men were Māori, whereas only 89 of the women were Māori. The proportion of Māori men connected with that service contrasts starkly with the proportion in the caseloads of the two Māori Cancer Coordinators for whom data is tabled, which align with the overall trend of gender disparity shown.

The disparity between the high rate of connection with men achieved by hospital social workers and the low rates generally achieved by other services is consistent with the general finding that men are 'reluctant users' of health and psychosocial services, and do not self-refer at a rate comparable with women. However, the success of the hospital social workers at connecting with men suggests opportunities for psychosocial intervention delivery which will be advanced later in this thesis. I also note that the Cancer Psychology Service does not routinely screen cancer patients for distress (E. Kent, clinical psychologist, CPS, pers. com. 9 October 2012) although it does accept referrals from hospital social workers, who may be regarded as providing informal screening (D. Baken, clinical psychologist, CPS, pers. com. 24 May 2013). It is my understanding that routine formal screening is rare worldwide, although it is gradually being adopted into best practice guidelines. Such comprehensive contact procedures

may be necessary to achieve gender equality in psychosocial service utilisation by cancer patients.

Summary

The picture of male disadvantage in health is fairly comprehensive: Men have a broad range of worse physical health outcomes with consequent shorter life expectancy; they arguably have poorer general mental health and seem to be more vulnerable to depression in later life and to increase in depression rates after diagnosis with cancer; their presentation of depression may not be recognised and may go undiagnosed and untreated, and processing of depression may pose more gender-based problems for them; men make less use of primary physical and mental health services, and local data suggests they make less use of psycho-oncological services too. The relatively poor health outcomes for men are not explained by biological differences, and one might think that the traditional privileged socio-economic status of men would provide them with a health advantage. The fact that it does not begs explanation, as do the facts concerning underutilisation of health services. Answers appear to lie in cultural definitions of what it means to be a man in the context of health. These will be elaborated in later chapters, but first I expand on psychosocial adjustment issues relevant to cancer.

2 PSYCHOSOCIAL ADJUSTMENT TO CHRONIC ILLNESS

Men and women face different psychosocial issues and have different resources available for coping with the adjustments required by chronic illnesses like cancer. In this section I first background psychosocial adjustment to chronic illness, particularly cancer, and then focus on men adjusting to cancer, including mention of psychosocial interventions, and, finally men's distinctive use of social support.

In the context of chronic illness generally, 'psychosocial adjustment' has been defined in a number of ways, ranging from the absence of psychological disorder or negative affect through to outcomes on multiple domains including mastery of disease-related tasks, preservation of function, quality of life, retention of purpose in life, and maintaining positive mood (Stanton, Revenson, & Tennen, 2007). Definitions cover both interpersonal and intrapersonal relations, as well as cognitive, behavioural and physical health, and involve regulating distress, preserving self worth and relationships with others, and recovering physical functioning – or finding alternative means or resources to make up for losses, or to make living with losses tolerable. Positive affect and personal meaning and growth are also gaining recognition as adjustment domains (Stanton, et al., 2007). In cancer, the focus in recent years has been on fatigue, pain and depression, and it is acknowledged that adjustment is a gradual and uneven process, altering with contextual factors (Stanton, et al., 2007).

Contributors to variability in adjustment to chronic illness are both distal and proximal. Distal contributors are those that shape the social context such as socio-economic variables, culture and ethnicity, and gender. Proximal contributors, which have more direct influence, include interpersonal processes, personality characteristics, cognitive appraisals and other aspects of coping processes (Stanton, et al., 2007). In their review, Stanton, Revenson and Tennen found little research regarding distal contributors to adjustment and so were unable to reach conclusions about their influence except to say that poverty and associated variables such as low education level are likely to obstruct adaptation, and so are rigid and extreme gender roles. However, the authors found more research regarding proximal contributors to adjustment, and were satisfied that there was sound evidence for a number of protective and risk factors: emotionally supportive relationships support adjustment while criticism, social constraint and isolation impart

risk; positive expectancies (general and disease specific) support adjustment; so do a sense of control or mastery (general and disease related); and active, approach-oriented coping facilitates adjustment whereas avoidance of disease-related thoughts and feelings predict elevated distress. A recent meta-analysis involving cancer and HIV/AIDS patients (Sawyer, et al., 2010), found that personal growth in terms of enhanced appreciation of relationships, change to self-appraisal (i.e. recognition of greater strength or resilience, or acceptance of vulnerabilities or limitations), or change in life philosophy, values and priorities, was associated with reduced negative mental health indicators, increased positive ones, and increased subjectively assessed physical health. A distal moderator which predicted stronger effect was non-white ethnicity, which the authors suggest may be due to stronger emphasis on family and spirituality by non-whites.

Men coping with cancer

Masculinity interacts with coping moderators to disadvantage men in adjusting to cancer, in that men have less social support, and their coping strategies are less adaptive. The U.S. literature shows that women's coping strategies for physical and psychic pain tend to involve identifying and expressing emotional and physical needs while, in contrast to this, men's tend to involve unhelpful avoidance-oriented coping strategies like distraction and externalising, drinking, denial, suppression, withdrawal, and attempting to conceal the illness (Courtenay, 2002, 2003; Fife, Kennedy, & Robinson, 1994; Sabo, 2005; Stanton & Courtenay, 2004). Masculine norms predispose many men to avoid admission of psychic or physical pain or vulnerability and therefore they have fewer confiding relationships and tend to adopt avoidance-oriented strategies, which are maladaptive. Since many men lack health knowledge and do not wish to display ignorance by asking, they are also disadvantaged in achieving a sense of mastery or control. And men with more traditionally masculine attitudes experience more psychological distress and adopt more maladaptive coping strategies (Stanton & Courtenay, 2004).

In their meta-analytic review of studies measuring how men cope with prostate cancer Roesch et al. (2005) found best effects when men approached their diagnosis directly, whether using problem- or emotion-focussed strategies. Helpful problem-focussed

strategies included accepting responsibility, managing external aspects of the stressor, seeking instrumental support (e.g. information and practical assistance), and planful problem solving. Helpful emotion-focussed strategies included self-control, gaining emotional support and making positive reappraisal of the situation. Strategies of emotional avoidance (distancing or escape-avoidance, such as denial, emotional discharge, or wishful thinking) were not helpful. Specifically, approach coping was associated with improved affect (self-esteem, positive affect, depression, anxiety, quality of life), physical measures (energy/vitality, pain) and objective measures of adjustment (return to pre-cancer activities and social functioning); while avoidance coping was associated with both poorer affect and poorer physical functioning. Analysing this finding in terms of Lazarus and Folkman's (1984) transactional model of stress and coping, Roesch et al. suggested that the men who used approach strategies had appraised the stressor – cancer – as a challenge rather than an overwhelming threat, and were therefore inclined to take action to give themselves increased control over it, including seeking information and participating in treatment decision making.

In coping, men also express less physical pain and less fear or distress than women, but more anger and hostility (Courtenay, 2003; Stanton & Courtenay, 2004). If it is necessary to activate a fear structure in order to process traumatic stress, in accordance with the fear processing theory of Foa and Kozak (1986), then men's socialisation to repress fear and sadness and express anger instead could be another obstacle to recovery from cancer-related stress (Cason, Grubaugh, & Resick, 2002).

Research on the effectiveness of psychosocial interventions to assist the psychosocial adjustment of cancer patients generally uses disproportionately female and middle class Anglo-Western participants (Heron, 2009; Heron-Speirs, Baken, & Harvey, 2013) and so offers questionable guidance as to what treatments and modes of delivery may be effective with men. Research on interventions designed specifically for men also suffers some significant limitations relating to sampling (predominantly Anglo-Western men with early stage disease), method quality, and reporting, which has again thwarted the drawing of useful and firm conclusions (Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011; Dale, Adair, & Humphris, 2010). However, for men with prostate cancer, there are some indications that educational and/or cognitive behavioural interventions in the supportive context of a group format can improve psycho-social

adjustment and quality of life (Chambers et al., 2011, that physical activity interventions can improve quality of life (Chipperfield, Brooker, Fletcher, & Burney, 2013), and that interventions targeting sexual functioning (commonly featuring education, cognitive-behavioural strategies, peer discussion and support, and skills for communicating with one's partner) can improve sexual functioning (Chisholm, McCabe, Wootten, & Abbott, 2012). Given that men generally have less health knowledge (McKinlay, 2005) and that masculine culture can exert pressure on men to avoid acknowledging physical vulnerability and obtain help (as described in the next chapter), interventions which provide needed information and which normalise their experience of vulnerability and provide social support could be expected to assist psychosocial adjustment.

Men and social support

A key contributor to both physical and mental health is the availability of personal support from family, friends, and work or community networks, and particularly from one's spouse or intimate partner. In a recent large meta-analysis, Holt-Lunstad et al. (2010) found a clear association between lack of social support and mortality in that people with adequate social relationships had a 50% greater likelihood of survival compared with those who had poor or insufficient social support, regardless of follow-up period (the average was 7.5 years), age, sex, initial health status, and cause of death. It is recognised that older men can be especially vulnerable when they lack adequate social support, which is pertinent in the context of cancer since incidence associates with older age (Courtenay, 2002; McKinley, 2005). In Western societies at least, men have smaller social networks, fewer and less intimate friendships, are less likely to have a confidant (especially someone other than their spouse), and mobilise less varied support in times of stress. Courtenay goes so far as to suggest that most men may have no close friends other than their spouse. Indeed, this was borne out in an Australian study of 'mateship' (Butera, 2008), and has also been shown in a population based Swedish study (Helgason, et al., 2001) which compared male prostate cancer patients with men in the general population and found that both suffered the same threats of isolation: more than one in five had no-one in whom to confide their emotional concerns; of those who lived with a partner, seven in 10 confided in their partner only, and only one in 10 reported confiding in anyone else; of those who did not have a partner, nearly seven in 10 had no one to confide in. The study also found that men

who had no one to confide in were less likely to report feeling alert and strong, calm, energetic, and happy, and more likely to report feeling depressed, sad, tired and worn out. An Israeli study of colorectal cancer survivors (Goldzweig, et al., 2009) also found that unmarried men were significantly more poorly adjusted (worse depression, intrusive anxious thoughts, anxious preoccupation, and helplessness) than women or married men. Clearly, the tendency of men to have less social support leaves them more exposed to distress in the context of cancer.

Men are likely to have smaller informal networks because theirs are based on work or leisure activities which fall away with age and the deterioration of health, according to a review of gender and social networks later in life (Scott & Wenger, 1995). Men then become more dependent on networks generated and maintained by their wife, and on their children and neighbourhood, and tend not to replace lost friendships, whereas women continue to make them throughout their lives.

Gender and marital status are thus important factors for psycho-oncologists to take into account (Goldzweig, et al., 2009), and unmarried men with cancer may be more likely to suffer greater distress. Also, special effort may be required to tailor social support services to the needs of male patients and to connect men to them (Helgason, et al., 2001). However, two meta-analyses of psycho-oncology interventions have concluded that intervention can be particularly effective with men, producing about twice the effect size (Heron-Speirs, Baken, & Harvey, 2013; Rehse & Pukrop, 2003). This may be because men begin intervention with greater need (distress) arising from their disadvantages regarding distress processing and social support (Heron, 2009). If this is so, single men would be positioned to make the greatest gains from intervention.

Summary

'Psychosocial adjustment' to chronic illness is defined in various ways, often sampling a range of mental, social and physical domains. In the context of cancer the domains often include depression, pain and fatigue, which have considerable impact on quality of life. Amongst distal predictors of maladjustment to cancer are rigid gender roles and economic deprivation, and amongst proximate predictors of adjustment are emotionally supportive relationships, positive expectancies, a sense of control or mastery, and active, approach-oriented means of coping. Personal growth during adjustment can help

counterbalance some of the negative impacts of chronic illness. Unfortunately, men often make less use of emotional expression and support as means of coping. Indeed, they have fewer confidants and fewer social contacts generally, especially as they age, and are particularly vulnerable if single. Some men adopt maladaptive avoidant strategies to cope with the perceived overwhelming threat of loss posed by chronic illness in the context of masculine norms which emphasise strength and independence. However, other men adopt approach strategies, using emotional support and planful problem solving to beneficial effect. Men's particular needs regarding health information, normalisation of vulnerability, and social support provide some indications as to interventions which may be effective in helping their adjustment to cancer, but few conclusions can be reached on the extant literature.

3 CONCEPTUALISATIONS OF MASCULINITY

In this section I overview some prominent conceptualisations of masculinity, applying them to the context of health. This material is key to understanding and conceptualising the particular nature of distress that men suffer when seriously or chronically ill, and the means of coping available to them. While the overseas literature has much relevance in the New Zealand context, I include some specific discussion on Māori and Pākehā masculinity.

The significance of masculinity to health

If it is true that 'being a man' is the strongest predictor of health status (Stanton & Courtenay, 2004), but that male sex explains little of the gender difference (Courtenay, 2002, 2003; McKinley, 2005) then cultural factors relating to masculinity must have considerable power:

It has been said...that the male gender culture in many aspects is pathogenic rather than protective of health, and the majority of negative aspects can be categorised under the rubric of 'lifestyle choices and occupation'. (McKinlay, et al., 2005, p.7.)

These authors are saying that self harming behaviours involving alcohol, diet, suicide, and also employment in more hazardous occupations, problems controlling anger, risk taking (including unlawful behaviour), and reluctance to use primary healthcare, underlie many of the poor health outcomes for men, and that, as chosen behaviours, they are the result of social factors and, importantly, are amenable to change.

Theoretical conceptualisations of masculinity focus on the social, political and psychological realities that shape men formatively and also influence their behaviours at times when they must negotiate the complexities of health issues. For example, what stimuli are recognised as stressors, and what strategies are recognised as available for coping, are both subject to such interpretative influences. Without an understanding of these social, political and psychological realities, psycho-oncological intervention cannot be optimally effective either in engaging men or in delivering useful and effective content. Indeed, a lack of understanding of such realities amounts to a kind of

cultural blindness and gives rise to the 'deficit thinking' and blaming mentioned earlier, stalling progress towards correcting inequality.

Different conceptualisations of 'masculinity' have emerged from psychology, anthropology, and sociology. A number of authors provide convenient summaries of the main perspectives, which vary greatly, and include biological, psychoanalytic, social psychological, historic, social-constructionist and poststructuralist formulations. The following discussion draws from summaries by Connell (2005), Good and Brooks (2005), Levant (1992), and Robertson (2007). I conclude this section by explaining the theoretical approach that will be taken for the purposes of the present study.

Socio-biological views of masculinity

Early perspectives on masculinity were essentialist in nature, explaining distinctive masculine behaviours and roles as developing from biological differences (e.g. differences in hormones, neurotransmitters, and brain structure) for the adaptation of the species, with particular expressions tempered by social constraint or encouragement. The practical significance of this perspective for men's health is that unhealthy behaviours associated with the expression of masculinity (e.g. poor diet, excessive alcohol consumption, risk taking, and belatedness in seeking medical help) are viewed as substantially inherent in the biological make-up of men and therefore not open to significant change. Courtenay (2000) suggests that this essentialist conceptualisation remains very influential and explains the passive acceptance by the medical fraternity, and by society in general, of the contradiction between the notion that men are 'the stronger sex' and the reality that men suffer a raft of poorer health outcomes together with shorter life expectancy. Masculine unhealthy behaviours are taken for granted as simply 'the way men are', blinding the vision and paralysing the will to effect change.

A British study of the accounts of doctors and nurses supports this view (Seymour-Smith, Wetherell, & Phoenix, 2002). The authors found that doctors' and nurses' discourse on hegemonic masculine norms was, on the one hand, critical of their detrimental effects on men's health, and, on the other, indulgent, humorous about, and protective of, the norms, accepting that they simply reflect 'how men are'. Men were depicted as at once irresponsible about their health (passive, incompetent and ignorant

about health issues, 'hapless and helpless') on the one hand, and as respected serious and stoic users of the health service on the other (in contrast with women who were depicted as possibly hypochondriac, using the service for trivial concerns). In the same vein, Robertson (2007, p. 28) quotes a general practitioner's humorous comment:

But will [men] abandon their traditional Saturday afternoon shin-kicking and beer-swilling in favour of a warm community centre, a slice of lentil bake and a group discussion on better foreskin hygiene? I doubt it. Aggression and foolhardiness are carried on the Y chromosome and there's not a lot government or anyone else can do about it. (Hammond, 1994, p. 64.)

An evolutionary/biological perspective underlay Freudian psychoanalytic theory, but Freud also strongly posited the construction of character through the conflict-ridden processes of childhood. Although his focus on the individual man and his family of origin did not take into account broader social and political influences, Freud advanced understanding of gender by recognising that it is not fixed by nature, but is constructed, and that femininity is part of a man's character (Connell, 2005).

Male Sex Role Theory and traditional masculine norms

The next major step in building a social science of masculinity was the development of the concept of 'the male sex role' in the middle of last century, supported by the work of psychologists, anthropologists, and sociologists. Again a socio-biological perspective, this theory assumed innate biological gender differences which were exaggerated by socialisation through rewards and sanctions delivered through societal institutions (such as family, school, media, and work place) in accordance with cultural expectations. Importantly, this approach began to recognise a diversity of masculine expression between cultures, and shifted the focus to social structures. 'Masculinity' was thought of as an internalised role or identity, and the development of a 'secure gender role identity' (i.e. internalised traditional gender norms) was considered vital – not only to the personality of the individual but to the stability and function of society.

Four core themes of the traditional male sex role were famously listed by David and Brannon (1976, p.12) and collected into the similarly well known Masculinity Scale by Brannon and Juni (1984) thus:

1. No sissy stuff: Avoid femininity (e.g. help seeking, empathy), conceal emotions
2. Be a big wheel: Breadwinner, admired and respected, powerful, strong, competitive, instrumental orientation
3. Be a sturdy oak: Toughness, 'male machine', independence, self-confidence, self-reliance
4. Give 'em hell: Take risks, face danger, demonstrate bravado, adventure, aggression

These themes have been reduced to three moderately correlated clusters by factor analysis (Thompson & Pleck, 1986): status (achieve status and respect); toughness (physical, mental, emotional, including self-reliance) and anti-femininity . To these, Levant et al. (1992) added an objectifying, non-relational attitude towards sexuality, and homophobia (although some authors place the latter under anti-femininity).

Burke (2002) summarises the norms again (p.41): "Men suffer under a code of masculinity requiring them to be aggressive, dominant, achievement oriented, competitive, rigidly self-sufficient, adventure-seeking, willing to take risks, emotionally restrictive, and avoidant of all things feminine (Levant & Pollack, 1995; Maier, 1999; Mooney, 1995)." Men are rewarded at work for such behaviour – being competitive and 'in control' of their emotions, and appearing invulnerable by not seeking help.

In the context of health, Stanton and Courtenay (2004) summarise the American literature with the assertion that men with more traditionally masculine attitudes adopt more maladaptive coping strategies and risky behaviours and are at increased risk of death. They give an example of bragging, 'I haven't been to the doctor in years', as a gesture towards proving manhood – as if neglecting health checks was an honourable thing and a defining characteristic of a 'real' man.

Anti-femininity was primary in masculine identity for Brannon and colleagues (Brannon & Juni, 1984; David & Brannon, 1976), and, in the context of health, the prohibition from behaving in ways that may be considered 'feminine' has enormous implications because critically important behaviours such as caring for oneself and

seeking help can be viewed as feminine. Furthermore, predominantly female staffing of the health system can also be interpreted as indicating that it is not a place for men.

Breadwinner status is also important in the present context. Axelrod (2001) suggests that the way that men feel about their work is characterised by a unique intensity because mastery at work is associated with securing a sense of masculinity. It is necessary to constantly prove and re-prove masculine status by constructive productivity and achievement. Thus the meaning of work is tied closely to an individual's sense of masculinity, which is jeopardised in the face of chronic illness or disability, possibly contributing to distress.

Maintaining emotional control is a common thread in the Brannon list, and is also threatened by chronic or serious illness. One aspect of maintaining emotional control is concealing vulnerability, which involves suppressing the expression of intimate feelings in conversation with others. Butera (2008) discusses the phenomenon of 'mateship' between men in Australian culture and how communication is maintained on a very superficial level which suppresses emotional intimacy, thus creating a relationship which is in fact the very antithesis of friendship. The concealment of vulnerability is necessary, however, if people consider themselves in competition with each other and likely to be hurt by confidants, as is the expectation between men according to masculine ideology. In Butera's study, the only people with whom her older cohort of participants (64-87 years of age) felt safe to communicate intimate feelings were their wives. All 15 of Butera's older cohort described their wife as their best friend and closest confidante and the only person with whom they would share deep feelings and thoughts. Men from both the older cohort and the middle aged group (in their 40's) demonstrated how expressing emotion was regarded as improper e.g. by apologising when some emotion slipped out in the interview.

Is Brannon's description of masculine ideals now dated and irrelevant? Levant (1992) claimed that traditional masculine ideology was, even when he wrote, in a state of collapse, leaving men uncertain as to their role and ill-equipped to meet new roles such as nurturing. Butera (2008) showed that some traditional masculine prescriptions were fading for younger cohorts, but not for the retired cohort of men: the younger generation (in their 20's) were more open to emotional disclosure and expected more

emotional support from their mates than men in their 40's or of retirement age; the older cohort (64-87 years of age) were guarded in self disclosure, expecting to exchange purely practical support with their mates; the middle aged group were caught amidst changing attitudes, with some feeling comfortable with traditional levels of relating, and others expressing frustration or disappointment that their peers might avoid or reject their overtures at a deeper emotional exchange. Since cancer incidence is associated with greater age, it could be expected that the traditional masculine prescriptions found applicable to older and middle cohorts of men will be relevant to the present study.

In New Zealand, Pākehā masculine ideology has traditionally reflected the 'strong and silent' ideology described in Anglo-Western literature, but with local colour. The renowned social history by Phillips (1987) embeds Pākehā masculine culture in images of rural pioneering hardship and toughness, equality and mateship at war, larrikinism and hard boozing at the pub, stoicism on the rugby field, practical unpretentious heroics (e.g. Sir Charles Upham, Sir Edmund Hillary), settled family providing, and equivocal relationships with women, including alcohol fuelled violence. Norms of anti-femininity, non-disclosure of vulnerable thoughts or emotions, physical practicality, and toughness dominate, and there is an ongoing tussle between the rough and tough 'man's man' of colonial days, and the domesticated responsible family man.

Of particular interest in the present context is Phillips' (1987) discussion of the significance of mateship among the soldiers during World War II. As 'mates', soldiers physically and emotionally supported each other whilst the competitive element of masculine culture spurred them on to acts of courage and larrikinism. Non-disclosure of vulnerability was key in the support mates gave each other. Phillips (1987) says that men knew that if they showed fear or weakness before the other men, they would be ostracised, with critical consequences. On the other hand if they were fearless in battle, they might be killed. They weighed a certainty against a gamble and behaved fearlessly, maintaining the support of their mates. Emotional support was shown without words or other expressions that might be interpreted as feminine, but through 'rough housing', an understanding gaze, or practical gestures. Most of the men who are experiencing cancer today grew up during or shortly after the war, at a time when the Returned Services's Association was booming and this stoic mateship was most

honoured. It is to be expected that many of them will share the masculine norms of that culture, in which a man's greatest fear was of showing fear.

Māori masculine ideology may have been perverted to fulfil the racial expectations of European colonisers, exaggerating the importance of physical strength. Māori have been stripped of many of their traditional institutions and ways by their experience of colonisation, which included cataclysmic loss of population in the late nineteenth century, and education policies which not only prohibited the speaking of Te Reo (Māori language), but also restricted the curriculum of Māori schools to practical – rather than academic – subjects, in accordance with the opinion held by Pākehā officials as to where Māori strengths lay. Hypermasculine images of Māori such as 'noble savage' (including the fierceness of the Māori Battalion in World War II), 'Jake the Muss' (the pathologically violent lead in the film 'Once were warriors'), and All Black (rugby) hero have alleged and emphasised innate and threatening physicality in Māori men, at the expense of intellectual and nurturing qualities (Matahaere-Atariki, 1999). According to Hokowhitu (2004, 2008), Māori men have generally internalised such simplistic racist stereotypes of themselves, adhering to ideals of physicality and patriarchy to the point where they themselves believe that their strengths are limited to sport and 'practical' vocations. Yet Māori culture imbues both men and women with value for family, intellect, and spirituality, and with compassion and practical concern for others. Thus Māori masculinities are particularly complex, drawing from both a caricature of Anglo-Western norms and a remnant of true Māori norms. In the context of cancer, the emphasis on robust physicality potentially exposes Māori men to great loss, but remnants of traditional values may offer important coping resources.

Although traditional masculine ideologies remain relevant today, Sex Role Theory itself has succumbed to a large number of criticisms and is now to be considered obsolete (Connell, 2005; Robertson, 2007). Criticisms include that it wrongly assumed that sex roles were well defined, could not account for change because of its essentialist nature, was ethnocentric, could not account for the extent of diversity and multiplicity in individual men revealed by life history studies, and ignored power dynamics both between the sexes and between men. The essentialist base of Sex Role Theory meant that biological sex and gender were not adequately separated and the social construction of gender was not sufficiently acknowledged. However, its recognition that there are

socialised gender ideals for men set the stage for recognition of the stresses produced by the reality that those ideals are unachievable (Burke, 2002), which is the foundation concept for Gender Role Strain Theory.

Masculine Gender Role Strain Theory

The dominant psychological paradigm currently is Pleck's (1995) Gender Role Strain Theory. It posits that gender roles are internalised as a result of socialisation to the gender dynamics in contemporary local society, which is a process that rewards conformity to socially expected roles and punishes violation of them. For men, the consequences of failure to conform – shame and social ostracism – are particularly severe, inducing over-conformity and compliance with dysfunctional behavioural expectations (e.g. dangerous drinking). Masculine social norms are often inconsistent, violation of them is frequent because they are impossibly difficult to adhere to, and gender characteristics produced by the socialisation process may be psychologically dysfunctional (e.g. aggression, social isolation).

Pleck theorised that much relational dysfunction and psychological distress can be felt by individuals as a result of a stressful gap between the gender expectations they perceive apply to them, and their perceived performance of those expectations ('role strain' or 'role conflict'). The dysfunction may manifest as affect, behaviour, conscious cognition or unconscious behaviour, and may be directed at self or at others. It is associated with self-reported shame (Thompkins & Rando, 2003). For example, strain based behaviours may take the form of acting out aggression or risk taking, which may be seen as an over-performance of masculine ideals such as strength and independence. The model predicts that more strain – and more unhealthy behaviours – will manifest in the lives of those men who have internalised most completely, and adhere most rigidly to, traditional masculine ideals, and there is literature to support this hypothesis (e.g. Liu & Iwamoto, 2006). Two main sources of role strain can be distinguished: (1) 'discrepancy strain' is the psychological distress felt when a man fails to live up to his internalised gender norms, and (2) 'dysfunction strain' is psychologically dysfunctional behaviour (e.g. endangering health) which results from rigid adherence to sexist or restrictive or otherwise unhealthy traditional masculine ideals (Levant et al., 2003).

Levant (1992) posits that the socialisation of boys under traditional norms can have 'traumatising' effects leading to important skill deficits, namely impaired emotional awareness and expressivity ('normative masculine alexithymia') and distance in domestic relationships. The distance arises from a fear of losing separateness – of having one's virile independence smothered. Restricted emotional expression is encouraged by traditional masculine ideology as it preserves an appearance of invulnerability, strength, and control. The socialisation process actively punishes boys for displays of pain, fear, or other vulnerability by shaming ('sissy'), and directs boys to be stoic ('big boys don't cry', 'no pain, no gain'), including to the detriment of their health. A subclinical level of alexithymia is normal for many men, and likely a product of gender socialisation (Levant, 1992; Levant, Hall, Williams, & Hasan, 2009). The one emotion that is accepted as masculine – anger – becomes over used as an outlet for emotions which are unacceptable because they express vulnerability (e.g. sadness, fear). Levant et al. (2009) have presented meta-analytic evidence of a small gender difference in levels of alexithymia, and there is also evidence that men who endorse more traditional masculine norms tend to be more alexithymic (Levant, et al., 2003; Wong, Keenan, & Rochlen, 2006).

According to Gender Role Strain Theory, gendered ideals are unachievable yet there remains a relentless burden of expectation to strive to achieve them (Good & Brooks, 2005). This burden is like a never-ending series of tests of manhood, posing the constant threat of failure as a man (Levant, 1992). Health issues, such as those that arise in relation to cancer, pose many such tests. A man might be challenged as to how to handle issues like the following: "Do I take this symptom to the doctor now or do I try to 'tough it out'?"; "Can I afford for my work mates to know that I am being treated for prostate cancer and urinary incontinence, or will that forever damage my manly status in their eyes?"; "How can I cope with my despondency without letting anyone know that I feel damaged and afraid?". Men who subscribe to traditional masculine norms of strength, competence, and silence in the face of suffering, may have a narrow and isolating range of options for dealing with such challenges because of the perceived pressure to 'pass the masculinity test' in each.

Because a man's gendered norms are associated with his contemporary social context, they vary by factors such as social class, occupation, race and age – as well as

individual socialisation experiences – so the potential for gender role strain also varies. For example, men who work manually for relatively low pay, and who perceive the ability to do that work to be central to manliness, are particularly vulnerable to distress in the event of debilitating illness (Liu, 2002). Since Maori are represented disproportionately in this group, and are also subject to cultural expectations of physicality (discussed above), they may be particularly exposed to strain when a serious illness such as cancer interferes with their physical strength.

Much of the criticism of Gender Role Strain Theory has come from outside of psychology. Connell (2005) asserts that its definition of 'role' is vague, it exaggerates the degree to which social behaviour is prescribed, and it still bases role enactment ultimately on biological difference rather than social relations, which leads to categoricalism – the reduction to two homogeneous categories characterised by reciprocity and polarisation. But as a sociologist, Connell's main complaint is that the theory does not grasp issues of power and social inequality well, so is politically reactive, failing to open up strategies for social change. Social justice certainly does not appear to be the theory's *raison d'être*, but rather, its general paradigm has been applied in treating men's distress clinically and in 'life coaching' (Sweet, 2012).

However, the theory has also been criticised by psychologists (Addis, Mansfield, & Syzdek, 2010), first, because research based on it operationalises masculinity as a set of – usually negative – traits that an individual may possess to varying degrees, which encourages essentialist thinking and promotes a negative view of men, and second, because it overlooks the importance of cues in the social context when a given behaviour is enacted. These authors propose a functional social learning approach which posits the production of gendered behaviour in two steps and employing principles of operant conditioning, reinforcement, punishment and modelling: first a person builds a repertoire of behaviours according to his or her socialisation experiences, and then he or she selects and enacts a behaviour according to the social cues in the particular context he or she is in. The authors hope that this approach to gendered behaviour will be more predictive, and therefore more useful in changing behaviours (e.g. by changing contextual cues), and also that it will better promote social change since socialisation experiences, contextual cues, and whether or not the resulting behaviours are desirable, become the foci, rather than gender as such. Already there is

research supporting the theory's hypothesis regarding the importance of contextual cues (Jones & Heesacker, 2012).

Both this social learning theory and Gender Role Strain Theory recognise the significance of formative socialisation to masculine norms drawn from local contemporary society. Both also recognise that traditional prescriptions of masculine behaviour offer a narrower range of acceptable behavioural options. While the social learning approach may improve prediction of behaviour, the role strain approach directly explains gender-related distress, which is pertinent to the present thesis.

Masculinity as a Relational Model

Connell (1995, 2005) has developed a post-modern relational model of gender which has been widely used, particularly in sociology and related disciplines. Like Gender Role Strain Theory, it has a social constructionist base, and also asserts that men constantly have to prove their masculinity in different social contexts. However, Connell's model places fundamental emphasis on power relations. It asserts multiple masculinities, with hierarchically orderable groupings both within and between genders. 'Hegemonic masculinity' is at the top of the social order, defining and legitimising 'normal' practices, and attracting prestige, power, and wealth. Although enacted by individuals, gender identity is not a concrete concept, and is found in 'configurations' of social interaction and practice which are sustained in societal institutions. Although change is possible, vested interests constantly press to perpetuate the social order.

Connell's (1995, 2005) model posits the following masculinities:

- hegemonic masculinity, i.e. the 'superior', and most visible masculinity which assumes a dominant social position over both femininities (i.e. patriarchy) and other masculinities. It is not necessarily the most commonly enacted masculinity since it's demands are exceedingly difficult to live up to (Connell, 2003);
- subordinated masculinity, i.e. subordinated to the leading position, e.g. gay masculinities;
- marginalised masculinity, which reflects the interaction of gender and class, and comprises practices on the skirts of participation in society e.g. the masculinities of disabled men;

- complicit masculinity, i.e. those men who do not live out the practices of hegemonic masculinity themselves, entering into extensive compromises with women rather than naked domination or uncontested displays of authority, but nevertheless partake in the dividend that patriarchy legitimates.

Because masculinities are not sets of pre-existing norms which are passively internalised and enacted by individual men, but are dynamic social conventions which are constantly constructed and used by political interests, Connell's (1995; 2005) focus is on processes, conditions, and the relationships they produce. Critical to note is that hegemonic masculinity is a relative position amongst gender relations, not a fixed character type, although Connell (2003) does acknowledge that hegemonic practices are likely to be those identified in psychological literature as 'the male role'. It is the stress associated with losing – or anticipating losing – status in the gender hierarchy that is of most salience for present purposes. It is also to be noted that gender, as a way of structuring social practice in general, interacts with class and race. For example, white men's masculinities are constructed not only against white women's femininities but against black or poor or gay men's masculinities. The effect of belonging to a marginalised or subordinated socio-cultural-economic group is exclusion and limitation – "glass ceilings and walls" – and consequent increased rates of psychological disorder, including substance abuse and suicide (De Las Fuentes, 2012).

In terms of health, this relational model conceives of masculine practices as politically laden social action. Health is not just a state of being but is 'done' in certain ways by men as a means of reinforcing and justifying their privileged power position in patriarchal societies. Hegemonic masculine ideals of strength and invulnerability are displayed in a disregard for personal health and safety as a form of social action which conveys justification for male dominance over women, who are, by contrast, portrayed as the sicker and weaker sex (Courtenay, 2000; Lohan, 2010; Robertson, 2007). Beliefs and practices such as the assumption that men's risk-taking and violence are innate to their sex, the portrayal of men utilising the health system only when 'really ill' and women over-utilising it, the tendency to report depression rates from treatment data which is confounded by gender differences in help-seeking and makes women appear to have higher rates of the illness, together with the gross under-diagnosis of depression in men, the practice of non-confiding by men who have depression, and the shunning of

health care and prudent health behaviours by men, all help construct men as the deservedly dominant sex (Courtenay, 2000).

Since the economic and social circumstances at the disposal of particular demographic groups of men differ, they are likely to select different ways of displaying their masculine status. For example, since personal healthcare is seen as a feminine concern, declining health care may be used by a poor man to prove 'toughness' and avoid appearing 'soft' to others, whereas a more wealthy man might choose the risky activity of skydiving to demonstrate his manhood (Courtenay, 2000).

Regardless of the practice, the political objective of concealing male 'weakness' and distancing men from illnesses or practices considered feminine all serve the purpose of obtaining or retaining position in the social hierarchies between the genders and within masculinity. This means change is likely to be slow:

Naming and confronting men's poor health status and unhealthy beliefs and behaviours may well improve their physical well-being, but it will necessarily undermine men's privileged position and threaten their power and authority in relation to women. (Courtenay, 2000, p. 1397.)

The relational model implies that any attempt to bring about change in men's health practices, or utilisation of services, will have to address the politics at stake. It may therefore be easier to improve men's health practices by appealing to particular hegemonic ideals which circumvent the negative health practices associated with others, rather than by openly challenging hegemonic ideology.

Useful for the present purpose

Academically, Connell's (1995, 2005) relational model is generally regarded as more sophisticated than Gender Role Strain Theory, being more complex and fluid, accounting better for differences in behaviour according to social context, within an individual's behaviour, and across time, and highlighting the driving influence of political power between large groups of people. But role strain theory may still provide a useful perspective in explaining the distress of individuals, and, with the additional recognition of contextual social cues, useful prediction of individual behaviour. I do not

see role strain theory as importantly at odds with Connell's model for the practical purpose of the present research, since it shares the important premises of social constructionism and the constant pressure on men to conform to masculine ideals. Both perspectives offer insights in the context of men and health, and they share with earlier conceptualisations the recognition of an influential set of traditional (Anglo-Western) masculine ideals. However, an essentialist conceptualisation may be, as Courtenay (2000) suggests, still current and most influential amongst the general public and the medical profession.

For the purposes of this research I used the different approaches according to the task at hand: when discussing preliminary results with teams of participants, none of whom had tertiary education in social science, a more essentialist conceptualisation was acceptable; when analysing participants' talk, I bore in mind the pressures on men to avoid shame and loss of masculine status and their need to deal with perceived discrepancies between their masculine expectations of themselves and their new realities; and when designing intervention strategies for lowering men's cancer-related distress, I chose to work with select hegemonic practices rather than directly confront other problematic ones, and to avoid suggesting interventions that may shame men according to traditional stereotypes of masculine behaviour.

4 MASCULINITY AND SERIOUS HEALTH PROBLEMS

Having overviewed the main theoretical approaches to masculinity, and contextualised them to health in a general way, in this chapter I develop some issues pertinent to the present research, and conclude with the research rationale. First I discuss the significance of a healthy body to masculinity, including the concern that non-normative bodily appearance or function – as can result from cancer or its treatment – can impact masculine status. This leads to a more detailed discussion of the pressures men must negotiate in order to 'do health', i.e. to approach health issues, use health services, and adjust to chronic illness, without losing social status or while compensating for such loss. As will be seen, this process is characterised by the complexity of balancing conflicting demands, 'role strain', and confrontation with a number of 'identity dilemmas'. Flexible strategising and focusing on the helpful potentiality of masculine norms may be key to successful navigation of this perilous adjustment process. A challenge for those working in this field is to make use of masculine norms, such as risk taking and problem solving, to encourage men to learn and use helpful coping strategies, notably, emotional expression, which is key to enlisting social support. The rationale for this research is thus driven by both the inequities that men suffer, and their coping strengths.

The body, health, and masculine status

Within the relational model of gender relations, the human body is not only a biological entity, delimiting physical possibilities, but is also a cultural symbol, associating the person with a place in gender hierarchies of power and status (Connell, 2005; Gerschick, 2005). People with bodies that are non-normative in their socio-cultural context, are assigned stigma associated with the perception that they are weak, passive, and dependent. The stigma results in them being avoided, overlooked and ignored, diminishing their social status (Gerschick, 2005). Assessment is undertaken continuously by others as to whether individuals are 'doing gender' appropriately, and sanctions are applied if they are not.

"One's body serves as a type of social currency that signifies one's worth.

Consequently, people with less-normative bodies are vulnerable to being denied social recognition and validation." (Gerschick, 2005, p.372).

A body can be less normative in many ways including race, ethnicity, class, age, physique, weight, height, disability, appearance, and skin colour. Diminished status due to disability will vary according to the visibility and severity of the difference, whether it is physical or mental, the particular social context, and the person's age, ethnicity, and class (Gerschick, 2005). Thus most cancer patients, who are older people, may already have diminished social status on account of their age, before taking into account any disability resulting from their cancer that is apparent to others.

When a man is confronted with a loss of status due to a new non-normative body feature, he has three possible responses: accept the inferior status, hide from or deny the dilemma (e.g. in alcohol), or reject aspects of the hegemonic stereotype and redefine manhood for himself: acceptance, denial, or redefinition (Connell, 2005). The first and last options require conscious adjustment of the man's self-image and accompanying practical and social circumstances, which can be emotionally demanding. Some men are better equipped than others to make this adjustment, which requires both internal and external psychological resources, and the nature of the bodily change gives some men more time to make the adjustment. Denial may be the option selected by men with too few resources or too little time to adjust.

The taken-for-granted functionality of men's bodies is also central to understanding the meaning of health to men. Traditional masculine norms emphasise strength, self-reliance and control – functionality – and Connell (2005) points out that doing rather than being is central to hegemonic masculinity, therefore a functional body is both essential and 'normal'. A man's expectation is that his body will be capable of doing manly things, such as being physically active and fulfilling the provider role – that it will be functionally strong and invincible, with its workings under control (Robertson, 2007; White, 2001). This may be particularly true of men who rely heavily upon their physical functionality for income provision. Because the prospect of being ill or disabled is considered abnormal, it is threatening to a man's sense of masculinity, and so drives efforts at avoidance (Robertson, 2007; White, 2001). Men may not, therefore, recognise problems and changes with their bodies, or may not want to recognise them given this socialised expectation (White, 2001). They may therefore see health assessment as a threat, as found in a New Zealand study by Mitchell and Horn (2006).

The complexity of accessing health care

Accessing health care can pose a number of different threats to masculinity. Autonomy and control are central to masculine status, and accessing healthcare can threaten these. In his recent and substantial Australian qualitative study, Robertson (2007) found that because of this threat men would resist accessing health services. Furthermore, he found that men hold a strong dichotomy between health and illness, which has implications for retaining masculine status. To negotiate accessing health services, a man might have to accept a position of diminished status in terms of Connell's (2005) hierarchy, or else use some other strategy to avoid alienating himself from hegemonic norms. For example, he may emphasise privacy, confidentiality and anonymity in receiving services, or he may legitimate service use in some way, such as saying that he has a nagging wife, noting that the risk is so high that it would be irrational not to go, or noting that he has observed ill-health in significant others or has a family history of a particular problem. Furthermore, health situations and talk are regarded as feminine (Robertson, 2007). Men perceive that traditional health services are for women and children, for example, by the fact that opening hours are geared to their needs (White, 2001). Since traditional masculine norms regard things feminine as diametrically opposed to things masculine (David & Brannon, 1976), health situations are threatening to masculinity. Thus Robertson says that men cannot simply 'do health', but must negotiate their way through a number of significant threats to their masculinity inherent in accessing health care.

The health encounter itself is also laden with threat to the hegemonic masculine identity. A perception peculiar to men is that a visit to the doctor should provide a straight-forward fix, like getting a car repaired. This 'fix it' mentality means that if such an expectation is not fulfilled and rest is prescribed, a man may prematurely try to return to work to regain a sense of manliness, stressing himself and his partner by endangering his health (White, 2001). Another problem is that men fear that taking concerns to the doctor risks them being unfounded, and of being labelled a hypochondriac, or of wasting everyone's time (self, employer, doctor). On the other hand, men also fear that concerns will prove well founded, and that they will be diagnosed with some condition that threatens their strength and has broader implications for their masculine roles (Mitchell & Horn, 2006; White, 2001). Some men fear that simply negotiating time off

work to get to a doctor's appointment may threaten their image at work and the security of their employment. Consequently they put off going for as long as possible (White, 2001).

Complexity and balance in handling health

Robertson (2007) found a number of points of complexity and balance in the way men handled their health: continuous balancing was required of risks related to their construction of masculinity (e.g. the risk of social exclusion for not smoking versus the risk to health from smoking); a 'healthy balance' was also required between needs for control and release (i.e. the moral duty of self surveillance of health-related behaviours on the one hand, with the felt need to escape the pressure of this from time to time on the other); and management of a 'don't care / should care' dichotomy of public expression of non-concern about their health to demonstrate masculinity, while privately expressing a feeling of moral obligation to care about their health. Complexity is also evidenced in Robertson's observation that men were willing to accept individual responsibility for health, seeing it as maintaining their control over their own bodies and excluding professional 'interference'.

Echoing these findings, a New Zealand focus group of occupational health workers felt that men experience health,

...as a complex dynamic between their health status, their continuing employment, their role in family support and, ultimately, their self-esteem and self worth. Further, any threat to their health – real or imagined – carried an implicit threat to their employment, their family and their view of themselves. Health assessment was seen as one such threat. (Mitchell & Horn, 2006, p. 16.)

It was felt that men struggled with and were stressed by the need to manage these tensions, and that if the environment is not sensitive and supportive to them in this, then they may manage their stress in ways that are in fact hazardous to their health (e.g. risk-taking recreation, excess alcohol use). Thus both complexity and the continuous need to balance the contradictory demands of masculinity are emphasised by both studies.

The integration of illness into masculine identity

Maintaining masculine status is problematic in the face of disability or chronic illness, and such 'gender role strain' may drive significant and on-going distress, therefore an exploration of underlying dynamics is appropriate for the present study.

Complexities regarding the meaning of health to men imply that incorporating disability or chronic illness into a masculine self image will be problematic. Indeed, given that masculine self image is defined by strength and action, Robertson (2007) finds it so. He says that because a man might construct masculine embodiment as drinking, sexual prowess and the ability to perform skilled labour, he might feel that he is no longer "a red blooded man" (p.79) if his confidence to do these things is threatened. Disabled people and women are the 'other' against which the norm of a masculine body is defined (Robertson, 2007, citing Shakespeare, 1994) and physical impairment may be thought of as implying mental impairment, which could lead to the rendering of a man as a non-person (Robertson, 2007). He gives an example (p.80) where participant Frank, in frustration at people talking over him to his wife, or shouting despite being told he was not deaf, finally halts this behaviour by standing up out of his wheelchair to repeat that he is not deaf and to attempt to intimidate the person, i.e. he resorted to the normative masculine imagery of being tall, strong, and dominating.

An important grounded theory study by Charmaz (1995) incorporated Connell's (1995; 2005) perspective on masculinity in her explanation of how health crises create identity dilemmas for men. Charmaz said that a man's self concept is drawn from his activities and roles and, therefore, when deteriorated health encroaches upon the ability to continue with these activities or roles, his identity as a man is threatened. While raising self-doubt about his masculinity, illness can also shift his power relations with women and with other men, relegating him to marginalised masculinity status in Connell's gender order. The process of loss that men experience as they integrate chronic illness or disability into their masculine sense of self can be characterised as an ongoing dilemma. She identified four aspects of this dilemma:

1. Awakening to death: Radically modifying lifestyle for the benefit of his health *versus* retaining valued identities. Resolving this dilemma can become overwhelming when illness comes suddenly, challenging a man's masculine mastery

and competence, and thwarting his masculine problem solving. He can become depressed by a dramatic sequence of identity loss after diagnosis which accompanies activity and role loss, e.g. loss of employment, marriage, and the need to comply with a rigid treatment regimen. Despondency then makes preserving valued aspects of the self and seeing opportunities for new identities more difficult.

2. Accommodating to uncertainty: 'Bracketing' the illness, *versus* defining his relationship to the illness. A man may compartmentalise the illness separately from the main flow of his life, conceptualising it as a crisis event (i.e. minimising or denying its permanence or significance) so as to avoid having to confront change and accommodate his behaviours and masculine self-image to it. If and when a man acknowledged that his uncertain health status is lasting, an ongoing process of defining illness, and his relationship to it, begins. If his view of his masculine identities is inflexible, he may cling to the bracketing strategy longer, and when it can no longer be sustained, he may become despondent.
3. Defining illness and disability: Characterising the illness in position to the self. Illness was characterised as an enemy; an ally; an intrusive presence; and/or an opportunity. These characterisations both reflect and shape how a man knows himself, can raise or resolve identity dilemmas, and guide responses. He can hold several characterisations of the illness at once or over time, depending on how aspects of the illness and its treatment are perceived to be affecting his identities. He musters resources to fight an 'enemy' illness or disability, as it threatens his identity; he embraces the 'ally' illness into his identity, perceiving the advantage it gives him in the long term (e.g. help with life priorities, or health promoting behaviours); he resents how the 'intrusive presence' illness stigmatises him and alienates him from the identities he had; and he appreciates the space for reflection opened by the 'opportunity' illness, reappraising productivity, achievement, and relationships, and possibly altering behaviours.
4. Preserving self: Maintaining a sense of coherence while experiencing loss and change. Preservation of qualities and identities valued as central to a man's self concept is achieved by limiting encroachments by illness and intensifying control

over both the illness and his life generally to minimise the visibility and intrusiveness of the illness or disability. Before this is learned, men may assume that they will recapture their past self and then lapse into invalidism or despondency when unable to do so, yearning for the past.

Charmaz (1995) also found specific points of dilemma at oppositions of: active *versus* passive stance; independence *versus* dependence; autonomy *versus* loss of control; public persona *versus* private self; and domination *versus* subordination. For example, a man has to weigh up whether he should exercise hard and continue to hold a private and public identity as an active athlete, or lose this valued masculine identity and play it safe by becoming a passive patient. She also found men were more likely to characterise illness as intrusive or an enemy than women, with a need to control it. In particular, she noted that men attempt to control the visibility of disability in public so as to try to avoid reduction in stature in the hierarchy of men, displaying a greater stake in preserving self/public identities than women.

All of these aspects of the dilemma again demonstrate how traditional masculine norms and roles render masculine self concept problematic when confronted with ill health. There is a fundamental misfit between the 'strength and independence' of manliness and the 'weakness and dependence' of illness which pervades the complexities and which must be balanced, negotiated, circumvented, or otherwise managed strategically to minimise damage to a man's masculine identity, self-esteem, and status.

However, the sharpness of this fundamental problem may be softened when a man has the support of a wife. Charmaz (1995) found that a married man's masculine identity could be affirmed as he noted how his wife was constantly attentive and supportive. Although physically dependent, this care affirmed his position in the household as it demonstrated the wife's role as helpmate or caregiver. This identity support was not available to single men, for whom dependency and loss of identity were accelerated. This slide could result in despondency, and suicide could be perceived as a means of resolving a man's identity dilemmas. Consistent with these findings, Gordon (1995) also found that the unwavering support and sexual interest of a wife was very important in minimising the impact of testicular cancer on a patient's sense of manliness.

Another way to manage loss of masculine identity and maintain positivity identified by Charmaz (1995) was by perceiving opportunities to take action to create new valued masculinities. This requires a flexibility that not all men have. Echoing Connell (1995), Charmaz asserts that, "When sexual performance forms the foundation of their conception of masculinity, impotency undermines their identities as men. Preserving a past identity becomes particularly problematic when the basis for that identity is lost" (p. 281). Loss of traditional breadwinner status may also go to the core of a man's self image. Rigidity in clinging to particular expressions of masculine identity is thus of critical disadvantage to rebuilding masculine identities in the presence of chronic illness. Charmaz found that if a man was unable to grieve and accept lost aspects of his identity, he may become depressed or rebellious against treatment regimes, to the detriment of his health. Openness to grieving and flexibility towards creating new masculinities are therefore vital skills for adjustment.

There is also a process of adjusting masculine identities that must be undertaken. In relation to testicular cancer patients, Gordon's (1995) research revealed a process with three stages (though they often chronologically overlapped):

1. A short initial phase involving intense fear of death, disfigurement, and suffering.
2. A phase of working through the meaning of the experience, beginning once a man knew he had good chance of survival. A man might reassess his priorities and draw on cultural meanings and social practices to reaffirm his masculine identity, eventually maintaining or strengthening that identity despite physical loss. Many aspects of Gordon's findings in this regard coincided with those of Charmaz (1995).
3. Arrival at a set of meanings that made sense of the experience, with identity issues settled.

A process of initial preoccupation with life threat, followed by confronting the threat to masculinity using various strategies, and then finally resolving that threat is thus identified. However, in Gordon's (1995) sample it appeared that the ability to return to normal sexual functioning was important in resolving concerns about masculinity which were felt initially as a result of the temporary effects of treatment. For sufferers of other

cancers, returning to normal functioning is often not possible, despite the availability to some of technology to assist (e.g. injection, vacuum pump or implant to enable erection for radical prostatectomy patients) so the adjustment required is greater. On the other hand, testicular cancer afflicts younger men, whereas most cancer afflicts older men, many of whom may expect significant loss of functioning as part of normal age-related life changes. Thus older men may be making identity adjustments and accepting a degree of lost masculine status regardless of their illness, so the illness itself may have less potential to create crisis.

The research described above illustrates the complexity of integrating chronic illness or disability into masculine identity. Processes involving both grief and making meaning have to occur, and both masculine cultures pertinent to an individual man, and other circumstances concerning the illness and coping resources available to him, will be relevant to how the process is navigated. Accordingly, much variation can be expected in whether and how individuals ultimately achieve integration.

Positive potentiality of masculinity on health

The literature that I have been reviewing throughout these introductory chapters consistently indicates that it is problematic to 'mix' masculinity and health. However, as noted earlier, it is important to resist becoming trapped in deficit thinking. Courtenay (2003) asserts that it is men who adopt more traditional stereotypic beliefs about masculinity who are at worst risk, since these beliefs are more strongly associated with risky behaviour, physiological and psychological signs of stress, and with maladaptive means of coping. Rigid adherence to traditional norms or adherence to 'negative' masculine characteristics are alleged to be the real factor associated with poorer health by other researchers also (Hammer & Good, 2010; Helgeson, 1995; Helgeson & Lepore, 1997). In the context of cancer, Hoyt (2009) found that masculine gender role strain predicted distress in men with various cancers. Hoyt and colleagues (Hoyt, Stanton, Irwin, & Thomas, 2013) also found that it predicted decline in urinary, bowel and sexual functioning in men with prostate cancer. They posit that role strain likely shapes the emotional coping response, diminishing emotional self-efficacy and depriving men of the strategies that it could otherwise have facilitated (such as self care

and mobilising social support). Thus, again, it is more extreme and rigid masculine beliefs that are indicated as problematic.

There are other masculine norms which directly promote health enhancing behaviour (such as maintaining physical fitness). Furthermore, the complexity and contradictions which characterise masculine norms potentiate the normalisation of other health behaviours, to the ends of preventing and treating both physical and mental illness, including intervening against cancer-related distress. For example, masculine identities rest on valued roles and images, including family provider, lover, employee, sportsman, rescuer and adventure-seeker. To fulfil such roles a man needs to be healthy, and the desire to fulfil them can motivate and/or legitimate health behaviours and help-seeking that would otherwise be shunned as counter to masculine norms (O'Brien, Hunt, & Hart, 2005). Fire-fighting is a valued service role carrying a masculine image. O'Brien et al. found that fire-fighters legitimised early help-seeking for medical issues in order to assure fitness for work. These men saw the discourse of endurance without help as 'old school', and recognised instead that their masculine identities rested on physical health and strength, which required seeking help promptly. However, O'Brien et al. also considered that the fire-fighters they spoke to had more freedom to deviate from the masculine norm of stoicism because of the secure masculine status of their occupation. These authors also found that maintaining or restoring sexual function was another highly valued masculine end which legitimated help-seeking. This study illustrates the opportunity afforded by the wide range of masculine norms and images to focus attention on those that are adaptive in a given health context to negate the negative health impact of others.

Particular masculine norms could also be harnessed to promote physical and mental health generally. While risk taking and independence contribute to health problems in men, these norms – together with coolness in the face of danger, decisiveness, teamwork and problem solving mentality, and the desire to recover from and 'fight' illness – also have potential to help men re-establish a life they find worthwhile after debilitating illness (Burke, 2002; Charmaz, 1995; Courtenay, 2003; Levant, 1992). And Helgeson (1995) has suggested that a desire for information and a problem-focussed coping style should make men amenable to educational interventions and to addressing unhelpful aspects of traditional norms and receiving emotional support. She notes that

men with strong masculine traits may especially benefit from information and emotional support since their masculine gender role leaves them with needs in these areas.

Intervention efforts will be limited in their acceptability by the range of behaviours that masculine norms are perceived to allow. Rigidity in conceptualising masculine behaviour can leave a man feeling that he has no options, and set the stage for depression as he sees his masculine status becoming marginalised (Charmaz, 1995). But a man can simultaneously enjoy the strengthening of some valued masculine identities while suffering the weakening of others as he adjusts to chronic illness, and may move between masculine identities, depending on the context and his own perceptions of what is valuable (Charmaz, 1995). The importance of social context on the expression of masculinity has also been noted in the context of Gender Role Strain Theory (Addis, Mansfield, & Syzdek, 2010).

In recent years, opportunities presented by aspects of traditional masculine norms, and aspects of less traditional ones, have been utilised increasingly to promote health behaviours in men. Whether through public health promotion campaigns, the way services are presented, or the way health issues are framed by professionals as they talk with men, there are opportunities to link masculinity with being proactive about and protective of health. Modern media offers the opportunity to change cultural images to an extent previously unknown, and recent campaigns by famously masculine men like All Blacks Sir John Kirwan and Buck Shelford are beginning to take advantage of this. Sir John is sensitive to men's need to avoid weakness by normalising depression with his slogan, "Its not a weakness, its just an illness" (Ministry of Health, 2009), and Buck Shelford utilises the traditional male relationship with automobiles to promote heart and diabetes checks by sporting a tee-shirt emblazoned with an eight cylinder engine made to look like a heart and the slogan, "Checked your engine?" (Health Promotion Agency, 2013). CSNZ has also recently begun a major campaign promoting men's health called "Get the tools", which includes a prize winning website (<http://www.gethetools.org.nz>) applying the mechanical metaphor to body parts and utilising 'blokey humour' and video stories presented by male survivors. When combined with structuring health service delivery to better meet male needs, real progress should be possible. The inequity of men's physical and mental suffering cries out for research and action at many different levels.

The rationale for this research

In drawing a close to these introductory chapters, I return to my opening quotation:

"Men and women experience cancer differently" (Nicholas, 2000, p.27). It will now be appreciated that men experience cancer differently in both physical and psychological respects:

- Men suffer disproportional incidence and mortality from cancer
- Men may suffer a disproportional increase in depression incidence after being diagnosed with cancer, but their despondency may be concealed or expressed in ways that are not recognised
- Men may cope with cancer-related distress in ways that are maladaptive, and they may lack adequate social support
- Men can enjoy substantial beneficial effect from psychosocial interventions designed for cancer patients, but...
- Men tend to underutilise the services that deliver such interventions, and...
- These inequities are likely compounded for men who are poorer, less educated, single or non-Pākehā
- These inequities have been largely overlooked or misattributed by the medical fraternity, researchers and policy makers.

To begin to address the disadvantage that men have in dealing with cancer-related distress, it is necessary to understand their experience of that distress, and to locate their strengths in coping with it. The services currently provided appear to be failing to connect with men, and this may be because services are unattractive to them or because they do not fit with men's knowledge or lifestyles. It is necessary therefore to better understand men's cancer-related distress and their strengths in coping so that interventions that meet their needs can be designed and implemented. From this objective, my research questions are: How do men experience distress related to cancer? And, how do they cope with it? Flowing from the answers to these questions, in order to prompt discussion of the practical application of my findings amongst service providers, I want to envisage some practical interventions that will target men's distress drawing on their coping strengths. Throughout the exercise, I will seek to prefer the needs of men who are poorer, less educated, single or Māori.

5 METHODOLOGY

The method and results chapters are approached in chronological order. First I discuss the project's methodology, namely, participatory action research. Then I describe the method for the first phase of data collection and analysis – individual interviews and thematic analysis of their transcripts – followed by a detailed explication of findings, which are at this stage regarded as preliminary. Next comes the method for the second phase – team discussions to validate and critique preliminary findings – followed by the explication of findings from that, and integrated summaries of findings from both phases.

Approach: Participatory action research

The objectives of this research are qualitative in nature, requiring an exploration of the experience and needs of men with cancer. The exploration should inform the drafting of low level theory of local relevance, which can then be used to make practical suggestions for new or improved psycho-social interventions for men with cancer. Both the theory and these suggestions are end points of this research. The emphasis is thus on practical context and direct contribution to change in that context, rather than on contribution to high level literature which is distant from the site of action (Gergen, 2009), although explanatory theory is still necessary towards suggesting effective change to current services.

A practical approach to research of this nature was described by Kurt Lewin (1946), and called 'action research'. Lewin proposed that theory could be generated from a particular practical context, used to inform the design and implementation of interventions for change, and then those interventions could be tested in an ongoing cycle of development until those involved in the research are satisfied with the outcomes being achieved (Seymour-Rolls & Hughes, 2000). The cycle is illustrated in Figure 5-1, below. It begins with data gathering, from which an explanation ('theory') is formed as to how the phenomenon of interest works. From that an intervention to change the phenomenon is planned, and then it is trialled. Data is collected from this trial, which allows reflection on the aspects of the intervention that were successful and those which were not, refinement of the theory, and the modification and re-trialling of the intervention and so the cycle goes on until participants are satisfied.

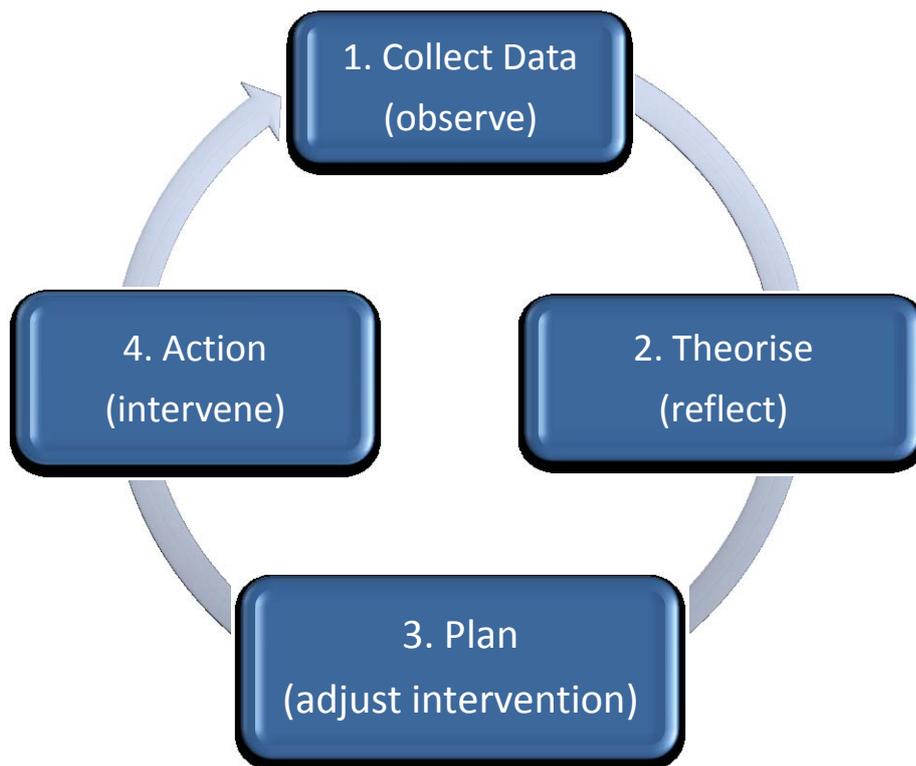


Figure 5-1. Action research cycle

The product of action research is thus both practical and theoretical knowledge (McNiff & Whitehead, 2006). The product is also inherently acceptable in the applied context, since those who will be affected are involved in its development. The flexibility of the approach towards methods of analysis, together with its practical product and this inherent acceptability, advantage it relative to other qualitative methods when the object is to effect change in an applied context, as is my object. It is often therefore used in educational contexts, for example. Vaccarino, Comrie, Murray, and Sligo (2007) used it to develop a programme to engage parents in reading to and with their new entrant children at a very low socio-economic status school in Castlecliff, Whanganui. They advocate action research as an excellent approach when the objective is to understand the circumstances and contexts of an issue better and discover what changes can be made to improve a situation. The knowledge produced is emergent from the local context, and data gathering and evaluation are aimed at achieving practical objectives rather than providing evidence for a theoretical or outcome hypothesis. However, theory, albeit at the local level, remains the underpinning enabler of those objectives. As Lewin famously put it, "there is nothing so practical as good theory" (1951, p.169; Friedman & Rogers, 2009).

Ideally, more than one cycle of planning-action-observation-reflection is conducted. But engagement in full and repeated cycles of action research requires considerable time and resource commitment by researchers and participants, and this is often not practical. Beneficial outcomes can still be advanced, however, from a partial application of the method. For the present project, which had limited funding and time available, only the first part of one cycle of inquiry was envisaged, namely, data gathering, theorising, and intervention conceptualisation.

Although better accepted now, action research has been accused of being too applied, and inferior in terms of the theory it produces. From the time of Lewin (1946), however, its adherents have argued that 'good theory' is an explanation of action and outcome that works sufficiently precisely to be useful in the field (Dick, Stringer, & Huxham, 2009; Friedman & Rogers, 2009). It is sensible that action is informed by theory, and theory by action, because theory – 'knowledge' or 'understanding' – is what links action and outcome. Theory informs action to make it effective, and explains the potential for change (Dick et al., 2009). Thus it is appropriate to build theory 'close to the action'. Dick, Stringer, and Huxham (2009) urge that, in a given study, phenomenological theory (i.e. that derived from the stakeholders involved) ought to have primacy over the more generalised and abstract theories drawn from the social and behavioural sciences. He cautions against the injection of big theoretical terms too early, saying that they can inhibit the development of theory well grounded in experience and expressed in common sense words. Participants should be allowed to work with the concepts that they understand well, and other perspectives should have to prove their relevance before being drawn in. This is the approach I have taken.

Collaboration

Values.

PAR is a methodology with 'democratic' values in a number of respects. First, it is inherently both discovery oriented and collaborative (Lewin, 1946), seeking to privilege the knowledge of the 'critical reference group' (CRG). The CRG is the 'stakeholder' in the 'social arena' whose interests the research seeks to serve, and whose understandings are often little known, and subjugated to those of other stakeholders (Genat, 2009). PAR advocates not only recognise participants' expertise deriving from their lived

experience, but also assert that participants are capable of critical thinking and of generating their own answers to research problems (McNiff & Whitehead, 2006).

The current research recognises that services available at present are not serving men as well as women, and assumes that this is because men have differing needs that are not sufficiently understood and accommodated. Men's expertise deriving from their lived experience must be sought out and used to reform service delivery. However, in reality, few members of the CRG relevant to the present study would have sufficient knowledge of the complexities of cancer medicine and modern hospital and social-service systems to generate answers to the inequality men suffer. Indeed, as discussed earlier, men's relative ignorance of such matters is part of the cause of this inequality. Therefore, as researcher, I had to take responsibility to lead formulation of suggestions for 'action'. However, I did this as deferentially as I could, carefully listening to men's expressed needs, formulating suggestions for intervention from these using my knowledge and experience of cancer services, and referring suggestions back to them for comment, amending the suggestions accordingly.

Second, PAR is 'democratic' in the sense that it commonly espouses values of social justice (McNiff & Whitehead, 2006). Accordingly, the present research seeks to address an inequality affecting men. PAR purists may assert that such research should spring from the CRG itself (Herr & Anderson, 2005), but this poses a dilemma where the cultural norms of the CRG result in its acceptance of its unequal status. As discussed earlier, our society generally – men included – seems to have accepted the inferior health status of men as 'the way things are', undermining the likelihood that a substantial movement of men will rise up to take collective action to improve their lot. This dilemma is analogous to that which can immobilise victims of racism who internalise the racist beliefs of society's institutions (Jones, 2000). It also poses a dilemma when the CRG is not organised or resourced to tackle or even identify a research problem. People at the margins of society may be the ones who most need the benefits that PAR can bring them, but by definition are not organised or resourced to initiate such work. Men may be in the same position but for the opposite reason: they have been socially dominant for so long that organising and fighting for themselves in the cause of a 'vulnerability' may not be in their repertoire (Dr Don Baken, pers.

comm.19 July 2013). In either situation it is necessary for research to be initiated from outside the CRG, but to work to elicit and understand the views of members within it.

The men who the present research most seeks to benefit have demographic characteristics of low income, low education, Māori ethnicity, or single relationship status, which place them at risk of marginalisation in terms of their ability to take full advantage of the systems and services available to limit or reduce their cancer-related distress. Unfortunately most of those demographic characteristics also disadvantage men from representing their own interests optimally or in an organised way. Indeed, judging from what participants in the present research told me, many of these men are not aware that helpful services, such as those offered by the Cancer Society, are available, and may also be unaware when they are receiving a service or medical communications of substandard quality. Again, the initiative and control in the present research therefore had to rest with me, as researcher, while I made every effort to privilege the voice of these men. I did this by ensuring that they were well represented in the interview sample and were selected for the team discussions that followed (as detailed in due course).

Finally, PAR is 'democratic' in the sense that it seeks to privilege the phenomenological knowledge of CRG members to at least the same level as that of the abstract theoretical and technical knowledge of the researcher and the level of the phenomenological and expert knowledge of other stakeholders in the social arena (Genat, 2009; Seymour-Rolls & Hughes, 2000). The CRG is recognised as the group whose lived experience forms the foundation of expertise for data collection and theory construction. The views of its representatives should therefore have critical influence in both the direction and conclusions of the research.

In the present research, the privileging of the CRG (particularly those with the vulnerable demographic characteristics mentioned) over both the researcher and other stakeholder groups was ensured by the emphasis on the participants' interview data and team discussions, which drove both the building of theory and the construction of suggestions for 'action'. Other stakeholder groups had no input into theory building (i.e. regarding men's distress and coping), and their opportunity to contribute to 'action' will

be secondary in the sense that it will be by way of refining intervention suggestions for implementation.

The role of stakeholders.

Ideally, PAR not only utilises the lived experience of participant researchers (PRs) drawn from the CRG, but also the expertise of other people involved in the social context, regarding what their experience of the context is, why that may be, what change is needed, and how that might work. Genat (2009) identifies these 'stakeholders' in the 'social arena' of the research as those identifiable parties who have an investment in particular understandings of the phenomenon in question, from whom data should be gathered to enable the theory that is constructed to be optimally informed.

Uhlmann (1995) argues that stakeholder involvement is important to affect 'real' change in the problematic situation which is the focus of the research. By real change, Uhlmann means change that is workable, equitable and which delivers sustainable outcomes. This is not only because 'two heads are better than one' but also because stakeholders are able to:

- identify the issues clearly
- bring to the discussion the history of what has been tried and what is culturally acceptable
- take action themselves and evaluate the suitability of solutions for their particular environment
- continue to use the knowledge and other product of the project once it is finished, having learned more about the issues and developed useful relationships and so being better equipped to further advance solutions

In other words, stakeholder involvement grounds the research in the nuanced social context where they operate, making the research more likely to be accurate and relevant, and therefore useful and 'owned' by all involved. Involving stakeholders is therefore a matter of both academic rigour and contextual respect and relevance.

For the present research, the social arena, including stakeholders and CRG, might be drawn as in Figure 5-2 below.

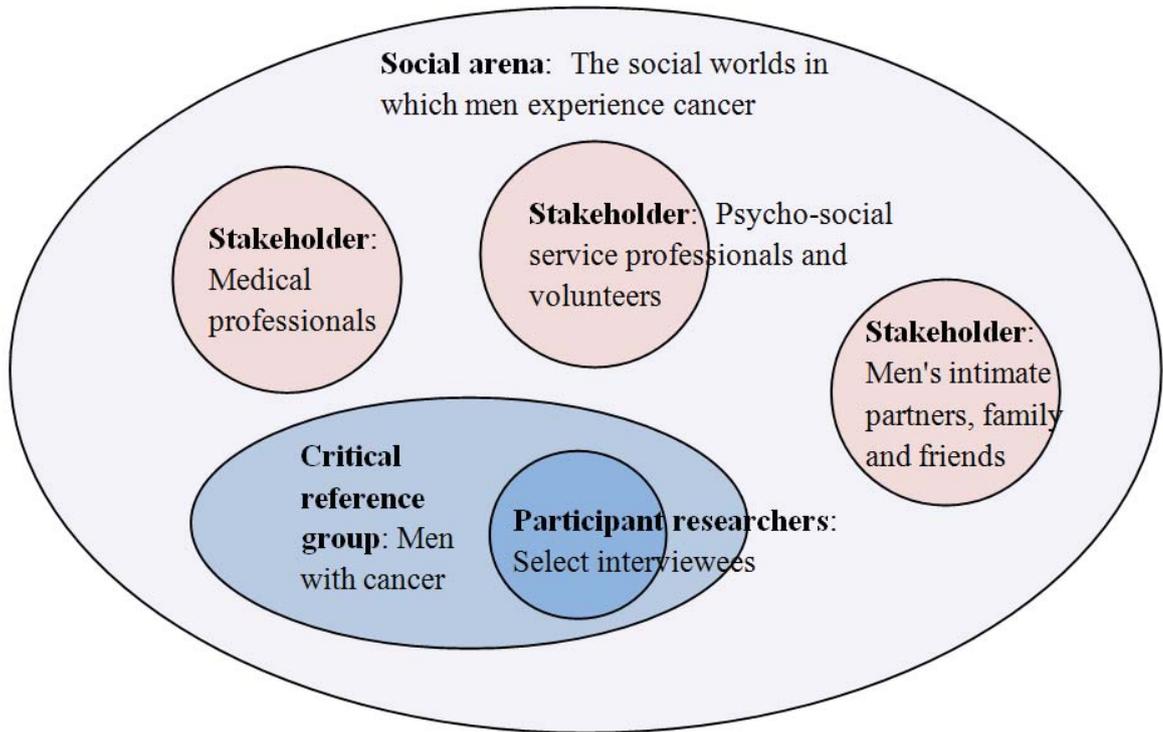


Figure 5-2. Diagram of social arena

The figure shows, in broad simplicity, the stakeholders who are relevant to the experience of men with cancer in New Zealand. There may be other social worlds that have relevance, such as men's work or cultural or spiritual contexts, but these would be much more important to some men than to others, and men's health is not their primary focus. The figure shows the CRG as men with cancer, and the PRs as a subset selected from that group. Other important stakeholders in the social arena are identified as men's intimate partners (i.e. mostly wives), family and friends, their medical professionals, and the professionals and volunteers who provide psycho-social services to them. Amongst the medical professionals there are general practitioners and practice nurses, cancer specialists (surgeons, medical and radiation oncologists, urologists) and specialist nurses, primary health organisation (PHO) community nurses, and hospice nurses (who also see patients living at home). Amongst the psycho-social service professionals are cancer psychologists and other psychologists and psychiatrists, social workers associated with hospitals (including those associated with Māori services, called *kaiāwhina*) and with community based service providers, such as *runanga* (Māori tribal organisations) and NGOs (non-governmental organisations) notably, the Cancer

Society of New Zealand (CSNZ). The latter two organisations provide, respectively, Māori Cancer Co-ordinators, who are field workers tasked with assisting Māori cancer patients to make best use of services, and CSNZ fieldworkers, base staff, telephone nurse advisors, and volunteers, who provide a range of practical resources and services (such as transport to treatment appointments, information on cancer and treatments) and programmes (such as men's and women's support groups, courses on adjusting to living with cancer) to assist cancer patients and their families. Straddling both the medical and psycho-social provider groups is the Central Cancer Network (CCN), which is a government funded body with the role of strategic coordination of cancer services in the regions from which participants in this study are drawn.

Comprehensive stakeholder participation in a PAR project requires a substantial investment from both the research team and the various stakeholders, and the resources and time for this are often not available. The present research is a small project and therefore focuses on the CRG, from which PRs are drawn, who provide interview data regarding distress and coping, assist with the refinement and authentication of theory built from that data, and assist with the development of intervention ideas arising out of that theory. As noted, one of the end points of the present project is the creation of a set of suggestions for intervention which can be handed over to the stakeholder groups who provide services and have the power to further develop and implement them. Whilst it would have been preferable to incorporate medical and psycho-social provider stakeholders in the development of the intervention suggestions in a formal and thorough way, a number of people from those groups have had input into the research from its inception, or periodically throughout, which has helped to ensure its relevance:

- Dr Don Baken is a clinical psychologist with the Cancer Psychology Service run by Massey University and the MidCentral DHB and was one of three supervisors of the research project, which he was involved with from inception;
- Mr Roger Twentyman was manager of CSNZ Central Division over the period that most of the research work was conducted, and had regular input in his role as a 'critical friend' (explained below);
- other representatives of CSNZ at national and local level contributed to the development of the research question and had the opportunity to comment on suggestions regarding CSNZ services;

- Dr John Waldon, is another of the research supervisors who was involved from inception, and has a background in research about Māori and cancer, is a life member of CSNZ, and is a member of the board of Cancer Control New Zealand, which is an independent body which provides advice to the Minister of Health.
- Ms Jo Anson, manager of the CCN, reviewed the draft list of intervention suggestions produced by this research. She then undertook to coordinate meetings of service providers to consider those suggestions, thus helping to carrying the research product forward towards 'action'.

The contributions of all of these people helped ensure the relevance of the research to service providers. Providers have the opportunity to refine and develop the intervention suggestions that they feel have potential, before implementing them. Hopefully some of that development work will be done in discussion with me and with other stakeholders, but my formal involvement, for the purposes of this thesis, concludes with presenting theoretical findings and the intervention suggestion list to them. I can only hope that the most important suggestions will be actioned, and that further research may trial their effectiveness, thus completing one action research cycle and preparing the way for further refinement of those interventions and for their transfer to other geographical regions and/or to the contexts of patients with other types of chronic and serious illness.

Research question development.

In the present case, the CRG – men with cancer – have no representative body to consult with, so the research questions were initially generated in consultation with people interested as psycho-social service providers, as mentioned above, together with myself, and my lead supervisor (Professor Christine Stephens, a health psychology academic). These parties discussed the purpose and approach of the research in several meetings during 2010.

Since PAR is an unfolding process and a collaborative effort, dependent on input from participants, the questions developed as the research progressed. The exploration of men's distress was addressed by means of a thematic analysis of in-depth interview data provided by participants. In the process of coding for this analysis, the means by which men coped with their distress, and the process of experiencing and resolving their distress, emerged as interesting and important understandings which could help inform 'the planning of action'. Findings, regarded as preliminary, were then put to small teams

of men, selected from the interview participants, for validation and adjustment, together with a number of ideas for intervention drawn directly from the interviews or generated from the preliminary findings. Adjustments to both the theoretical findings and the intervention suggestions arose from these team discussions. The method for each of the interview and team phases of the process is detailed in separate chapters below, each followed by its findings.

Rapport building.

Because PAR is a collaborative effort, the credibility of the researcher and her ability to build rapport with, and win co-operation from the other collaborators is critically important. Not only was rapport important to the quality of interview data, but also to the willingness of PRs to assist in the team discussions which followed. I was aware that rapport would be affected by all my interactions with PRs, including the information sheet used for recruitment, the interview questions, and my demeanour and personal background and characteristics. My objective was to enable men to feel as 'on the level' and 'safe' with me as possible, to give them confidence to share their deeper thoughts and experiences, providing a quality database from which to draw theory.

On the information sheet used for recruitment (Appendix 1), I briefly described myself, provided a photograph of myself with my dog, noted that I had experienced both breast cancer and depression, and provided a contact number for any questions. I also included a testimonial from a man who had provided a pilot interview with me and was able to recommend the research, saying that he found me easy to talk with and understanding.

It was clear in the interviews that the fact that I had experienced cancer and depression was important to a number of men, as they often acknowledged their respect for my experience and their confidence that I 'knew' what they had been through. A few participants showed interest in knowing more about my cancer, and I briefly summarised my disease status and treatment experience. This appeared to consolidate feelings of mutual respect and safety. Some men stated explicitly that they would not talk about their cancer with someone who had not personally 'been there'. With few exceptions, I gained the impression that men had expressed to me events and emotions that represented the substance of their experience. This impression was built from the explicit detail in which many explained the most distressing and personal side effects

they suffered (incontinence, sexual performance failure, and mental health issues) their direct statements that they had told me things that they had not told anyone else (including their wives), and their expressions of pleasure and gratitude at the end of the interview, saying that debriefing their experience in full had been valuable.

I think that my general demeanour around men would have helped establish a trusting and frank relationship. Throughout my life I have had male friends, particularly in the contexts of studying and practicing law, and farming and church life. I also have four brothers. I feel relaxed and natural with men and do not feel that I have to live up to any particular gendered standard. A 'professional friend' stance, as distinct from stereotypical female roles such as nurturing mother, relationship-managing mate, emasculating domineering female, or demure and sexy love object, is advocated by some women as the most productive one in working with male clients as therapist or 'coach' (Morse, 2012; Steigmeier, 2012). Although there is an element of 'nurturing' in the therapist's role, and as a researcher I strived to be a sympathetic listener and in that sense was 'nurturing' of participants, my aim while interviewing was to be transparent, 'on-the-level', and kind, as a trusted friend would be, in keeping with my lifelong experience of friendships with men.

Other personal characteristics of mine which appeared to help build confidence included my mature age and academic qualifications. In the context of an interview question asking what credentials they would prefer in a cancer counsellor or cancer psychologist, many men noted academic qualification plus 'life experience'. One man said that he would have asked me what my qualifications were had I not already noted them on the information sheet, and I am sure that my age helped provide safety around sexual issues.

My spirituality was also often helpful in building rapport. When I sensed that a man was approaching the topic of spiritual meaning with some hesitation, I was able to normalise the man's experience by disclosing that I also have Christian faith / spiritual experience. In the most extreme case, a Māori participant repeatedly stated his expectation that his spiritual experience would not be respected and would be deleted from the transcript of the recording of his interview, indicating that it had been disrespected in the past by mental health professionals. I provided him with repeated

reassurance, and he told of his series of divine interactions, repeating that he expected I would wipe this account from the recording. I told him that I did not find any of what he said incredible, being able to relate to his experiences myself, that such deep experiences were to be expected in the life-and-death context of cancer, and that his account was valuable and would not be wiped. I believe that this participant would have been willing to share this account with few researchers – Māori or Pākehā.

My rural upbringing and knowledge of small town life in the district where most participants lived (the Horowhenua) also seemed to help with rapport, making small talk over a cup of tea easy. My rural accent and contribution of home baking to our tea break may also have conveyed that I was 'down to earth', and helped overcome any initial intimidation that men with less education may have felt due to my occupation and academic qualifications. I withheld information regarding my legal background to minimise such intimidation.

I designed the order of my questions to help build men's confidence in the interviews, but also gave them the freedom to tell their story in their own way, regardless, to the same end. (Question content and order is discussed further under Interview procedure, below.)

Another factor that influenced participants' co-operation was their keenness to help other people. Almost all participants had this motivation for participating, perhaps coupled – in the case of many retired men – with a desire to feel useful.

The building of relationship with service provider organisations and their employees who assisted with recruitment is discussed under Recruiter support and approval, below. Clearly, the support of such providers is vital to the ultimate implementation of intervention suggestions arising from this research. One of the main psycho-social service providers is CSNZ, which was also a funder of this study. A number of people involved with the project had pre-existing relationships with CSNZ, including myself, and these have been enhanced by many interactions with national and local office staff since the research design stage.

So why PAR?

In sum, PAR methodology was chosen for its collaborative philosophy and practical action-level focus, as described above, which made it more appropriate to the objectives

of this research than other possible research approaches. Whether qualitative or quantitative by methodology, most other approaches are driven by the researcher, rather than by a collaboration including the CRG and stakeholders, and are directed at a distance from the site where change is desirable. The power of other approaches to bring about practical change is therefore indirect, and dependant upon uptake and application of theoretical findings by service providers or other (non-CRG) stakeholders who were not themselves party to the research and may not consider it relevant. Although in the present study resource limitations precluded the full engagement of such other stakeholders, the involvement they did have (described above) ensured that the project was relevant to them. The sensitivity of the present approach to direction from the CRG also ensures that the practical intervention suggestions arrived at are highly likely to be relevant and appropriate for men (from demographics to which findings can be expected to be transferable) if implemented. Most research approaches – in which the research questions and findings are developed at a distance from, and insensitively to, the views of the CRG – are therefore inappropriate when the ultimate object is to offer actionable suggestions for practical change. The disadvantages that men suffer in relation to health which have been elaborated above make clear the importance of an approach that will not reinforce a system that 'misses the mark' for them, but will be sensitive to their experience and preferences. Unlike other research approaches, action research – particularly PAR – is specifically designed to engage those who it is meant to benefit in its direction and the creation of its findings.

Ontology and epistemology

Because PAR privileges the views of participants, seeking understanding through their worldview, it inherently leans towards social constructionism in its ontological and epistemological philosophy. Social constructionism defines what counts as real, and how that reality is captured as 'knowledge', by the worldview and social/linguistic traditions of research participants (Gergen, 2009). However, within the PAR method there is a great range of researcher positions possible, in terms of the degree to which the process is orchestrated by a researcher whose identity and interests are distinct from the CRG. As noted, in the current research, because the CRG does not have a representative body and did not initiate this research, my position, as a researcher from 'outside', is more influential in the process than would be the case in much PAR: I have

initiated and designed the research and gathered the data, and while I try to hold the discovery process 'with a loose reign', I am aware that I have a great deal of influence in it. I know that I will be blind to some aspects of the worlds of the participants, that I am in a position to make more of some issues and 'findings' and less of others, and that it is predominantly my voice that will go to press in the end. (I remind myself and you, the reader, of this by often writing in the first person.) So what are my scientific philosophy and personal values?

My ontological and epistemological perspectives are inevitably coloured by my Christian faith. I adhere to Jesus' claim that He is "the truth" (John 14:6), which assumes that an objective reality exists before and apart from any discourse or interpretation of it. However, it is interesting that the Bible also describes Jesus as "the Word" who existed before all things, and through whom all things were made (John 1:1-3). Undoubtedly volumes have been written to explore the meaning of this seemingly cryptic statement, but one implication that I take from it is that reality and words are closely linked. I feel this is certainly the case in relation to social reality, being persuaded by Gergen (2009) – a leading advocate of social constructionism – that as soon as one puts 'reality' into words in order to think about it or express it, one employs a tradition laden with cultural assumptions drawn from human relationships located in particular time and space. The constructional bias that language brings to a discussion of reality is thus inescapable, and fundamentally shapes one's apprehension of it. Psycho-social 'reality' therefore looks very different through the spectacles of different cultural traditions and discourses, and if research is going to be helpful, it needs to appreciate the lived realities of the people it seeks to serve.

My research premises are also coloured by my orientation towards social justice. Like many New Zealanders, I espouse values of egalitarianism and self determination, which I see as a matter of professional, cultural, spiritual and personal respect. Such values may be termed 'democratic' in terms of power distribution and are characterised by the sympathetic listening stance which is appropriate to the method of this research. Social justice itself is broadly espoused by qualitative methodologies. My motivation for entering the legal profession – my original career – was originally in pursuit of this value, but I now feel that psychological research and practice are more effective avenues.

Social constructionism emphasises the utility of research, and an appreciation of complexity, leading towards the opening up of options for social change. The object is to create multiple means to ends rather than to discover a single objective truth, and contradictions are anticipated as normal (Gergen, 2009). The present research must take into account the worlds that men live in, in order that its conclusions may be relevant to, and of use in, serving the needs of men and lifting their position towards health equality. These worlds include the worlds of poor men, of uneducated men, and of Māori men, since, as Connell (2005) points out, masculinities are plural.

The trustworthiness of findings

Given my assumptions that although there is such a thing as reality, the ability to apprehend it is inherently subjective and infused with meaning particular to one's worldview, what authority can I speak with in presenting research conclusions? The themes that I 'find' in my analysis of participants' interview data are not objective findings at all, in the sense that seashells are 'found' on a beach by someone out walking. Notwithstanding the common talk of 'findings', or themes 'emerging' from interview transcripts, the research paradigm underlying social constructionism acknowledges that a researcher cannot passively collect and interpret what is 'out there', but must interact with participants and data to actively construct theory (Gergen, 2009; Guba & Lincoln, 1982; Smith, Jarman, & Osborn, 1999). The researcher's worldview, beliefs and values, personality, experience and academic knowledge will all interact with the research process – *I* choose where to focus attention and what to ignore, and what I identify in the data will derive from this interaction (Braun & Clarke, 2006; Genat, 2009; Guba & Lincoln, 1982; Smith et al., 1999).

Because it is thus not possible to make a truth claim about findings, the scientific trustworthiness, or 'validity', of the work will instead boil down to its plausibility in the eyes of stakeholders – especially the CRG – and other researchers in this field. Guba and Lincoln (1982) have set out four criteria by which the trustworthiness of research from this 'naturalistic' paradigm may be assessed. I address them now:

1. **Credibility:** Are the realities of participants represented and interpreted in a way that they find believable?

The means of assuring this were through keeping close to the interview data when developing theoretical findings, and reporting back to small teams of interview participants inviting their validation and critique of those findings. The involvement (as supervisors and critical friends) of other men who have stakeholder expertise provides further assurance, as does supportive literature.

2. Transferability: Is sufficient description of the sampling setting provided so that judgment can be made as to whether research products might be useful in other specific settings?

This is a matter of comprehensiveness and transparency in reporting sampling procedure, which the reader may judge from the detail provided in the Method chapters.

3. Dependability and confirmability (I group these two similar criteria together): Could the process used and interpretation offered by this research be seen as reasonable and fair for its purpose by peers? These criteria also require careful reflection on one's own epistemological assumptions, reasons for designing the study in the way chosen, and personal biases or prejudices relevant to the context and problem. These criteria require transparency, reflection, and the willingness to put oneself in the position of other researchers to test the reasonableness of the method and interpretative decisions, asking, 'Can these choices be reasonably justified?'

I have explained my choice of method (PAR) and my epistemological assumptions (broadly social constructionist) above.

Personal biases and prejudices are an ever present challenge in human research, especially those biases which are cultural or worldview assumptions. In the present study, my gender differed from that of the CRG, and my race from a number of the men in it, posing the likelihood that I would be blind to, or clash with, some of the participants' perspectives. Cultural assumptions are by definition invisible to the person who holds them, and, like other qualitative researchers, I found the reflexivity required

to bring them into awareness the most difficult challenge in the research. Indeed, I wonder if the challenge is impossible to meet without outside help: how can one 'see' the assumptions which form part of the very tool that one uses for 'vision'? Yet these assumptions are glaringly obvious to people with other worldviews! My approach has therefore been to listen carefully and respectfully for differences between my worldview and those of the participants, and to construct opportunities for peers to point out such differences. (I further discuss the ethical issues arising from my gender and race in the next chapter.)

The 'critical friends' group (McNiff & Whitehead, 2006) was created to facilitate the latter strategy, and generally to help ensure that the research was sensitive to masculine perspectives. As noted earlier, this group comprised three men: Dr Don Baken, Dr John Waldon, and Mr Roger Twentyman. Don and John were drawn from my supervision team and Roger from the local division of the funder (CSNZ); Don and Roger were working in psycho-social service provision for cancer patients, and John in psycho-social cancer research; John was additionally able to advise on Māori issues, being a Māori researcher and advisor to cancer-related organisations. I established this group at the beginning of the research and sought their comment before critical steps were taken: I met with them before deciding on research design, before deciding on the content of the interview schedule, before undertaking the interviews, and before finalising the report to CSNZ which provided summaries of data relevant to their health promotion and service provision work and made suggestions for improvement; when it was not possible for these men to meet with me prior to the commencement of team discussions, I wrote to them for advice and then discussed the matter over the phone with the one who offered substantive comment; and I sent them my draft theoretical findings (including those integrating findings into the masculinity literature) and draft intervention suggestions paper, inviting comment. These consultations gave rise to a few points of advice regarding gender sensitivity / masculine perspective, along with much useful general practical advice.

More importantly, I was always conscious that my critical friends were available to assist with my ongoing efforts at reflexivity. On one notable occasion, during analysis of interview data, I felt that I was losing respect for some of my participants as a

reaction to what appeared to be excessive and pompous posing and boasting in their interviews. A loss of sympathetic respect would obviously damage my ability to perform a credible analysis and work in collaboration with participants, and my annoyance also triggered awareness that a worldview issue might be at play, so I raised the matter with the group by email. Their feedback was most helpful, and included an important insight which restored my sympathetic stance by enabling me to reinterpret the previously irritating material as a response to the threat that illness and retirement pose to masculine status and self-worth. The insight was also consistent with a key analysis finding of an association between a strong emphasis on traditional masculine values and restricted emotional expression. The critical friends group had helped me better understand, at a 'lived' level, the pressures that masculine norms place men under, and the apparently dysfunctional behaviour that can result – an issue which is fundamental to the context of the research (as explained in the introductory chapters).

I also found the assistance of Dr John Waldon, from a Māori point of view, most helpful in challenging my cultural assumptions. John consistently spoke from a different perspective at every supervision or critical friends meeting, and I found this constantly challenging and refreshing. Indeed, it was after an initial meeting with John that the design of the research changed fundamentally, from quantitative to qualitative. This was a direct and substantial response to the challenge that John's different assumptions posed to my own.

Regarding the reasonableness and fairness of my design and interpretative choices, a detailed account of the decisions taken regarding both is provided in this thesis and its appendices, allowing the reader to make his or her own judgment. The coded anonymised transcripts could also be made available if scrutiny at that level was required. I also enjoyed the support of a very capable supervision team who were prepared to challenge any points of inadequacy in my work – and frequently did! During phases of the research when design decisions were being made, we met approximately monthly. During data collection and analysis we met less frequently but I was in contact with them by email and phone when required. I made frequent use of their ready availability. The nature and quality of the research design were also examined in proposal form and accepted by CSNZ (on behalf of Movember, who

provided funding for expenses) and the ethics body (refer Ethical issues, in the next chapter).

Finally, my interpretations and conclusions can be judged against the literature for sensibility. These checks against external reference points serve to provide a 'triangulating' check on the reasonableness of my conclusions.

A wide range of other tests of the validity of PAR and other qualitative work are suggested in the literature, but the ultimate test is whether the final products are useful in catalysing change in the field (Gergen, 2009; Herr & Anderson, 2005). This will not be known for certain at the end of the current project, but whether or not the work has the potential to do so should be apparent both from assessment against the criteria set out above, and from the interest of service providers who receive the intervention suggestions paper (Appendix 2) and presentation (Appendices 3 and 4) drafted for their discussion. Indication of this response is provided in the final chapter.

Researcher's position and background

Who I am – my culture, beliefs, values, socio-demographic characteristics and formative experiences – will inevitably contribute to the shaping of the process and products of this research (Minichiello, Aroni, & Hayes, 2008), as will my position and motivation in relation to the topic and the participants, so they need to be explained for readers to take into account.

I have noted above, in the context of rapport building, that I am female, Pākehā, originally practiced law, have experienced both breast cancer and depression, am spiritually aware with Christian faith, and was raised in the Horowhenua – the district from which most participants were drawn – on a farm, where I still reside. I note also that although I have had the privilege of a university education, I was the first from my line of family descent and from among my siblings to have this privilege (our family occupations were in small business, primary industry, and trades), my primary and secondary education were at state schools which drew the majority of their students from lower income families, and my personal friends have long been a mix of those with and without tertiary education.

I recognise that as an inheritor of family land, I am truly privileged. However, my attitude towards that land is not the typical commercial one associated with Pākehā. Our family's association with it is multigenerational extending back nearly 100 years, and my wish is that the land remain in the family for future generations. This long term view affects not only my management decisions, but also my investment in the community, which comprises both Māori whanau and a number of other Pākehā families with a similar heritage and attitude to my own. I feel that my position in relation to land and community is somewhere in between the typically understood Pākehā and Māori models.

In terms of 'life experience' – which participants in this research often stated was of paramount importance to them – I am one of six siblings, mother of three grown children, divorced, 51 years of age at time of writing, and have spent a good many years (between law and psychology) raising the children and providing care for my ailing mother, whilst dealing with my own health issues. And I have had various roles arising from my responsibilities towards my sister, who has severe intellectual disability, and my charitable and community involvements.

Thus, although as a woman I am an 'outsider' to the masculine worlds of all of the participants, and as a Pākehā I am an outsider to Te Ao Māori, in respect of other personal characteristics I have more experience and worldview in common with my participants than might be superficially apparent from my socio-demographic labels. I hope this positions me to have some effect as a bridge, representing the needs of people who bear labels of powerlessness to those who bear labels of power.

'Insider' status provides advantages and disadvantages in obtaining and interpreting interview data (Minichiello et al., 2008). An insider may have advantages in quickly building rapport and the insight to recognise and follow-up issues that an outsider might overlook. I feel that my experiences of cancer and of depression were invaluable in both these regards. An insider may also be more likely to challenge extant theory, will have a natural sense of urgency, and will have a better understanding of what is possible in practical terms for the ultimate application of research products. I feel that my personal experiences have equipped me with some of these advantages also. Whereas an outsider might bring a more open mind to data interpretation, he or she may alienate

participants by ignorance, and therefore not obtain such full data in the first place. Cancer treatment is a highly technical field, and it would be easy for a person who has neither medical knowledge nor direct experience to alienate participants by displaying their ignorance.

I feel that my 'insider position' as a cancer survivor powerfully advantaged this research beyond establishing credibility with participants, however. I feel my experience, including the loss of a breast, generated an atmosphere of respect, safety, and affinity which enabled many men to confide their vulnerability (e.g. the damage to their masculine self esteem, life satisfaction, and intimate relationship due to loss of sexual potency) and encouraged their cooperation. In interviews and team discussions, men often noted their respect for people who had 'been there and done that' with cancer, and if they asked for detail about my experience, they invariably expressed their respect upon hearing it. This formed a powerful affinity between us. One of the participants described other cancer patients as 'whānau' to him. All of the men who I telephoned to ask for help with the team discussion phase of the research were keen to assist, and I feel that the key factors in that willingness were their desire to help others and the sense of affinity and team purpose that had been forged between us during the interview phase.

From this it can be seen that my position towards the participants was a sympathetic alliance towards a cause. However, it was not entirely uncritical. Connell, Hearn, and Kimmel (2005) mention four possible researcher positions: nonproblematic (taking the views of participants at face value), sympathetic alliance, subversion, and ambivalence / critical standpoint. While I allied myself with participants, attempting to understand the challenges of their experience through their eyes, I was not satisfied to take all expressions of 'no distress' at face value, since traditional masculine norms constrain the expression of vulnerability. I brought to interviews an awareness of that dynamic from a prior reading of the literature on masculinity in the contexts of health and the expression of psychological distress. For example, my background in litigation law and my reading of interview technique informed me against asking 'leading' questions generally, but my awareness of masculine reluctance or inability to express vulnerability concerning sexual or emotional matters prompted me to put an important yes-or-no question in one case and to offer a range of alternatives as a standard approach in

another sensitive area. I brought the same literature-informed scepticism of participants' reports of 'no distress' to my analysis of the interview data also.

In terms of my values, I have already mentioned my spiritual orientation and my espousal of egalitarianism and respect for self determination. As for motivation, this research arose from the findings of my Masters' research. I noted that men with cancer are under-served in terms of gender-specific psycho-social intervention and research, yet were capable of deriving twice the beneficial effect from interventions targeting distress (Heron-Speirs, Baken, & Harvey, 2013; Heron, 2009). Read together, these facts suggested that research of the present nature could have significant utility.

In sum, while there are parts of my background that ally me with demographic characteristics of power, there are others that affiliate me with the powerless. My 'insider' positioning as a cancer and depression survivor, and as a middle aged person with life experience, gave me critically important advantages in eliciting cooperation and openness in both the interviews and the team discussions with participants. My motivation is to help move men towards health equality, and I come to the topic sympathetically predisposed to them but not naïve to the literatures on masculinity and cancer-related distress.

6 METHOD: INTERVIEW PHASE

Participants and procedure

This chapter first details the procedures and eligibility criteria for recruiting participants to the interview phase of the research, and the materials and procedures used in data collection (i.e. interviews). Ethical issues (relating to the whole project) are discussed next, and then the process of analysis (relating to the first phase), concluding with note on how findings are presented (again, relating to the whole project).

Recruitment

Although qualitative research differs ontologically, epistemologically, and in many practical respects from positivist quantitative research – including that it does not engage in sampling that is formally 'representative' – it remains important that the sample of participants reflects the socio-demographic features of the populations that conclusions are intended to transfer to so that data expresses the range of realities that these groups experience (Minichiello, Aroni, & Hayes, 2008). If the research aims to build, rather than test, theory, then a broader sample pool is appropriate (Minichiello et al., 2008). It is also necessary to take into account the resource limitations of the research project, together with ethical considerations regarding the strength and ability of particular participants to do the work of participation.

The present research aimed to build theory and to particularly benefit men from vulnerable demographic groups. Participant recruitment criteria and strategy were therefore designed to recruit a good number of men, and to ensure that those from vulnerable demographic groups were well represented – a sample that could be regarded as 'convenient but purposeful'.

It was anticipated that obtaining the participation of a sufficient number of men might be challenging, since men are often under-represented in psychological research, so it was appreciated that strategising and effort would be important to successfully recruiting the target sample size of 20 – 40 men. Further, eligibility criteria and recruitment method were designed to ensure that participants were from groups which are vulnerable when dealing with cancer: men from rural districts, and particularly men with lower income or education, and Māori men. This was achieved through the setting

of recruitment eligibility criteria, through obtaining the recruitment assistance of a large range of medical and psycho-social service professionals, and through communicating to them the importance of recruiting men from vulnerable groups.

Eligibility criteria.

Eligibility criteria for the first phase of the research (interviews) were designed to capture a cross-section of men with the relevant experience of cancer from four rural geographical regions characterised by poorer cancer and socio-economic statistics. It was also important that, on the one hand, participants had significant lived experience of cancer treatment, and, on the other, they were still in the process of adjusting to the issues and stresses posed by the disease and its treatment, i.e. that cancer was still a 'live issue' for them. Therefore, eligibility criteria for the first phase were:

- Adult (18 years and over) male diagnosed with cancer
- Domiciled in the Horowhenua, Otaki, Whanganui, or South Taranaki
- At one of the following stages of disease/treatment:
 - a) Through the most demanding phase of curative treatment (e.g. surgery and chemotherapy) but within six months of the completion of that phase,
OR
 - b) Diagnosed with prostate cancer and currently on a 'watchful waiting' protocol,
OR
 - c) Being treated palliatively or in ongoing care for recurrent illness (e.g. leukaemia or melanoma).
- Able to speak English sufficiently to explain his own thoughts and feelings
- Free from significant cognitive deficit (e.g. dementia, intellectual disability) or serious psychiatric disorder (e.g. active psychosis, severe depression)

The population (CRG) to be sampled was thus all male cancer patients in the specified regions for whom the disease was a live issue and who were capable of telling their story in English. It was not possible to include men who could not express themselves in English because of the ethical demands and costs associated with the use of

translators. Note also that men on 'watchful waiting' protocols were included because persistent worry arising from uncertainty around whether their cancer may be progressing and whether they have made the right treatment choice, together with urinary flow problems, can impact their social interactions and quality of life to the extent that affective distress may be at levels similar to those experienced by radical prostatectomy patients four years on (Bailey, Wallace, & Mishel, 2007; Joseph, Thibault, & Ruttle-King, 2006; Steineck et al., 2002).

Cancer and its treatment are each so various that drafting simple eligibility criteria appropriate to every case is not possible, and although men were turned away because they responded outside the six month guideline, the following participants were included since they fulfilled the spirit of the criteria, namely, that cancer and its treatment remained a live issue for them:

- A man who understood that he had been treated curatively for prostate cancer and had finished his radiation therapy more than six months earlier but was monitored monthly for side effects. This man had miscommunicated his current cancer status when discussing eligibility with me on the phone prior to the interview, but it was clear in the interview that aspects of his experience had been traumatic and anxiety provoking for him and that cancer was still very much a daily concern, which explained the miscommunication.
- A man who was unsure whether his treatment had been for cure or control, but had undergone a radical prostatectomy, the removal of his bladder, and extensive chemotherapy to treat prostate cancer, and was under three monthly surveillance. Although from what I could glean from the interview it seemed that this man's treatment probably had curative intent, and had been completed more than six months earlier, it was also clear that the traumatic effects of surgery and lack of information regarding the disease and services that he had suffered meant that he was still very much in the process of adjusting to 'the new normal' and cancer remained dominant in his daily life. The frequency of his surveillance also suggested a doubtful prognosis.

Procedure.

To address the possible reticence of men to participate in a psychology research interview, and particularly to overcome any reticence felt by Māori men or men with

less education, a more effortful recruitment strategy was required than simply mailing out invitations to participate. I also avoided recruiting directly through men's cancer support groups to ensure the sample included men who did not know of them or had chosen not to use them, and in case the groups attract only a limited range of men. Assistance with recruitment was elicited from a broad range of health and psycho-social service professionals, with whom it was assumed men would have established relationships of trust and respect which would lend credibility to the invitation to participate.

The professionals who assisted with recruitment are listed with their organisations below (Table 6-1). They include: specialist doctors and nurses at the Regional Cancer Treatment Service (RCTS) at Palmerston North Hospital where the great majority of participants were diagnosed and treated; specialist nurses at smaller local hospitals; and staff at community based services, including medical practices, hospices, PHOs, CSNZ, and Māori providers. Note that, unlike patients in the Horowhenua and Otaki regions, patients under the Taranaki and Whanganui DHBS were not served by a Māori cancer or chronic illness coordinator, despite the high proportions of Māori living in these districts. The assistance of other Māori service providers was sought as a substitute, but in the event these were not effective in obtaining recruits. Most recruits came through the RCTS, CSNZ, hospices, a general practitioner in South Taranaki, and the Māori Cancer Coordinator in the Horowhenua.

Recruiting professionals were asked to review their patient lists and offer a brief verbal introduction and an information sheet to eligible patients at a normal appointment, pointing out how I could be contacted using the free-phone number on the sheet. When men telephoned me, I checked their eligibility and their understanding of what would be required of them (as described on the information sheet) and arranged to meet them at a convenient private place for the interview. Six men were declined because they had not started treatment, or because they had completed it more than six months before. One was accepted but lived at considerable distance and by the time it was convenient for me to see him, he was no longer well enough for the interview.

Table 6-1. *Recruiters*

Region	Organisation	Staff involved
All regions	RCTS, Palmerston North Hospital, MidCentral DHB	Medical oncologists Radiation oncologists Urologist Specialist colorectal nurses Medical oncology dayward (chemotherapy) nurses Radiation therapists
	CSNZ, Central Districts Division	Field workers in all four regions
Horowhenua and Otaki	Palmerston North Hospital, MidCentral DHB	Urology nurses
	Horowhenua Health Centre, MidCentral DHB	Assessment, treatment and rehabilitation ward charge nurse
	Māori Health Unit, MidCentral DHB	Kaiāwhina (social workers)
	Arohanui Hospice Service Trust	Community palliative care coordinators
	Central PHO	Community cancer nurses
	Te Runanga o te Raukawa	Māori cancer co-ordinator
Whanganui	Ngati Rangī Community Health Centre Inc., Ohakune	Medical staff
	O Taihape Health Ltd	Medical staff
	Whanganui Hospital, Whanganui DHB	Oncology nurse specialist Urology clinical nurse specialist
	Hospice Whanganui	Community nurses
South Taranaki	Ngati Ruanui Tahua Trust, Hawera	Medical staff
	Taranaki Hospital, Taranaki DHB	Outpatient and treatment charge nurse
	Hawera Hospital, Māori Health Unit, Taranaki DHB	Māori Health Unit nurse, Māori Mental Health Unit nurse
	Patea Medical Trust	Medical staff
	Toiora Healthy Lifestyles Ltd	Health promotion worker
	Southcare Medical Practice, Hawera	Medical staff
	Hospice Taranaki	Community nurses

Interview procedure

Interviews were conducted in privacy, mostly in participants' own homes, and otherwise at CSNZ rooms. (In a few cases, a man's wife was within earshot for part of the interview and I was not able to pursue the issue of privacy further because it would have

caused significant inconvenience.) I commenced with some rapport building chat to establish a "productive interpersonal climate" (Minichiello et al., 2008, p.82). The photographs on display in men's homes and my farming and local backgrounds provided ready points of connection in many cases. I explained how we would progress through the topics of the interview, then asked the participant whether he had any questions, and reminded him of his rights and the safety provisions on the information sheet. I obtained written informed consent on a form which also noted what, if any, study feedback he desired, and a pseudonym to protect the privacy of the recording and transcript. I then switched on the recorders and began by filling out a biodata sheet.

Having completed the biodata, we progressed to the substantive interview, using an in-depth semi-structured format. This format was chosen to allow greatest flexibility for developing meaning, while staying within certain subject areas (Rice & Ezzy, 1999). The main topics I wanted to address were highlighted as 'purposes' on the interview schedule, while detailed questions were listed to assist me with approaching sensitive topics or as reminders of detail which might be relevant to some individuals.

The questions addressed the participant's experience and feelings in roughly chronological order: first his pre-cancer knowledge of the disease; then the processes of his diagnosis and treatment; concluding with his current feelings and thoughts about the overall meaning of the experience. I took time to explore any issues that seemed to cause discomfort. Included towards the end was the most sensitive question, which concerned the impact of cancer on the man's feelings of masculinity. Leaving that question until late in the interview allowed men to build their confidence and to have already explained relevant background material.

I encouraged each participant to digress from the order I suggested and tell his story in his own way if he wanted to, and most did. In such cases I allowed the participant to complete his narrative, asking him to expand on points along the way, and then returned to any questions relating to chronologically earlier material that had not been addressed. Often men provided a brief factual overview of their cancer diagnosis and treatment, which I used as a framework from which detail and emotional experience could be unpacked. I also used the word 'stress' rather than 'distress' in my questions as I felt that, although these words have similar everyday meaning, many men may feel

uncomfortable acknowledging 'distress', so the word 'stress' allowed us to approach the discussion of vulnerable emotion more safely.

This recursive and conversational approach allows a natural flow that gives participants greater control and reward in the interview (Minichiello et al., 2008; Rice & Ezzy, 1999) and which I felt built a foundation of confidence and respect which was more likely to elicit expressions of deeper personal meaning. A social constructivist approach recognises that meaning is built interactively between interviewer and interviewee, and that it is not appropriate to attempt to secure reliability, from a positivist perspective, by asking all the same questions in the same way at each interview, rigidly adhering to the schedule (Minichiello et al., 2008; Rice & Ezzy, 1999). In order to promote this natural style while retaining thoroughness, after a few interviews I reduced the main points that I needed to cover to a one page reminder list and only referred to the longer schedule occasionally, as needed.

The literature notes that it is important to 'leave the field' – to disengage from participants – in a way that is respectful and fulfils moral obligations to them. This both holds open the possibility of future interaction, and honours their contribution to the study (Minichiello et al., 2008), which are matters of particular importance to PAR. To this end, I concluded my questions on a high note, asking men if anything good had come from the experience or whether they had any other comment they would like to make. I had handed them a \$25 service station gift card by way of appreciation at the beginning of their interview, and thanked them again verbally at the end, following up with a 'thank-you' card a few days later, accompanying – for those who wanted it – a CD of their interview provided without cost. (CD postage was by registered mail.) I always took home baking or fruit (for diabetics) to the interviews for our refreshment break. I felt that all the interviews were warm and concluded on excellent terms. Often men expressed their appreciation of the experience, and I was often able to provide some useful resource or service contact information to men, as further described below. Most interviews lasted about two hours, including a refreshment break of about 15 minutes mid-way through.

Materials

Interview

The information sheet for the interview phase is presented as Appendix 1. The full interview schedule and the one page summary are presented as Appendices 5 and 6 respectively. The interview questions progress through the cancer experience – factual and emotional – chronologically, from pre-diagnosis, through diagnosis, treatment decision-making and experience, to post treatment and/or present experience. The biodata sheet is presented as Appendix 7. Biodata included socio-demographic, cancer and treatment characteristics, and any use of psycho-social services in the context of cancer.

I drafted the interview schedule taking into account literature relevant to psycho-oncology, masculinity, and interview process, and put it to representatives from CSNZ, my supervision team, and the critical friends group for adjustment. I then pilot tested the schedule and my interviewing style on School of Psychology kaumātua, Te Harawira Turoa Haronga, who is himself a cancer survivor, and two volunteers from the Palmerston North CSNZ men's cancer group.

Recorders

Two battery powered Olympus WS-450S digital voice recorders were used during both the interview and the team discussion phases.

Analysis software

The analysis software used was ATLAS.ti version 6.2.27 (1993-2013, ATLAS.ti Scientific Software Development GmbH, Berlin, www.atlasti.com). It provided for the efficient marking and collation of segments of interview transcript with codes which summarised their meaning, and offered tools which assisted in discovering and depicting associations between coded data.

Ethical issues

As a study with potentially vulnerable human participants, by a researcher who had different gender to all participants and different ethnicity to some, this research raised a number of ethical issues.

Gender and age disparity

I personally conducted all interviews and team discussions, and was aged 49 and 50 years respectively, at the time. Only one participant, aged 23, was younger than me, and many were more than 20 years my senior. The potential of 'culture gap' impacting data collection and analysis thus arises in relation to both age and gender.

New Zealand male researchers into men's health issues, Mitchell and Chapman (2001), comment (2001) that they do not have a problem with women researching the lives of men but they are astonished that there is often no critique or acknowledgement of the issues that consequently arise around possible loss of male voice. They cite Denzin and Lincoln (1994) for the caution that 'giving voice' to participants does not become a reconstruction of their reality in the voice of the researcher. As a woman researcher, with a woman lead supervisor, conducting research with and for men, I was acutely conscious of the priority of reflexivity regarding my gendered world view, and took the precautions described earlier, notably utilising the critique of men who were my supervisors and 'critical friends', referring preliminary findings back to participants for validation and critique, and reading scholarly literature on masculinity and the relationship dynamics between male clients and their male or female therapists.

In terms of eliciting quality interview data, which is a different issue, I believe that my position outside of the competitive dynamic which can present itself between men who espouse traditional masculine norms may have worked to my advantage for winning the cooperation and confidence of participants. As a woman in a helping profession, I would represent nurturing safety to men with traditional norms, and may therefore be more likely to hear the expression of their vulnerability. It may be that after overcoming initial fears of criticism by other men, a man may be more prepared to speak freely with another man about his inner thoughts regarding particularly masculine topics, such as sexuality and male role issues, feeling that only another man can truly relate to his journey (Rabinowitz, 2012). However, in the one-off-interview context, there is very limited opportunity to build sufficient confidence to overcome such

intimidation, so a female interviewer may be advantaged because of the safety associated with the feminine role of nurturance. In the event I believe that the men felt safe with me, as I was often surprised at how explicit they were about sensitive topics such as impairment to their sexual functioning and continence, and a number commented that they had told me things they had not told anyone else. I also note that when asked whether, in the event that they visited a counsellor, it would matter whether that person was male or female, all participants replied 'No', and most without hesitation.

I do not think the age disparity – a generation or less – posed a significant barrier to my understanding of the issues of importance to older participants. Being from a large family and with much exposure to older people, I have had a good deal of personal experience with communicating across this 'gap', such as it is. I also have confidence in the ability of older people, who have such a depth of life experience, to communicate across this gap. I believe that my life and cancer experience were more important matters which enabled relatedness and mutual respect.

Māori

The present project is not 'Māori research' as such, but since its objective is to promote equality for men, and particularly for men from socio-demographic groups who are least able to take full advantage of services, it was important to ensure significant Māori participation and sensitivity to cultural considerations. Such protection is also a requirement under the Treaty of Waitangi and the Health and Disability Ethics Committee rules.

Regarding cultural sensitivity, I was grateful to receive considerable assistance from Māori researcher and advisor Dr John Waldon (Ngai Tūhoe and Ngāti Kahungunu), who, as previously noted, joined the project at an early stage both as a supervisor and as a 'critical friend'. John provided influential advice regarding both the design of the research and many practical matters, and also introduced me to other Māori leaders who provided assistance in various capacities namely: School of Psychology kaumātua, Te Harawira Turoa Haronga, who assisted with piloting the interview, as mentioned; the kaumātua at MidCentral DHB in Palmerston North, to whom I explained the research;

and Te Aira Henderson from the Māori Health Unit at Palmerston North Hospital, who offered comment on my recruitment plans.

I focussed my best efforts on obtaining and communicating with recruiters who had access to Māori patients, in the hope of obtaining an over-representative proportion of Māori in the participant group. In the event, six of 27 participants were Māori, which was only slightly over-proportionate compared with Māori in the general population. Whilst this was a little disappointing, it still provided significant Māori input, particularly as three of these men were eligible for and willing to assist with the team discussion phase.

I also put particular effort into my communications with Māori men, aware of the cultural preference for personal communication and the poorer education and literacy levels amongst this demographic. For example, I spent more time explaining the research over the phone or in person, arranged the team meetings to be longer and to break over lunch so that we could share kai (food) and talk generally, and incorporated pictures into the powerpoint presentation as an aid for those with low literacy. I also designed intervention suggestions bearing in mind Māori cultural preference for personal communication, and limited literacy and low income (e.g. my DVD suggestion for conveying information about cancer and its treatment), and was pointed in asking the Māori team for their opinion about how culturally acceptable and useful such interventions might be. The Māori participants themselves repeatedly commented about health and psycho-social service professionals, that their concern was not 'about the colour of the skin' but simply that they be treated with openness, honesty, caring and respect. I felt that the Māori participants quickly connected with me, warmly and openly in the spirit of our joint venture to help others, and that I was able to provide tokens of reciprocity including the gift cards provided as part of the research protocol, by taking trouble to provide quality kai and to answer their questions relevant to their personal circumstances (e.g. how to obtain prostate screening for a son), and in other small ways.

Note that the project was, regrettably, not big enough to consider the perspectives and needs of men from ethnicities other than Māori and Pākehā.

Participant age and illness

Eligibility criteria recognised the agency of cancer patients who do not have significant cognitive disability, including those who were aged and terminally ill, to choose to participate. This accords with ethical requirements (Ministry of Health, 2006a) which entitle aged or terminally ill patients to the same opportunity to participate in research as others, and to weigh the personal costs and benefits of participation for themselves, recognising that the opportunity to contribute to the welfare of others may be valued. I facilitated such agency by presenting potential participants with clear written and verbal information about the research, and by supporting them during the interview by making provision for fatigue (checking whether they felt well enough for the interview before I left home on the day, and taking breaks during the interview)(Rice & Ezzy, 1999). I did not include any very ill participants in the team discussion phase because of the lack of flexibility that that context imposed, but arranged to visit the two educated men at their homes individually, in order to facilitate the involvement of one who had been ill. It was clear that some men, although terminally ill and physically weak, nonetheless highly valued the opportunity to participate in the research in order to help others.

Personal agency was also respected in allowing participants to decide for themselves whether they were strong enough to be interviewed whilst completing active treatment. Eligibility criteria required that participants had completed the most demanding phase of treatment, but sometimes an element of judgment was required to determine this, and in several cases I undertook an interview towards the end of a course of chemotherapy when a man had undergone more demanding treatment earlier and assured me that he felt well enough. (I did not interview men while they were still completing radiation therapy, conscious that the worst side effects might not be felt until the end of the course.)

Costs and benefits to participants

The interview and team discussion processes provided significant benefits to some men and a low risk of detriment. The risk of detriment was the possibility of causing distress through the raising of painful issues. However, potential participants were fully informed of the content of the interview in the information sheet, were told that free professional counselling would be provided through the Cancer Psychology Service or

CSNZ if needed, and, in the event, there was no indication from any participant that he found involvement distressing.

It was anticipated that participants would generally value and enjoy the opportunity to share their stories with a keenly interested researcher, and this was certainly borne out in both the explicit comments and body language of interview participants.

Involvement appeared to be particularly valued by those who lived alone or were fully retired. Several men expressed their thanks for how the interview had helped them process their cancer experience, and one, who knew himself to be depressed, said that he had volunteered to participate because he anticipated that talking through his whole cancer experience for the first time would be therapeutic for him – and that he felt it was. Nearly all men were motivated to participate by the desire to help other people.

The interview provided the opportunity to give participants information about useful services and resources to those with need of them. I found that men who had undergone radical prostatectomy were not aware of options to assist with sexual performance problems, either physical or psychological, and I was able to provide them with materials and contacts. I also recommended the Cancer Psychology Service to interviewees generally, correcting misunderstandings that some men had about the nature of psychological counselling. One man pursued this option after saying during the interview that he could not see himself ever using such services, and another expressed interest if I would personally introduce him to the psychologist, which I did. The interview also identified the extreme social isolation of one man despite his use of CSNZ services, and I was able to discuss some further ideas with him afterwards, notably the local Menz Shed, which interested him greatly. I provided details of CSNZ services, including men's group meetings, to a number of participants.

As described earlier, interviewees were all offered a CD of their interview, a summary of findings in due course (which has been posted out at time of writing), and a service station voucher after both interview and team discussion as an appreciation for their time. I urged men to accept the CD saying that family members may value being able to hear their voice in the future. Most accepted the offer, and I have since heard of two families of deceased participants for whom the CDs have been deeply valuable. On

balance, I feel that the research benefits to men and their families greatly outweighed any costs.

Researcher self care

It was anticipated that, as interviewer, I may need support with 'vicarious distress'. Dr Don Baken of the Cancer Psychology Service was available to debrief and advise me as required. In the event I experienced no significant distress, greatly enjoying most of the contact with participants. Both the literature and my own personal experiences of depression and cancer had prepared me well for the interviews.

HDEC Approval

Ethical approval was obtained from the Health and Disability Ethics Committee (HDEC), Central Region, reference CEN/10/12/153. The application is set out in Appendix 8, and details technical ethical issues not discussed above (such as provisions for the confidential storage of raw data). Participant informed consent was provided on the form in Appendix 9.

Recruiter support and approval

The HDEC required sign-off from each organisation ('locality') which employed staff who assisted with recruitment. The form used is reproduced as Appendix 10 ('locality assessment'). To obtain this sign-off and the cooperation of staff and management, I contacted most of them in person or by phone to explain the research and request support before emailing further detail to them.

While recruitment was underway, I sent periodic progress emails to all recruiters as well as acknowledgements to recruiters who directed potential participants through to me. I also reported to and thanked all recruiters when the data set was closed and when results were available. I also gave a number of presentations to the staff of recruiting organisations at their request (e.g. as part of a professional development day).

Participant feedback

Those participants (and men who had offered to participate but were found to be ineligible) who had indicated that they would like feedback were posted or emailed a

brief report of findings and dissemination progress. I will also be emailing a copy of this thesis to those who indicated interest.

Analysis

Interview transcription

Interview recordings were professionally transcribed and anonymised, removing all identifying names and other features (e.g. place names), and also the names of other people (e.g. doctors). Because transcripts were intended for thematic analysis, non-lexicon utterances were not transcribed in detail, but only where to do so was necessary to ensure the clarity of the meaning conveyed (e.g. a long pause or deep breath). I undertook the transcription of two interviews from scratch and reviewed the remaining drafts against the audio recordings at length to ensure that meaning was clearly represented.

Thematic analysis of interviews

Ideally in PAR, participants are engaged in reflecting on their own experience and building theory, using a method of analysis that is at once scientifically robust and simple enough to be understood by novices (Dick, Stringer, & Huxham, 2009). The researcher facilitates this, for example, by drawing out the assumptions in participants' understandings to make them explicit (Dick et al., 2009). Clearly, the extent to which participants can be involved in theory building will vary greatly from context to context, with the researcher having less substantive input and a more facilitative role where the CRG is more clearly represented by an organised, resourced, motivated and capable group of representatives. This may be so in work settings, for example, where representatives of employees of a particular service sector can be called upon, in paid time, to apply their personal and professional skills to theorising the problem at hand. The CRG for the present research – men with cancer – did not have such a group of representatives, so this project had to rely much more heavily on the data analysis and theorising of myself as researcher. 'Participation in analysis' in this context amounted to verifying, amending and adding themes to a tentatively presented analysis, rather than building it 'from scratch'. It remains appropriate that the analysis method is

understandable to participants however, and as a novice qualitative researcher, it was also important to me that the method was a simple one.

Thematic analysis is arguably the simplest qualitative method of data analysis available to psychology, at the foundation of many others. It is also robust and flexible in its capacity to serve the assumptions of different epistemological and ontological stand points, including those, like social constructionism, which acknowledge the actively interpretative role of the researcher (Braun & Clarke, 2006). In a nutshell, it is a systematic means of searching across a data set for patterns of meaning (Braun & Clarke, 2006). Because of its simplicity and its capacity to summarise the meanings in transcript data, it was ideal for analysing the interview data in the present research.

The analysis process is described by Braun and Clarke (2006) and by Boyatzis (1998), and essentially involves iterative readings of interview transcripts, identifying and labelling themes. Labels (codes) are defined and refined, and related to others in map-like form to clearly illustrate associations between themes. The process requires systematic thoroughness and consistency, and the explication of definitions and decision rationales.

In the present case, I did not approach the analysis with a set of theme codes to apply from the literature, but the codes I developed were nonetheless informed by my reading of it. This implies a deductive perspective: I did not approach the data with a blank canvas but with some idea of what I might see. However, I tried to comprehensively describe (code) every meaningful chunk of data in every transcript, whether I saw theoretical relevance in those meanings or not at the time, to allow unanticipated meanings to emerge inductively (as in grounded theory). Thus I tried to bring an open but informed mind to the data, exploring the whole shape of the data set before reaching conclusions about its themes. It is by this process that the metaphor of distress processing and the description of coping emerged, which were additional to the description of distress that I was seeking.

I began analysis by thoroughly familiarising myself with the interview data by reviewing the transcript in detail against the recording, and by listening to the recording many times (e.g. while out walking). This ensured that I could 'hear' the participant speaking while I coded the written data, which helped assure the accuracy of the

meaning coded. The analysis software allowed for detailed definitions of codes to be tagged to them, and for refinements to code definitions to be made relatively easily, checking back through previously coded data to ensure consistent application, which I did often. As new codes were added, I revisited transcripts which had been coded earlier and incorporated any that were applicable. At three points in the coding process, including the end, I revisited all transcripts in order to ensure that coding was as consistent as possible. I used coding frequency data and my knowledge of the content of each interview to assist me with this.

The level at which themes were identified is termed 'semantic' as opposed to 'latent' by Braun and Clarke (2006): I identified patterns of meaning at a relatively superficial level, in order to form a description of themes and to interpret their significance in light of the literature, rather than to identify assumptions and ideologies which may be deeply embedded in the data. This level of analysis suited the applied nature of my research objectives.

I found that theoretical links began to emerge quite naturally as coding progressed, due to the obvious frequent association of some codes with others (e.g. 'openly expressed fear or anxiety' with 'life threat recognised'). I often spent time 'playing' with the software, testing whether my thoughts regarding code associations were borne out. I also used the code co-occurrence tool to find and consider associations that I had not thought of, and the memo tool to record theoretical ideas as coding progressed. By these means I was able to group meaningfully associated codes and reduce these to broader themes.

Note on the presentation of findings

Finally, in the presentation of findings, please note the following conventions in the presentation of interview quotations: 'I' means interviewer, 'P' means participant, '()' signifies an encouraging but otherwise insignificant comment by the interviewer has been removed (e.g. 'Yeah', 'Right', 'Really?'), and '[.....]' means a chunk of transcript which is irrelevant to the point being made in my written text has been omitted. The participant's pseudonym and first line number (in parentheses) are cited for longer quotations. To take an example of this, 'Bert (27, 984, and back to 307)' means this is a quotation from Bert, the first chunk of the quotation starts at line 27 of the interview

transcript, the second starts at line 984, and the third starts back at line 307. These three chunks are separated by '[.....]' in the margin. Quotations from team discussions do not have line numbers because the discussions were not fully transcribed.

When I incorporate phrases said by participants in my text, I use double quotes when the phrase is reported verbatim, and single quotes when there has been some unimportant element of paraphrasing or altering of tense in order to fit the flow of the text. For example, I indicate that I am quoting verbatim when I write, 'Peter said his wife probably found his complaints "a little bit boring"', and that I am paraphrasing when I write, 'Peter thought his wife had probably been 'a little bored' by his complaints'.

7 FINDINGS: INTERVIEW PHASE

In this chapter I first describe the participant sample and then explore findings from the interview data collection and analysis phase, first focussing on men's experience of distress, and then on their means of coping.

Participant characteristics

Twenty-seven men were recruited for interviews, and seven of these went on to participate in team discussions, with a further two assisting as individuals. Biodata for the sample are presented below (Table 7-1), with those for Māori participants grouped in the middle section of the table, followed by those for the one young participant.

They are summarised as follows:

- **Age.** Except for one 23 year old, the men were aged 52 to 85, with 18 aged 65 years or older.
- **Cancer site/type.** Sixteen men had (primary) prostate cancer; three, lung; two, melanoma; two, parotid gland; one, acute myeloid leukaemia; one, bowel; one, renal cell; and one had breast cancer. Seven understood their cancer to be terminal, but there were a number more who, from what I could tell as a lay person from their treatment regime, also likely had dismal prognosis. Seven appeared to have locally contained cancers for which a full cure was expected. The remaining men were suffering some level of disease spread, from which prognosis was not clear to them and/or me.
- **Domicile.** Sixteen men lived in the Horowhenua region, two in Otaki, five in South Taranaki, and four in Whanganui.
- **Ethnicity.** There were six Māori men; 21 Pākehā; and none of any other ethnicity.
- **Marital status.** Fifteen men were married/partnered, the rest were single, widowed, divorced or separated, and all but four of those lived alone. Note that none of the six Māori men were married/partnered at time of interview and during cancer treatment, although one had a caregiver living with him.
- **Income.** Eleven men received less than \$20,000 gross annual household income (receiving little/no more than government superannuation/welfare benefit); four received \$20,000 - \$35,000; three, \$35,000 - \$50,000; two, \$50,000 - \$70,000; and

seven received more than \$70,000. Of the six Māori, five were in the lowest income bracket.

- **Occupation.** Most of the sample (15, including two Māori) were retired, and another four (including three Māori) were in receipt of government benefits (unemployment, sickness or invalid), leaving eight in work (including one Māori). The spread of main occupation (former, if retired) types were: 13 workers/labourers (including all six Māori), eight self employed businessmen/farmers (including one who was, before retirement, a manager), and seven managers/professionals.
- **Education.** Nearly half the sample had no more than a secondary level education: three had only primary level; ten, secondary; two had partial and four had completed trade certificates; three had partial and five had completed tertiary qualifications. The level of education of Māori men was lower, with none having received tertiary education, and two indicating that they had insufficient literacy to read the information sheet for this research.

A sense for how representative these proportions are of the demographics I was most interested to capture can be obtained by comparison with statistics regarding the total New Zealand population derived from the 2006 census (Statistics New Zealand, 2013): 22% of the sample were Māori, compared with 14.6% of the total New Zealand population in 2006, or 4.1% of the New Zealand population which was 65 years old or older; 70% of the sample were retired or beneficiaries and 40% were in the lowest income bracket of under \$20,000 per annum, compared with 43.2% in that income bracket in New Zealand (allowance should be made for rises in incomes between the census of 2006 and data collection in 2011, and for relationships between age or gender and income); 33.3% of the sample had an income of over \$50,000 per annum, compared with 18% for New Zealand (with the same allowances required); and 48% of the sample had no more than a secondary level education, and the same percentage had worker/labourer (former) occupations, compared with 25% of the total New Zealand population with 'no qualifications' (but less education should be allowed for as normal amongst an older cohort). Thus, although the sample was not recruited by formally 'representative' means, the aim of strongly representing men who were poorer, had low income and/or education, and were Māori, was achieved.

In terms of cancer type, prostate was overrepresented in this sample, at 59% compared with 30% of cancer registrations amongst men in New Zealand according to official statistics for 2009 (Ministry of Health, 2012a). However, given that this research targets the particular male experience of cancer, that overrepresentation may be considered advantageous. Twenty-six percent of the sample was aware that their prognosis was terminal, and the same proportion had been treated for cancers that were clearly contained and with good prognosis. The prognoses of the remaining half of the sample were unclear or uncertain. Again, this would seem to represent a fair spread of experience. Two thirds of the sample was aged 65 years or older, which indicates an appropriate age representation given that 57% of cancer registrations in New Zealand in 2009 were for people in that age group (Ministry of Health, 2012a).

Although not asked directly, it appeared most participants, if not all, were heterosexual (or bisexual): only two men appeared not to have had children, and only one of them did not mention any female intimate partner during his lifetime, while the other had been in a long marriage. One man who offered to participate seemed – from our lengthy telephone discussion of his circumstances – likely to be homosexual or bisexual, but he was ineligible to participate because he had not yet received treatment.

Two men – Mike and Eddy – had mild cognitive impairment following stroke which they were aware of and which manifested during their interviews in the form of occasional delay in recalling a word or historic detail. One other man – Lewis – also appeared to me to possibly suffer impairment, but if so, he did not have awareness of it. I noted excessive focus on irrelevant matters (e.g. repeatedly trying to find a medical letter) and Lewis could not remember one significant matter, namely, how he came to be diagnosed. However, in all the circumstances affecting him, including that his diagnosis had been some years earlier (he was a prostate patient on a 'watchful waiting') and that he had had many medical consultations due to another condition, I could not be sure of the significance of that. Whereas I had no reservation about the quality of the interviews provided by Mike and Eddy, I did wonder about Lewis's interview. However, Lewis was clearly capable of independent living, and he seemed able to answer most interview questions without difficulty, so I chose to use his data.

Table 7-1. *Participant biodata*

Pseudonym	Age	Cancer site/type	Domicile	Socio-economic status				
				Ethnicity	Marital status	Gross annual house-hold income	Predominant occupation type	Highest education
Jacko	63	Parotid gland (mt liver, lungs) ☹	H	P	Ma	H	B/F	Sec4
Hank	66	Prostate (mt bone) ☹	S	P	Ma	HH	B/F	Sec2
Carl	74	Melanoma (mt parotid gland)	H	P	A ¹	LL	(W/L) R	Sec4
Freddie	82	Lung ☹	S	P	A ²	LL	(B/F) R	Pr
Harry*	76	Prostate sp	H	P	Ma	M	(M/P) B/F	Tir
Eddy	74	Prostate	H	P	Ma	L	(M/P) R	Tir-
Mike	72	Prostate	H	P	Ma	HH	(B/F) R	TC
Brucie	55	Prostate sp ☹	H	P	Ma	HH	M/P	Tir
Rodney*	59	Prostate sp	W	P	Ma	LL	W/L U	Sec3
Peter	52	Renal Cell (mt media sternum) ☹	S	P	Ma	HH	M/P	Tir
Cameron	81	Melanoma and skin carcinoma (multiple) and historic bowel	S	P	Ma	L	(W/L) R	Sec3
Arthur*	68	Prostate	H	P	Ma	LL	(W/L) R	Pr
Roger*	74	Prostate sp	H	P	Ma	LL	(B/F) R	Sec2
Lewis	83	Prostate sp	H	P	A	LL	(B/F) R	TC
Roly	85	Lung ☹	H	P	A	L	(W/L) R	TC
Boxer	76	Prostate sp and historic skin carcinoma	O	P	Ma	HH	(M/P) R	Tir-

David	79	Prostate sp?	H	P	A	HH	(B/F) R	Tir-
Bert*	73	Prostate	H	P	Ma	M	(M/P) R	Tir
Charlie	70	Lung (mt liver) ☹	W	P	Ma	L	(M/P) R	Tir
Colin*	58	Breast	W	P	A	H	W/L	TC-
Paul*	56	Bowel	H	M	A ³	LL	W/L U	TC- ☹
Moko	71	Prostate sp	W	M	A	LL	(W/L) R	Sec2
Monty	75	Prostate sp ☹	O	M	A	LL	(W/L) R	TC
Buck*	65	Prostate sp	H	M	A	M	W/L	Sec3
Tama	59	Acute Myeloid Leukaemia ☹	H	M	A	LL	W/L U	Pr
Richard*	52	Prostate (mt bladder)	H	M	A	LL	W/L U	Sec1 ☹
Jake	23	Hodgkins Lymphoma	S	P	A ⁴	HH (his parents' income)	W/L	Sec5

Asterisk (*) denotes involvement in the second phase of the research

Cancer site/type: mt = metastasised to named organ, sp = spread beyond a local and readily treatable presentation, ☹ = participant understood his cancer to be terminal. Note that many participants did not clearly understand their disease status so conventional indicators of spread cannot be provided. Also, some of the status information marked 'sp' is inferred from what participants said, and it was likely that several more participants had dismal prognosis, unknown to them.

Domicile: H = Horowhenua; O = Otaki; S = South Taranaki; W = Whanganui

Marital status: Ma = Married (or partnered); A = Alone i.e. single, separated, divorced, widowed and living alone unless noted as follows: A¹ separated but wife moved in during treatment; A² living with daughter; A³ separated but female caregiver lived with him during treatment, and he was partnered by the time he participated in the second phase; A⁴ living with parents

Income: LL = benefit/government superannuation/<\$20,000; L = \$20,000 - \$35,000; M = \$35,000 - \$50,000; H = \$50,000 - \$70,000; HH = > \$70,000

Predominant occupation type: Parentheses denote former occupation; R = retired; U = unemployed or in receipt of government sickness/invalid benefit; W/L = employed worker (e.g. technician, office worker, sales representative) or labourer; B/F = self employed businessman (e.g. tradesperson, business owner) or farmer; M/P = manager or professional (e.g. teacher, lawyer, accountant)

Highest education: Pr = primary (years 1-8); Sec = secondary, with 1- 5 indicating number of years (e.g. S3 = 3 years at secondary school); Tir = tertiary (university diploma or degree, polytechnic professional certificate); TC = trade certificate (e.g. electrical, boiler making); A minus sign (-) denotes less than the full qualification or completion of a brief qualification (e.g. TC- = partial completion of trade certificate or an industrial certificate that is achieved after study of only a few months; Tir- = some papers towards a university degree); ☹ = limited literacy – unable to read the information sheet for this research in full

Ethnicity: P = Pākehā/New Zealander of European descent; M = Māori

Thematic analysis of interview data

Distress themes

In this section I first report the themes related to distress that I identified, followed by the process of the experience of distress and its resolution as expressed in metaphors provided by participants. The specific codes related to distress and their frequency of application are detailed in the appendices (Appendix 11).

Most men fell into one of two camps regarding the expression of distress: they either expressed the emotions they had experienced freely, or they reported not having been stressed by the cancer experience, or having experienced only initial shock upon diagnosis, some regret or degradation, or some minor stress or inconvenience in relation to diagnostic or treatment interventions. Men who were in the relatively non-expressive group thus did not openly report suffering anxiety or despondency in relation to the significant uncertainty and losses that were part of their cancer experience, and which formed the main body of the distress-reporting of the expressive men. Some of the men who reported little distress were ambiguous in their expression, however, using words or non-verbal cues which sent a mixed message about their feelings.

The feelings that were reported unambiguously fell largely into two groups: those which were about change and uncertainty, which highlighted a disturbing lack of control, and those involving a major loss or threat of a major loss. There was also reporting of feelings of degradation, anger and self-pity. I will discuss the expressed distress first, then the 'no distress' reporting and the ambiguous expression of distress.

Shock on diagnosis.

Shock on diagnosis was nearly always associated primarily with the recognition of life threat, and was commonly compounded by suddenness. Other circumstances associated with this shock were either specific to the individual and their health/cancer knowledge or family circumstances, or related to how the diagnosis unfolded and was delivered. For example, many men had an image of cancer as a "death sentence" and/or a history of death from cancer in the family, and some were ill-prepared for the diagnosis, having little health knowledge, no family history or other expectation of getting cancer. Others were told their diagnosis in a way that was blunt/matter-of-fact/truncated or even

misleading (dashing falsely raised hope). One man who described this shock was Bert (27, 984, and back to 307):

P: ...he just came out – I can remember him washing his hands – and saying, 'You have prostate cancer. It's locally advanced.' And ah, straight, you know, just like that. 'And I want to do radiotherapy and hormone treatment.' Bang! [.....] It was very blunt. My wife was with me () and, you know, it hit me like a steam train.

[.....] That when I was first told – I mean it was, just, just a huge shock: You know, the normal, blood draining from the, from the face; the, the almost shakiness of, 'My God!' You know: 'How can I have this?' () Um, I just didn't expect it.

[.....] So, you know, we looked at one another, and, ah... I was, ah, I was really shocked. I didn't know whether to cry, or, (little laugh) or, you know. And then I sort of () well, you know, let's go further right away, and, ah, see the extent () and find out exactly what it's all about. () That was, that was it. And we just gave one another a hug, and she said, 'We'll get through this.' () And that was reassuring.

Bert's story illustrates the role of unexpectedness in heightening shock, and also the significance of feeling that control has been lost. The latter is shown in the reassurance he gained when his wife said, "We'll get through this". The issue of control is an underlying aspect of most kinds of distress reported, and a more visible one in the types of distress that occur in the early stages of diagnosis and treatment.

Shock was also characteristically linked with uncertainty about the future, including uncertainty about what interventions would be available and how successful they might be. For example Jake (166) said:

P: But when they actually told us that that's what it was, then I was pretty, pretty shocked, and um.... yeah, sort of didn't really know what the, what the next step would be, really. () Cos I guess what I'd thought of as cancer, I'd just thought of it as basically a death sentence, really, and you just thought that it was, um, yeah, pretty drastic, so um.... You don't know whether it's, whether it's going to be able to be cured or not, at all, at that stage really. ()

Stress from uncertainty and waiting.

This form of distress was essentially worry about the outcome of tests or procedures, about experiencing a feared intervention, about the meaning of symptoms, or about the meaning of behavioural cues of key medical professionals (e.g. quick action, or a comment about treatment which implied poorer prognosis than previously understood). Distress was resolved when a man knew "one way or the other" what his disease status

was, and what "the plan" was to deal with it (Colin), or experienced the feared intervention and found it easier than expected. Of course, learning that prognosis was poor might resolve the distress of uncertainty but mean that shock and then further distress relating to life threat was experienced.

Bert said he found the distress due to uncertainty and waiting the hardest kind to cope with, as his desires to plan and take action were frustrated, while he was acutely aware that time was of the essence (752):

P: And that, I do find, probably the worst aspect of all the treatment – () is the delays, and not knowing. () You know. And I don't know if it's, if it's a [trait from his former occupation], but, you want a decision, and you want to get on with it, and do what you can. Because it's part of your research: You can't really take one step forward when you don't know whether you're going to have to go one step back because of some possible complication.

The essence of Bert's concern, and of the relief Colin felt when he gained certainty, can be seen as an aspect of a need for control. The need for control is presumably also behind the fact that all men said they wanted to know the truth about their condition, despite some also indicating anxiety at anticipating what their doctor might tell them.

Stress regarding interventions.

Minor stress was expressed by men from across the whole spectrum of expressivity concerning the inconvenience, discomfort, pain or fright associated with unpleasant diagnostic tests or treatment side-effects. Prostate and bone marrow biopsies came as a shock to several men who were not warned about what to expect ("When they fire it, it's like a blooming .22 going off! () You know, it's, it's a hell of a shock!": Lewis). And treatment side-effects (most commonly, wearing a catheter for a period before or after prostate surgery, a period of incontinence after radiation therapy, and prolonged fatigue) were commonly regarded as mere "nuisance value" (Roger) although there were men for whom they were very anxiety provoking because they had a particular fear of the intervention, or of any medical intervention. This anxiety generally resolved after experiencing that the intervention was not as bad as expected.

A disturbing lack of control.

Some men experienced a disturbing lack of control, which was associated with feelings of alarm, annoyance, alienation, resistance or resigned capitulation. This disturbance usually arose in the course of their treatment and out of not being given full information

or forewarning about the disease, procedures, treatments or side-effects, or not being fully included in decision making about treatment or after-care. For example, Richard expresses how he felt his body and living space were invaded while he was "a little bit left out" of decision making (1124):

P: I thought that was pretty invasive as well – that some person can just () take over your house, and your stuff, and... () I, I seen it from the other, wrong side, you know. () I, I was looking at the wrong side. I, I wasn't looking at 'People were here to help me', I saw that 'People are...'. But, ah, the treatment and, ah, the () surgery and everything was invasive, and now they're bringing their people into my house, and () grrr! I'm feeling a little bit left out! And pushed to the side! Mmm!! (tense growly tone of voice).

On a broader level, losing control of life, due to losing control of health, is ubiquitous to and inherent in all of the tensions posed by cancer. Taking control by accepting the disease and its implications and uncertainties therefore ironically involves an element of releasing control over domains that have been one's responsibility. This adjustment process is evident in how Peter accepted his diagnosis (207):

P: How did I feel, then...? (pause for thought) I have faith... well, I accept things as they are. () Um. I suppose I was more worried about [wife]... I mean, I've got kids and family and everything. I sort of thought, well, you know, () I thought I've got to get that... () perhaps not particularly under control, but I sort of thought I had a few more years to, ah, () to provide for them properly and... ()

A disturbing lack of control was also a significant element in feeling degraded or disregarded.

Feelings of degradation or disregard.

Men felt degradation arising from two sources: distasteful medical interventions or side-effects, and interactions with medical professionals or acquaintances, but most commonly and seriously with diagnosing doctors. Feelings of degradation were noted in relation to disturbance of normal continence, such as wearing a catheter, or having to cope with incontinence of bladder or bowel after radiation therapy. Several men reported that they would have felt humiliated due to 'accidents' had it not been for their wife's sensitive and ardent support. Boxer described incontinence as a "disturbing" experience. One man reported feeling traumatised and degraded by a procedure to remove the contents of his bowel through a tube put down his throat after his bowel twisted during surgery.

Although most men experienced sensitive care from medical professionals most of the time, when that care was not shown, the raw vulnerability of their position meant that carelessness could impact severely as degradation. The most impacting instances were in communications with doctors and resulted in the man feeling alienated and perhaps seeking advice elsewhere. These were instances of delivery with perceived coldness ("he's a cold stone fish": David), unfeeling matter-of-fact bluntness ("it was a pretty, pretty direct hit, I suppose": Boxer), or truncated dispatch, e.g. Brucie (172):

P: And, I mean, he just, well he did, did the ultrasound, did the digital, and he didn't actually say a thing. () Just sat me down and says, 'Yep, you've got cancer. () Next time we meet, we'll be in surgery'. [.....] And, and we walked away from there going, 'Cor, blimey!' Just sat in the car in the car park for a while just trying to digest it all, you know. (Pause)

...and Harry (27):

P: But um, no, it was quite strange. When I went up there and they told me I had it, it was um, a slot in between the specialist's procedures, and he said, 'You've got this cancer, and we'll have to start thinking about what to do about it', and 'Cheerio. Goodbye'. And I sort of wandered out and, um, the nurse came along and said 'Who's driving you home?' and I said, 'I drove myself over'. And 'Have you been given any booklets?' 'No. Nothing like that.' And she got some booklets to give me, and ah, and at that stage I, I was sort of wandering out of the hospital with a few pamphlets and, ah, 'You've got an aggressive prostate cancer.'

Two men also felt disrespected by specialists who summarily dismissed their treatment suggestions, and another felt repeatedly disregarded as his surgeon dismissed his questions without serious reply and offered little information and no opportunity to choose a life threatening treatment which would have been his strong preference over a conservative treatment that left him lingering in social isolation.

Although the great majority of men unreservedly lauded nurses and radiation therapists for how they made them feel at ease and cared for, there were two instances of disrespectful-sounding communication which caused alienation. Also, one man (59 years old) reported his disconcert at being told he had "old man's disease" by a former drinking friend. Another reported being "absolutely disgusted" and feeling as if he'd been "kicked in the guts" when government officials were not satisfied with his medical certificate as proof of illness when he applied for a benefit. He said the experience lowered his "morale".

Anger.

Anger was experienced as: a stage of processing news of terminal diagnosis, and could be associated with either self-pity ("its not fair", or "why the pain Lord?") or self-blame (for not insisting on a PSA test earlier; for wasting time earlier in his life; for smoking against the advice of others, or for not following up on prompts to have doctor's checks) or blame of others (the health system for lack of a prostate screening programme, or for delays in obtaining a diagnosis); a general expression of depression around loss, which was undergirded by frustration at loss of control over normal responsibilities, loss of sex life, or shortened life expectancy; or a response to unreasonable, disrespectful, careless, or degrading treatment (mostly communications, as described above) by medical professionals or others in official positions. Anger was reported by men who were generally non-expressive as well as those who were emotionally expressive, and in each case it was experienced as transitory.

Self pity.

Self-pity was regarded as an unacceptable emotion by most men, who emphasised the practical importance of staying positive, e.g. Jacko (166): "...you just can't walk around feeling sorry for yourself – you just gotta get on with it." However, six men did report feeling self-pity at some point, perhaps in relation to the 'fairness' of their disease status given their circumstances, or in relation to how unworthwhile they felt their life had become given its quality. When fairness was an aspect of self-pity, it was accompanied by anger. Brucie was only 54 when he was diagnosed with terminal prostate cancer a year before the interview. His cancer was identified after he had pressured his reluctant GP into allowing him to have a PSA test. On two previous occasions he had asked GP's for the test and had been declined (183):

I: What were the sort of issues you were most angry about?

P: Ahhh (slowly, thinking). Well, there's, it's, it's... you become very inward looking and its all quite selfish. Um. Um, I was angry that, that it's just not fair. () Um. Angry, in, on a whole bunch of people.

Anxiety or despondency at anticipated or actual loss.

Anxiety was generally related to the threat of loss, and despondency could set in when the loss was realised, if the man was unable to develop a strategy to sufficiently manage, mitigate, or compensate for the loss. I distinguish this kind of anxiety from shock, in that it is ongoing for an extended time, and associated with in-depth

contemplation or experiencing of the implications of a diagnosis, prognosis, or treatment, but clearly there is some overlap in the concepts. The losses most frequently and deeply expressed were about life threat, sexual function, and time with family, but other particular losses were acutely felt by those affected, notably loss of social connectedness/loneliness.

Loss of life.

The circumstance most commonly associated with anxiety, fear or shock was recognition of the life threat posed by cancer, and uncertainty about, or knowledge of, a serious or dismal prognosis. For example, Colin was suspicious he may have cancer from when he first noticed a lump under his arm. He became anxious, losing weight and not sleeping well, until after his surgery, when it was found that his breast cancer had not spread far, and the life threat was small.

The recognition of how serious the disease was did not always derive from formal medical advice, but could also arise through the man's own recognition of a potentially serious symptom, from the expression or tone used by a medical professional, or from the advice of a family member. Therefore it could come at a range of other times, before or after diagnosis. For Peter (52 years) it did not come until specifics emerged about life expectancy (207):

P: I talked to [oncologist] about it and he says that, um, 'renal cell cancer'. And I said, 'Well how long does that give me?' kind of thing. He said, 'Well, could be, could be – with the new drugs, we don't really know – it could be a few months or many months.' () And that's as... oh the first time it hit me that, 'Shoot! This is quite serious!' kind of thing. () Um, he said with... Yeah, traditionally would have been... he said, reas-, reasonably quick. And he said, 'But that's ok – its reasonably painless, dah dah dah, you just go to sleep.' (both laugh) Time loss. Yeah.

I: Yeah. Ok. So.... Ok, so yeah. Tell me how you took all of that. How did that, how did it...?

P: How did we take that? Hmm. That was a little bit of a bomb-shell I suppose.

For Harry it came at diagnosis (333):

I: So how, how are you, um, ... how are you feeling at this point?

P: Oh, Jesus! You know: 'Ok, so we've got cancer! Oh well, so that's, so that's.... so we've got cancer! Mmm!'

It is interesting that even among the men who reported throughout their interview that nothing in the cancer experience stressed them (other than, perhaps, the shock of diagnosis), there were usually ambiguous indications of anxiety regarding the death threat cancer posed, for example:

Roger told how he thought about death more than he ever did before, and on two occasions had experienced a hallucination of a hand rubbing his back while he sat on the sofa. He felt it was meant to be a comforting hand and associated it with thinking about dying, but wondered what these experiences were telling him.

Charlie reported only feeling shocked by the realisation of the grave seriousness of his condition and regret at having smoked, but otherwise never being stressed. However, after the interview he acknowledged being "anxious" about the future.

Cameron consistently reported not being stressed throughout his series of diagnoses and surgeries for melanoma, except when asked directly how he felt when his doctor expressed concern about a particularly large spot. He said he was "a bit scared then" because he could see that "something was odd" from the speed at which the doctor moved to get him into surgery. But he qualified this report with the rationalisation, "Well you had to be scared, I suppose".

Hank also reported not being stressed but when questioned pointedly about how he felt when he saw the widespread extent of his bone metastasis on a bone scan he stated that he was shocked, and his turn of phrase suggested that he had suffered lesser stresses before: "...nothing was really stressful but probably the biggest shock was looking at the bone scan results the other day...".

These examples demonstrate men avoiding openly confronting their distress about the life threat posed by their cancer. The very fact that they felt the need to avoid this, as well as the 'leakage' of their distress through ambiguous expression, suggests the paramount significance of life threat in causing cancer-related distress.

Loss of time with family and of family roles.

An aspect of life threat that was prominent for some men was the anticipated loss of time with family, including the opportunity to support the family financially or morally, continue in valued family roles, and the opportunity to enjoy time with family members. Peter (52 years) had been concerned that he would not have the time he expected to provide for his family "properly" and work off family debts. Colin (58 years) was concerned as to whether he would "be around" for his daughters (one still dependant) in another year or two. For Charlie, it was "a primary regret" that he would not "be around" for his recently adopted granddaughter due to the lung cancer he suffered as a result of smoking. For Buck, a Māori man who had little education, the impacting meaning of his diagnosis was that it raised the question, "Am I going to be there for them [the children and the grandchildren]?" He wanted to see the grandchildren grown up, and, in particular, one granddaughter (993):

I: ...what is it particularly about your kids that's most in your mind?

P: Ok. I'm not going to see the grandchildren grow up. I want to see them. () I want to see that ten year old, () yeah, get to varsity. Do the things she wants. () Like piano, she wants. () Ballet, she wants. () Yeah. () And get to varsity, which she wants () to happen. () All those things.

Bert said he had become irritable at his wife with the distress of his cancer. I asked why (864):

P: I think generally, overall... Um, again, I said 'everything's a two-edged sword', well, having a lovely family – it's six, four kids and six grandkids, () and they're all great – and so... Some... A friend of mine who died, who had nothing, he came back from Hawaii, he had no money, had no... nothing! And we used to go down and try and help him. The family disowned him and all sorts of things. Now he had no reason to live, and he died fairly quickly. () For me the two-edged sword is, 'Bugger!' – You know, I've had a great life... I'm not one of these, 'Why me?' people. () But I think, 'Hell. I don't want to leave it.'

So for Bert, it was simply enjoying the family that meant most to him, and the possibility of losing that was a great cause of stress. Others were stressed by concern that they could no longer, or in the future may not be able to, perform family roles (e.g. as sexual partner, as protective or providing husband, or as father or grandfather) and also for imposing burden on other family members.

Loss of bodily function.

Loss of bodily function, strength and energy were common concerns, but loss of normal sexual function and of continence posed particularly severe challenges and were the cause of considerable distress to some men. These losses affected a number of men and related to issues of masculinity, relationship, and lifestyle. Each aspect is discussed individually below.

Loss of general strength and energy was usually experienced only temporarily during and immediately after treatment, so any concerns were usually mitigated by the knowledge that strength would return. However, such physical changes also signalled the beginning of old age to some men, who had previously considered themselves very fit and able to keep up with younger men. This realisation was not pleasant but accepted as inevitable. For two men loss of motivation and energy was a significant and ongoing stressor long after treatment had finished. They chastised themselves for being "lazy", and neither recognised this as possibly a symptom of depression.

There were other physical losses and changes that had the potential to impact on personal and manly identity, and these are discussed below. Here I note only that they included blows to physical appearance or the ability to pursue valued aspects of lifestyle, or the transient experience of 'feminine traits' as a result of hormone treatment (hot flushes and emotional fragility), and that their emotional impact covered the full spectrum, from no impact at all (except, perhaps, as the source of jocularly) to extremely severe impact.

Sexual function.

The loss of normal sexual function was a cause of significant distress for five men, and implied a loss of masculinity, pleasure and satisfaction in life, and quality of intimate relationship. Nine men knowingly traded off their sexual performance in exchange for survival by accepting prostate cancer treatments that curtailed their ability to have an erection. For some, this was reported to be at little, if any, emotional cost. However, for five it was an expensive choice made as a rational necessity: Harry (696): "...you know, if the cancer's going to go and kill me it doesn't matter – the other thing's a non-issue anyway."

The distress caused by both anticipation and realisation of this loss could be most

severe. In Richard's case, sex was foundational to his intimate relationship, and recognition that his diagnosis was likely to lead to this loss was the main element in his initial shock. It also became a lasting serious stressor, because it did indeed 'kill' his intimate relationship and a most important source of personal pleasure (465 and 538):

P: My head was blown in the sense that, um – even though I didn't know nothing about it – but what they had sort of described on... what the surgery was going to involve, () um, my head... seemed... No sex! () She's all over! () It goes 'boom'! Um. () It just blew my head!

[.....] Because before that our relationship was great. () Mmm.

I: Ok. So what was it about that diagnosis, do you think, that threw a spanner in the works?

P: Um... well like I said before, sex. () Once, once sex was not in the mixture... and then the plan... well, () as a male, I thought well, well, 'That's it. She's all over.'

I: Yeah. You felt that? Or did she indicate that?

P: Well I did, mostly, because, um, () it, I, you can't get an erection. () Um. Um. There's a lot of things that she's tried to do to help, um () to get it happening, but, um () it wasn't happening, was just all over my head, because, ah...

I: Yeah. Yeah. And so I guess what I'm trying to work out here... is it, is it more like... she's unhappy with you, or you're unhappy with you? You know?

P: Probably I'm unhappy with me.

I: Mmm. So sort of more, sort of, you withdrawing from that situation?

P: Yes. Yeah. () And I know she does try to help to get things happening, but ah.... () Because it just stresses me out that I know that it's not going to happen, and I end up, oh, being nasty to her.

The disruption that the loss of sexual potency caused to Richard's intimate relationship led him to seriously consider suicide twice, and only thoughts of his mokopuna (grandchildren) caused him to choose life.

Harry and Rodney also felt miserable as they were unable to think of any way around the problem. Harry said that what with not being able to eat what he liked also (he needed to lose weight for his diabetes) he sometimes felt sorry for himself and wondered, "What's the point?". Rodney had lost motivation in general and described his loss of sexual expression as "hard". Only Brucie was actively exploring new ways to express affection to his wife, and referred to the process as "a huge change" but a

"challenge" of redefinition rather than an unmitigated loss.

Those most affected usually found their loss difficult to verbalise, presumably because of the depth of the pain and vulnerability they felt. They revealed their discomfort in mixed signals (see the examples of Rodney and Roger under Ambiguous expression of distress, below). However, Harry had the confidence to express himself clearly (533 and 862):

I: So why do you think that they don't... that other... that not everybody talks about [their health] as much?

P: Oh, I, I think, you know, I think that us males are fools and we think that we're bullet proof and um, can go flat tack every day, and can bang off anybody they see, and for hours on end, and anybody that can't is not with it. () Mmm. You know, if, if you're not in that league, you're a sissy or not worth dealing with. [.....] You walk into the () urology clinic and the prostate clinic, and you see the look on the faces, and the look in the eyes. And say, 'That poor bastard, he's not getting any sex, he's living a hell of a life'. () Maybe that's me with my sex hang-up. People tell me that I turn everything into sexual connotations, but () but you know, you just see it, the hurt in their eyes. () You... I know, these guys have come up now and say, 'I've been through this', I can go up to a group of people and look them over and say () 'I bet he's had prostate cancer, and he's had...'

I: Yeah. And what, what is the meaning of that hurt? What specifically is hurtful about it?

P: Ah, well...! () Well, anybody that can't fulfil themselves physically and that... and I mean possibly more sexually than anything else... feels that () they've got nothing to offer. () The world's got nothing for ya. And that's the feeling that you can get the moment you feel sorry for yourself. () 'What the hell? No, nothing here for me'.

[.....] Physically, I'm coming right again. But I still say without the sexual content, I, I, I, feel inadequate, cheated, or um... not a whole man. And, like I guess that would go for most males, wouldn't it? [.....] You know, you get to the stage where you don't even, don't even bother to make any moves or advances or anything, because it's going to be... oh, I dunno.... if it was accepted, whether you'd be able to do anything about it. And you, you're not prepared to go through the process and, and, and fall by the roadside and look a fool. () Because you're inadequate. () So you don't start. In case you look a fool or... are a fool. () I suppose it's the old story you know, a man's ego stands on whether he can get it up or not. (laughs) () Simple as that. If he can't, well, people say, 'Why should you worry, when you're 76?' And I say, 'Well, why not?' () Why not?! () So... I don't know.

For Harry, although part of the damage was his perception that he would be diminished

in the eyes of other men, it went deeper than that: his loss of potency went right to the core of his being, enjoyment, and purpose in life. Without it, he struggled to fend off depression. The issue interfered with his intimate relationship greatly, made him feel inadequate and foolish as a man, and left him irritable generally. Not able to think of a solution to the problem, he distracted himself at the end of the day by watching television. These examples illustrate four aspects of loss as a result of loss of sexual function: diminished sense of adequacy as a man, perception of diminished manliness in the eyes of others, frustration in how to conduct intimate relationship, and loss of purpose in life.

But, as mentioned, several men reported that they were able to accept loss of potency fairly comfortably, because they had different expectations and lowered libido due to age or hormone treatment, and therefore felt little cost. Invariably they enjoyed the full support of their wives, and they also reported the great enjoyment and satisfaction they had in their ongoing roles with their children and grandchildren. Unlike Harry, these men had an image of masculinity that saw sexual functioning as optional in old age, so the self-image adjustment was one of accepting being an older man rather than of accepting a lesser masculinity. Eddy (74 years) illustrates this relatively simple adjustment (999 and back to 683):

I: Have you, ummm, felt that this has impacted your manhood as such? As a husband or father or...?

P: Only, only, ahhh... No, I'm still a father, and my sons and my daughter have no hesitation in calling me 'Dad' () [laughs] and things related to that. () Its not just a word, its ahhh... (). The sexual thing I, I, it hasn't worried me an awful lot. Probably that's the hormone treatment () that's stopped me worrying about it (). Ummm, it would be nice if it comes back, but I don't think it would destroy me in my feelings as a man if it didn't (). I... its not a thing that ...yeah...I suppose its been important in your life... its always important in your life, isn't it?

I: Yeah. [Pause.] But its not defining of you?

P: No, it just... part, part of growing old I think, yeah.

[.....] [my children] treat me like they normally treat me () – like a silly old man! [both laugh] – and, and I've got grandchildren and I love them, and... () and coming up and having the grandchildren here is a lot of fun.

Buck (65 years) shows discomfort at my raising the question, assuming it is a question

about sex, but is determined to define his masculinity in terms of an age-appropriate role in his whānau (wider family) and in terms of growth in empathy for others (1820):

- I: We want to know how has the whole cancer thing left you feeling as a man? Like people find, some, some people find, oh, they feel like oh, less of a man, or some of them feel like, 'Oh,
- P: Yeah.
- I: actually, I'm more of a man'
- P: I've got you. I know where you are.
- I: or 'a different man'.
- P: I know where you are. You're talking about sexual activity.
- I: Could be.
- P: And...
- I: It could be sexual, but it could be other aspects too
- P: Could be.
- I: of feeling like a man.
- P: Yep. Sure.
- I: Yeah.
- P: Sure. I don't care! () I've lived my life. () My kids are grown up. () I've got great grandchildren. Now. That's me.
- I: Yeah. But there's other aspects
- P: But sure, there's other people – there's other aspects – of course. () Less than a man? No, I don't feel less of a man. () No.
- I: Yeah. Do you feel more of a man in some ways?
- P: I never thought I was much of a man before this!
- I: (laughs) Ok. Well, has it made you more of a man? Going through all of this.
- P: Ah. Yes, it has. () I'm going to say 'yeah'. () Because ah, because I've faced up to demons and I've, I've ah, taken a step outside into other people's world, and ah, and have, have more empathy to my plight and others like me. () And ah, and understand () their pains and stuff. () And not scared to say so () or, or to show empathy towards others, () yeah, and really put an arm out () towards, towards people that way. () Yeah. And that – if anything else () – is, ah, I've grown. () Right there. () No worries. () Mmm.

Buck recognises his personal growth in overcoming fears and learning deeper empathy

and ability to care for others as manly things. He is thus not only saying that his loss of sexual potency is not critical to manliness at his stage in life, but also that he has expanded his manliness by the personal growth he has experienced in these ways. Paul had a very similar view. He also was not willing to "let negativity play" but focussed on his grandchildren and his personal growth in gaining perspective on life and empathy for others. His treatment for bowel cancer meant he would permanently wear an ostomy bag, but it also saw an end to his lifelong tobacco, marijuana and alcohol use, so overall he felt his mana (prestige) as a man was being enhanced rather than detracted from (791):

P: ... I'm still the same man as I was before, and hopefully I'll continue on through life to be the same man. () I haven't lost any mana. () Yeah, we're actually gaining it. () Yeah.

I: So, how, how is it gaining mana for you, in your life?

P: Well, now I can... yeah, cos I'm looking at life in a different perspective now. () Hey, you know, I've been through the hard things. I've been... bloody smoked dope, and drunk piss () and all that stuff. But now, in the last 12 months I haven't touched any of it. So.... () And it's good – now I can feel healthier and... I used to smoke cigarettes – only when I were drinking – I don't even touch them now.

I: Yeah. So what's your... what would you say your perspective of life is now?

P: Well, hopefully it's, ah, I'm gonna... everlasting! But I know it'll, that'll never happen. But I hope I get another 20 years out of myself, anyway. () Just enough for me to see the grandkids hopefully playing [sport] or () representing New Zealand in some shape or form. () I hope I last that long, anyway.

I: Right. Right. Um, because [Paul] said during our morning tea break that he's got a couple of [children] playing, playing

P: Yeah

I: professional [sport]. So um, so your priorities in life now are what?

P: Ah, just to be able to live every day, um, to the fullest. And um, try and help... if I can help anyone else that's got cancer, come round and have a yack to me, eh? I'm pretty outward going, and... It's no use trying to hide behind it and under the sheets, is it? Just bring it out and I'm here to listen or do whatever. Because I've been through it, and I'm, I'm here to help. If I can help in any way, shape or form... Then I tell them the truth – I don't fucking mince or mix the words or anything, eh? And um, hopefully, that's what I can do, and that's... and just to live a nor-, a normal life.

For both of these Māori men any loss to masculinity felt as a result of their surgery was

overtaken by gains in insights and roles within and without their families which they saw as important and appropriate to their stage of life.

However, accepting the loss of sexual potency as merely a natural stage in a man's life was not an adjustment mechanism open to Harry because he saw no reason why his sexual expectations should change with age. For him, the loss of sexual potency meant being pushed towards a second class form of manhood which was unacceptable to him. He expressed this while describing the decline in status of another man he knew who had had treatment for prostate cancer (688): "...he went from a lecherous old bastard to an () impotent old fool".

Whilst making the rational choice to preserve life may have spared men one form of serious anxiety, the loss of normal sexual function caused considerable and ongoing distress for some, and triggered transition to old age and/or new roles for others.

Continence.

Loss of continence also posed a significant threat to masculinity and dignity as noted in relation to degradation, above. For most men, this side-effect did not last long and the emotional distress associated with any 'accidents' was kept to a minimum by the circumstances that they occurred at home and that their significance was played down by a strongly supportive wife. The inconvenience of having to stay at home until the problem resolved may have been the greater concern for these men. But Harry's experience of incontinence was prolonged and significant. He described various arrangements he had to make to ensure he was always handy to a toilet, which included having to let others into his confidence. And one day he suffered the nightmare scenario (758):

P: ...for a person, a mature person and that sort of thing, heading into old age and incontinence is a scary thought. () And you don't want to do it until you've got there. And you're trying to lead a normal life like a... oh, what, ten days ago, I was in [shop] and I was looking at some stuff to read up to see whether it was what I wanted. And the pads I'm using have got a liner on the inside with a slit in it. And I didn't have the, things in the right place. And suddenly, 'What the hell?' () All on the floor in [shop] beside the [indistinct]. I was telling some people the other night, and they're, 'Oh, God, what the...?!'

Harry did not dwell on the embarrassment of this accident, but was concerned about his long term prospects: becoming old and incontinent was "a scary thought". The social

discomfort with this type of problem is evident in the response of his listeners.

Loss of relationships and social life.

Several men withdrew socially to some extent due to symptoms of illness or side effects of treatment (e.g. shortness of breath, fatigue, difficulties in managing a urinary stoma bag), or because of feeling despondent (induced by hormone treatment, or related to health status). About half of them noted feelings of loss or frustration at this, while for others benefits of conserving mental or physical energy compensated.

Roly and Richard were both seriously affected by social isolation as a result of cancer. Roly (85 years) was unable to continue with his social sport or his daily social walk around the block because of his shortness of breath due to lung cancer. Having lost his wife a few years earlier and having no family, he was so desperate for company that he attended both the men's and women's Cancer Society support groups. Ironically, even there he did not feel free to talk about his cancer, which he was keen to do. He felt that people generally did not want to discuss it and he was not game to "poke his neck out" and risk getting "knocked back". He said that he undertook the research interview to meet this need to talk through his cancer. However, Roly attributed most of his loneliness to the loss of his wife rather than to the social constraints imposed on him by his cancer. Cancer just made his situation worse, and the depth of his distress was obvious (1071 and 1296):

P: ... [I] sometimes break down a bit. And ah, you can't help it. () They say, 'Think of the good times'. Yeah. () Makes it worse. () Yeah. () You're used to certain things, and doing things, () and, ah, and it's cut off. () Yeah. () Oh, I've, ah, you know, I often do that. And there's purely that you're lonely. () Yeah. () Yeah, all that you've learnt through life, and that, means nothing to you, because you, you've got no one to discuss it with. () Yeah.

[.....]

I: ...how does [the cancer] affect you? How you feel about yourself as a man?

P: No. No, it's just.... only the loneliness and that. It's not being able to talk to people () and things like that. () That's the thing that affects me, mostly.

I: Yeah. And that's not directly related to the cancer?

P: No. No. () See the wife and I were together for 50-, 59 years. () But it takes a lot of getting used to. () And that's what I'm sort of getting at, is the, um, that loneliness.

For Richard, prostate cancer which had spread to the bladder caused the loss of both his intimate relationship and his mainstream social life. His urinary ostomy bag was very restricting on his lifestyle. He could no longer express his physicality in normal employment (labouring), chores (chopping wood), or recreation (running, swimming and contact sports), and lost the social contacts associated with these activities. Socialising at gatherings was "not a plan" because of the risk of accidents. As noted above, Richard also lost his intimate relationship, and was only kept from suicide by thoughts of his mokopuna. At the time of the interview, his social losses continued to weigh heavily upon him, and he still got "stressed out" about relatively small things at times, which he attributed to "not having a life". However, he retained the ongoing support of his whānau, and was beginning to forge new social connections and roles using his musical skills, so Richard could see a brighter future.

Reporting 'No distress'.

About one third of the participants reported that they were generally not distressed either when they were diagnosed or as they were confronted with losses associated with the disease or with treatment, but simply accepted each stage in the process and 'got on with it'. In this section I discuss some of the circumstances that were associated with such reporting.

For Paul (56 years, Māori, serious but uncertain prognosis) and Freddie (82 years, Pākehā, terminal prognosis), a relaxed attitude seemed to be associated with a sense that the timing of (possible) death was acceptable. Paul (181) said:

P: Well, I just thought, 'Oh, well', you know what I mean, I thought, 'I've had a pretty good life. I'm 56, so....' Or 55, I was at that time. 'Oh well', you know what I mean, 'there's not much I can do about it. Let's just get on with life, and...' () He recommended all what I can do and what I can't do, and, 'Would I be agreeable to these treatments?' I said, 'Yeah.' () And it didn't really hit me emotionally...

Some men had a strong general sense of optimism and confidence in their personal abilities to overcome difficulties. Jacko reported that he had maintained the attitude that he was going to "beat it" throughout his experience of cancer, and despite doctors explaining the seriousness of his disease. But he died about six weeks after the interview. His personal optimism and its nullifying effect on potential distress is displayed in his reaction to his diagnosis (156): "Nuh, it didn't really impact, because

all we were thinking was, 'Oh yeah, we'll do a little bit of radiation and that will whack the little sod'."

Hank had a similar optimistic and determined attitude despite being told that his cancer was terminal at the outset (96): "I actually said to [the specialist], 'If you tell me five years, to me, that'll be ten'. So, I just said that 'I won't let it beat me' sort of thing." Hank's approach proved very effective as he was talking to me nearly ten years after diagnosis, but the fact that this optimism involved an element of denied reality is suggested by the realisation that he had when he saw the comprehensive extent of his bone metastases in a recent bone scan (378): "Oh, it probably made me realise that I wasn't infallible. You know, I wasn't gonna... ummm... ummm... it wasn't gonna go away, yeah, I was going to have to keep battling (), and... it might beat me one day." Hank halts himself from uttering the realistic statement, "I wasn't gonna survive it", and opts for talk of ongoing battle in which the outcome is uncertain ("it might beat me") and distant ("one day") rather than definite and imminent. The bone scan result has confronted his apparent optimism that his cancer might 'go away', but even after nearly ten years of experiencing the progress of the disease, Hank does not concede the inevitable.

Potential anxiety was allayed for other men by the reassuring words or tone used by their doctors. Eddy was fairly settled by what his doctor told him of test results at the time he was diagnosed (626):

I:obviously, 'cancer', it carries a life threat, you know.

P: Yeah, well...

I: Did that, did that strike you at all?

P: It ... no, I, I... because they, I think they were very open with me, and, and I suppose there were some doubts in there but when they had done the bone scan and said it hadn't gone any further. () That sounded good to me.

But Lewis seemed to be reassuring himself by misinterpreting his doctor's calm tone as meaning that his cancer was not life threatening (395, and back to 360):

I: You wouldn't, wouldn't say that you were stressed at all by being diagnosed?

P: I've never, never been, never felt stressed () at all. () No. (clears throat)
Because of the... I presume that it was the manner that, ah, [oncologist] () put it

over, you know? () But he said, 'Oh, you know, we won't, ah, we won't sort of panic or anything, it, ah, we'll just keep you on watchful waiting'. And () of course when I said, 'What's watchful waiting?', and he said, 'Well we're just, just keeping an eye on it, and making sure it doesn't, ah, get any worse.'

[.....]

I: What about your feelings about the whole thing of, 'This is cancer, we know cancer's serious, it could, could pose a life threat.' Did that have any impact on you at all?

P: Well, he, he didn't say that it was, that my cancer was posing a life threat. () He, he, he, kept on saying, well, you know, 'Oh, yes – you're ok.'

It was interesting that in stating that they immediately accepted their diagnoses without distress, some men seemed to assume that the only alternative course of action was to indulge in self-pity, which was unacceptable to them. For example, Cameron (755) said:

P: [Repeated melanoma diagnosis] never worried me. () I accepted it. () I trust them. I believed them. () I've never been... I str-.... if I was honest, I've never been really worried about it. () It's never got a... it's never got into me like, well, () I start feeling sorry for myself. () I've just accepted, 'I've got something there, and that's, that's what's happened to me' sort of style.

... and Monty (337):

P: Oh, no, [diagnosis with terminal prostate cancer] didn't, didn't sort of, it didn't sort of worry me at all. () You know, I didn't sit around and mope, or... I just carried on, did all the normal things, () and... just like I do now.

For a number of men, having no control over whether they had cancer or would die from it meant that the only rational approach was to ignore or accept it. Jacko said that his mother had taught him to ignore things that he could not control, and not to "get wound up" over them. Roly associated anxiety about diagnosis with weakness and irrationality (459):

P: No, didn't affect me emotionally. I'm not afraid-. I'm one of these people... I'm non-religious and I'm, ah, not afraid to die. () Doesn't worry me. You know, you've got no control over being born or dying. () So that's the way I feel (unclear word) about life. () And that's how I think about it. Um, 'If I've got it, I've got it.' () But I want to know.

Lack of reported distress could also be associated with a surreal feeling at diagnosis, and perhaps a philosophical detachment. Boxer felt this way, despite his worst possible

score on the Gleason scale (prostate cancer), but his detachment was also contributed to by an urgent need to have heart surgery (377 and 426):

P: I suppose throughout it all I was quite philosophical about it all. Well, you know, I didn't really want to know about it. Didn't really want to know about it, but I needed to deal with it. [...] Well, I suppose I felt, um, a bit surreal in a way. I just sort of, ah, I wasn't, I wasn't worried about it. I thought, 'Well if I've got cancer, I've got cancer and, you know, we'll deal with all that when we need to.' () Um, I just had thoughts about getting things put in place, and the housekeeping issues, you know, () dealt with, in case it was () ah, you know, 'good night nurse'. () Ah, other than that, I wasn't, I wasn't really worried about it.

[.....]

I: How did you feel about [the cancer diagnosis] at the time?

P: I thought, 'Oh, bugger!' You know (participant laughs). Um. But again, pretty philosophical about it all. I was... you know, I suppose I was in a state of semi-shock, so, so... (laughs again) () yeah.

I: Ok. So talk to me about your philosophy again, in that situation?

P: Well, again, I, I felt, ah, pretty, I suppose, realistically, pretty 'ho-hum'. I thought, 'Well I'd better go get this heart done – seen to.' And um, I was never at any stage.... I suppose I had in the back of my mind, well, ah, 'This could, this could be the end of things,' um, because with the heart there's always some sort of risk () with that, no matter what. () And, ahh, that sort of pushed the cancer thing () out of my mind, I suppose.

Boxer's very practical and pragmatic approach illustrates the 'get-on-with-it attitude' particularly characteristic of men who reported no significant experience of distress. It suggests an undaunted, active, and control-taking stance, rather than a contemplative, concerned stance. Carl used the phrase, "Get on with it", repeatedly in telling his story, and also repeatedly said he had not been distressed because he was "not an emotional person". Mike spoke similarly, and when asked about the stress of being diagnosed, said, flatly, "I don't stress". He said his staff were amazed that he was "so level headed" about his diagnosis. It is also interesting how Carl selects his desire to "get on with it" to reason that emotionally supportive services were not useful to him, as if action and emotion were incompatible alternative options (0576):

I: Have you used any, um, non-medical cancer services? By that I mean things like cancer counseling, or men's support groups for cancer or anything of that nature? Um, phone line? Cancer phone line, nothing like that?

P: No. Um, I've got this attitude is, that, ahh, 'Get on with it'.

Interestingly, Carl later corrected himself, saying that he had attended one cancer support group meeting and, to his surprise, had enjoyed listening to everybody's experiences and suggestions, and intended to go again. He had surprised himself, having never felt comfortable talking in a group before. Mike also surprised himself when he experienced depression briefly, but deeply, during treatment. He later appreciated this for the considerable insight it gave him into the suffering of other people. Thus some ambiguity emerged for these men as cancer drew them into new experiences of themselves.

In sum, there were a number of factors that accompanied the reporting of no experience of distress: the timing of decease was considered acceptable; potential fears were allayed through personal optimism or the words or tone of doctors, which may have included an element of misinterpretation or denial of reality; the apparent assumption that self-pity – deemed unacceptable – was the only alternative emotional course; the belief that rationality required ignoring or immediately accepting a serious prognosis; a surreal state of awareness; and a pragmatic 'get-on-with-it' attitude. Whilst I had no reservation about taking such denials of distress at face value in the case of those men for whom the timing of decease was acceptable, or those who had confidence in the optimism conveyed by their doctors, an element of conscious or unconscious misinterpretation, avoidance, or denial, may have been affecting some of the other 'no distress' reports. Indeed, ambiguity was clear in some reporting.

Ambiguous expression of distress.

Ambiguity in reporting 'no distress' emerged in the talk of some men, usually in the contexts of life threat or loss of sexual potency. This took several forms: understatement or disguise, rationalisation or justification, and simultaneous expression and denial, perhaps with telling hesitations. There were also whole interviews which were characterised by ambivalent or ambiguous expression of distress.

Disguised distress often took the form of descriptions of strategies used to cope, or help that was appreciated, without stating explicitly what need was being addressed. In the following example, Rodney describes a cognitive strategy he used to cope ("I tried to take it calmly...") while denying that he was under any emotional pressure (199):

P: I dunno. Reading stories and that, and, and, and people who got cancer and that, and oh, it's a, it seems to be a big thing () – I dunno, it might be () – but I tried not to make a big hooaaa about it, and I () um, I tried to take it calmly: 'Ok, I've got it. It's ... () We'll see how... I've got no symptoms so it can't be that bad!' (little laugh). () But I didn't feel, feel anything emotional about it, or... () But I suppose that's just me, but...

Understatement often took the form of humour or colloquial cliché. For example, Eddy was diagnosed with diabetes, stroke and cancer together, just before Christmas, and said, "That weren't my best Christmas!", and Jake expressed his feelings regarding the difficulties of arranging a life-saving bone marrow donor (there were only two identified matches in the world) as "a bit of a worry".

Rationalisations of distress made the emotional seem obligatory, fending off any suggestion of weakness. They often took the form of asserting that distress would have been felt by anyone in the circumstances or by implying this by relating the experience in the third person. For example, Cameron denied being affected by any distress throughout his many diagnoses and treatments for melanoma and an earlier cancer, but when his doctor took unusually swift action after a biopsy, he rationalised his fear saying, "You had to be scared, I suppose". Of the several men who recognised they had experienced depression, all but one rationalised this as attributable solely to medication. Mike insisted on this rationalisation despite a sharp disagreement with his oncologist on the point, and his own awareness of a psychological triggering event.

The simultaneous expression and denial of distress was a particularly fascinating ambiguity. It took the form of statements in the same meaningful chunk of data which were incongruous, or of a statement coupled with a non-lexicon utterance (e.g. lengthy pause, nervous laugh) which undermined or contradicted the statement. The phenomena seemed to me to reveal that the man was wrestling with ambivalence about expressing – or accepting for himself – the full significance of a (threatened) loss. In the two examples below, notice how Hank (quoted above in part) and Rodney toggle between reporting or implying distress and reporting that they have not experienced it.

Hank (375) more than nine years after diagnosis with advanced prostate cancer:

I: What would you say was perhaps the most stressful point of any of those... of the whole process?

P: Yeah, its hard to... I suppose, nothing was really stressful but probably the biggest shock was looking at the bone scan results the other day, I suppose (). Just seeing how quick it had progressed through my bones (). Mmmm.

Rodney (429) following treatment for prostate cancer:

I: The fact that it carries a life threat... how did that, um, affect how you felt and how you thought? You know? Did that worry you?

P: (pause for thought) No. () Um. It did a bit, oh, because I thought my cancer I had was curable. () I thought, 'Ok. I'm lucky - I got the curable one, which () um, if I come out of it, I'm probably going to get another ten years.' () Oh, 'probably', I thought. () Um. So it didn't...

I: So it didn't stress you?

P: Didn't, didn't stress me by much, no.

I: No. Ok. Perhaps a little bit?

P: Mmm?

I: Perhaps a little bit?

P: Oh, yeah, because I knew that something was going to happen and then, um, um, there was some parts of life I wasn't going to () enjoy any more [referring to loss of erection].

I: Yeah. That's right. Ok. And that's a loss.

P: Hmmm? () Yeah.

I: And that's a loss. So how did you... how did you cope with adjusting to that loss?

P: (long pause for thought) I haven't, really. () Um. Oh, I've looked at it and... (pause) Oh, I've adjusted. Yeah. () But it's... it's... it's hard.

A number of interviews contained repeated assertions of no distress, but then one or two hints of experiences to the contrary, suggesting the discomfort that the man had with these experiences and/or with acknowledging them. Charlie's interview was an example of this. He acknowledged feeling shocked at his diagnosis of very advanced lung cancer, but otherwise he reported regret at smoking as his only emotional concern. He acknowledged that his wife might have found him more irritable and short tempered for a time, but attributed that to his treatment. He only obliquely referred to having been angry and having "shed a tear", but thought he had "coped well" by not "going all wimpy [and] sitting around [saying] bloody prayers and naked in a forest [and feeling] woe is me". He emphasised that he was pleased that his doctors did not "pussy foot"

when explaining his condition, since he and they were all "men of the world", and that he had no indulgence for self-pity or for the pity of others, but accepted that he was going to die and wanted others to "be realistic" also, and not "waste time and effort" coming from all over the world to his funeral. Despite this portrayal of toughness, after the interview, over a cup of tea, he acknowledged being "anxious" about the future. The effortfulness of his portrayal also suggested a different inner reality.

Roger's interview illustrated ambivalence about both recognising distress and admitting the impact of losing his sexual potency. He was injection phobic and had declined urgings to have a biopsy following a series of elevated PSA test results until a new GP enlisted the support of his wife to help pressure him into it. At diagnosis he was "absolutely totally unconcerned", thinking his wife's distress was "a lot of fuss about nothing". He continued to think that his diagnosis "was a minor thing" and that treating it was "along the lines" of taking an Aspirin for a headache, until his wife finally managed to convey to him that his life was threatened, at which point he felt it was a "whole new ball game". Even then he said he just accepted the situation without worry ("I've never been a worrier") and said he "never really felt stressed". He did acknowledge a little despondency, saying (527), "I've never been one for getting depressed or anything like that – never have done – but every now and then, I'd, I'd get a bit down. () And [my wife's] always there." He said he had chosen to accept treatment knowing that he would lose potency, and that "it didn't bother me that much". However, when asked whether cancer had had a positive or negative effect on him as a man, he replied with an emphatic "Negative!" which appeared to be a reference to the impotence, and was clear that he could not share the views of others that some aspects of the experience might enhance one's manhood. As noted earlier, Roger also told of two occasions when he was sitting on his couch at home and had experienced the vivid hallucination of somebody rubbing their hand across his back, which he thought was meant to be comforting. Presumably, this presupposed a need for comfort.

Jacko's ambivalence was expressed in the contradiction of the effortful action he took to put his legal affairs in order when told he had less than six months to live on the one hand, whilst repeatedly asserting his positivity about "beating the little sod" with the support of his "team" on the other. His philosophy was "quitters don't win and winners don't quit", and throughout the interview he used euphemisms rather than saying 'cancer'

("bugger", "nasty sod") or referring to his condition as 'terminal' (e.g. the bad news was referred to as "shit"). The use of these euphemisms allowed Jacko to describe his battle against cancer, while diminishing his foe and avoiding conceding its overwhelming strength. Jacko both accepted his prognosis in that he put his legal affairs in order, and resisted it in his battle talk (166):

P: Emotionally? () Um. It was a shock. Um. But I quickly got over that, because um, I had things I had to organise. And I just, you just can't walk around feeling sorry for yourself, you just gotta get on with it. () OK, you've been dealt a pretty shitty hand. () Um. You know, I've, I've never been known to quit in my life, so I ain't going to start now.

As with the reporting of 'no distress' in the previous section, the ambivalence described in this section seemed to display a discomfort or unfamiliarity with some negative emotions which meant they were not available to men for open expression, and perhaps also not available for experience. As I was coding the transcripts I became increasingly aware that most men displayed a response style that either consistently expressed distress openly, or consistently reported 'no distress' (or sent ambiguous signals). I also noticed that the latter style seemed to associate with other traditional masculine attitudes, while the former seemed to associate with more freedom to be oneself. I explored this thought by splitting the sample, and discuss how I did that and the implications for differential coping in separate sections below.

Distress process.

I asked men whether they had a metaphor to describe how they felt through their cancer experience. It appeared that most did not know what I meant by this, so I often provided Jimmie Holland's (1990) example of an 'avalanche' of stressors (I did not elaborate detail) or an example from my own experience of instantaneously and unexpectedly reaching a distant destination when out for a walk. Eight men responded to this question, but another five alluded to treatment with mechanical 'fix it' talk in the course of their interviews.

The (non-mechanical) metaphors of two men explained a single aspect of their experience which was personally significant, while those of the others traversed the whole, or a larger part, of the experience. The single-aspect metaphors were: realising that something was seriously wrong felt like running into a wall (Charlie); and living with the fatigue induced by palliative drugs felt like being an 80 year old (Peter). The

hallmarks of the latter feeling were not wishing to be bothered with social niceties or with continuing to work, but wishing to focus only on important matters.

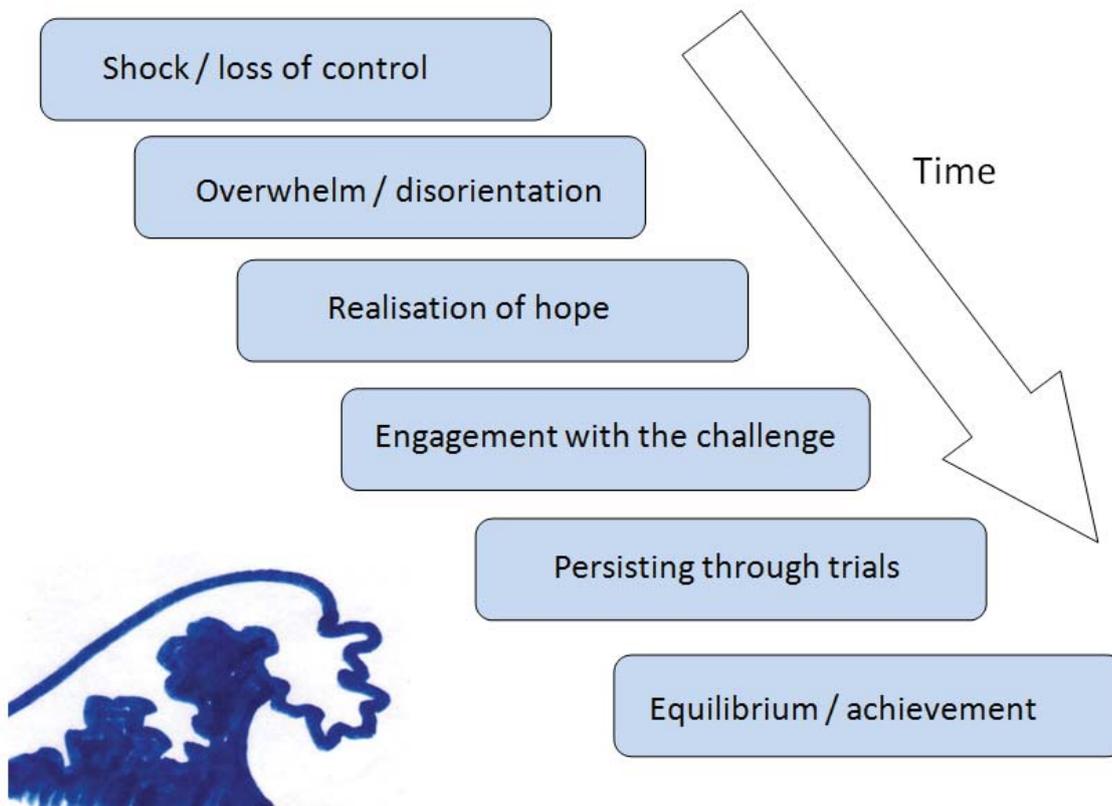


Figure 7-1. Distress process metaphor

The metaphors which traversed greater portions of the experience contained considerable thematic commonality, which I have drawn together in the stepped diagram shown in Figure 7-1 above. I use Bert's metaphor of being dumped by a rogue wave while at the beach. Bert fleshed out his metaphor in the most vivid and extensive detail of any of the men (984):

P: It was like a, um, it was like, I suppose, walking into a, into the sea when it's calm, and you, you're walking in and it's coming up to your waist. It's a bit cold – all the things that go through and, 'how long before I ...' – () and then suddenly a huge wave () knocks you over, () and back into the sand, and you're eating sand, and you're freezing cold, and you've bashed your head. That was the sort of () metaphor I would use. It, it, just... 'Bang!' () And, ah, then you recover: You get out of that, and you're dripping and you're (pretends to spit) spitting and you, you're doing everything. () And that's the recovery. Then you start to, to think, 'Well I, I'm not dead. () I, I, I'm not drowned. I'm not dead. I'm not... I'm getting out of here, and I'm doing this, this and this. () And I'm not going to... I'm going to be aware. And I'm going to be ready for

anything else that might come.'

The first steps of the process described by Bert and noted on the diagram are about shock, loss of control, overwhelm regarding the potential for loss and the array of unknowns, and disorientation. These were emphasised by Brucie and Richard also.

Brucie (278):

P: ... I felt really, um, overwhelmed. Buried beneath a whole bunch of stuff that I needed to fight my way out of. [.....] It was like, like I'd just been dumped on from a great height () and, and, there was only one person that was going to get their way out of it, and I had to do it on my own.

Richard picked up on the avalanche metaphor and emphasised disorientation, in terms of both the medical and the personal decisions he had to make (1572):

P: Mmmm. Don't know which way up is out, though. () Mmm. Because I know that () I know that when you're stuck in the snow, ah, to find that if you're up or down, you've got to spit. () Because of, if you don't know whether you're up or down, if you spit and it comes back on you, you know you're upside down. Mmm. () Um, it is pretty much like that. () Whatever use for... as life before, it isn't like that no more.

I: Right. And you're saying, '...and it's hard to know which way's out'?

P: Yeah. () Yeah. Which side do you spit down? (both laugh) () Mmm. It probably is like an avalanche sort of thing, it's so many things have... go, go down at the time, that...yeah. It's just... 'How the hell? What the hell am I supposed to do? Where do I go, or..? What shall I do, or...? Or who do I see, and...? () Shall I tell my Mum?' (little laugh) Mmmm.

The next steps in the diagram were the realisation of hope, and engagement with the challenge of working through the physical and social implications, and beginning to work towards emotional and/or physical recovery and the regaining of a satisfactory measure of control. In the above quote, Bert realised, "I'm not dead" and started to think about what he could do to "get out of here". Brucie took this step at the urging of his wife after a series of bad test results and a terminal prognosis had left them reeling in shock (138):

P: ...after that, [my wife] put her [specialist] training to work and realised, 'Yes, there was a bad prognosis, but there was a life to live in between times' () whereas I was still way back there in, 'Shit! I'm dying!' And I used to get angry with her, because she was trying to be positive, and I wanted to be negative. [.....] ...ultimately I started listening. () It took a little while. I started listening to what she was saying, yeah. (Long pause, tears.)

Several men emphasised the hard work and persistence that was required from this point on in the process. Brucie (quoted earlier, 278) talked of working his way out from under a dump of stuff, and having to do so alone. One of the issues he was grappling with was his loss of sexual potency, and the "huge change" involved in developing new ways to express affection to his wife. Another challenge was processing grief for major losses without becoming trapped in self pity. Brucie and Richard battled with several rounds of self-pity before moving on. Both Arthur and Jake used metaphors of a tough uphill slog, and Jake – whose family found a successful trial treatment for him overseas after he had run out of options in New Zealand and was facing death – emphasised the need to persist through trials and "never give up". The emotional trajectory of the whole process was described in terms of a graph by both Colin and Bert, who identified symptoms/test results and treatment news as high and low points along the way. These 'ups and downs' may be about processing new losses, or about processing a deeper level of implication regarding a loss already contemplated, and about relief or achievement when favourable progress is signified.

The final point in the process I have labelled 'equilibrium' because it is a point where a man is satisfied with the adjustment he has made to his losses and the measure of control that he has been able to take back in his life. Bert expressed this regaining of control as arriving at a point where he is "aware" and "ready" for anything else that might come. It is also labelled 'achievement' because a number of men related that they were pleased at how they had handled the challenges of the experience, or that they had faced and overcome the previously feared "bogey" (Harry) of cancer, or that their work and attitude had successfully brought them through to good health. Arthur explained what he meant by his metaphor of summiting Mount Everest after a tough climb (1435):

P: Um, oh... achieving, achieving the utmost... of, () of the problem you had. () Ah, um. () How would you say? Um, like, 'Well, I've conquered it', is the word. () I've conquer-, I've, I've conquered it, you know. 'Aarghh, yes! I've conquered it!'

In this process metaphor, the themes of distress identified earlier may fit as follows: shock on diagnosis is at the beginning, and anxiety relating to uncertainties and treatment concerns also tend to be early on, although may recur at later times, requiring re-adjustment. Loss, in its many and varied forms, is the main focus of the distress felt and adjusted to throughout the process, so grief and despondency could be expected

along most of the trajectory, once the busyness of the initial shock and need to address treatment decisions is past. Feelings like degradation, anger and self pity may occur in the earlier stages of the process, as part of confronting loss or dealing with intervention, or else later on, as part of the work of adjusting to loss and finding a new point of equilibrium. There may be some issues that are readily or steadily processed, and others that 'get stuck' along the way, leaving a man despondent. Loss of potency causing despondency could be conceptualised as a common example of this, e.g. a man may not have moved on from feeling a loss of control and overwhelm from this loss, because he may not feel able to recognise that he has lost his potency, given the magnitude of the implications. Alternatively, he may not have had the epiphany that there is hope to be found in broadening his definitions of what it means to 'have sex' or to express affection or manliness in other ways.

This process metaphor, by definition, came from men who were more expressive about their emotional experience. Such description of emotional churning and working through was quite at odds with the reporting of the absence of distress by other men – an essentially 'flat line' emotional experience, except perhaps for the shock of diagnosis. I wondered how the non-expressive men might relate to such a metaphor: Would it 'awaken awareness' of their own emotional experience? Or would it leave them feeling alienated? In the original 27 interviews I did not have the opportunity to ask them this, but in a passage already quoted, Rodney said he had read about the feelings of other cancer patients but could not relate to them (199):

P: ...Reading stories and that, and, and, and people who got cancer and that, and oh, it's a, it seems to be a big thing () – I dunno, it might be () – [...] But I didn't feel, feel anything emotional about it, or... () But I suppose that's just me..

Splitting the sample: Traditional and restrictive *versus* free and expressive.

To check whether there was an association, in my sample, between non-expressivity about cancer-related distress and traditional masculine attitudes towards issues of strength and vulnerability generally, I collated data for each man under indicators of: (1) more traditional stereotypic masculine attitudes regarding strength and vulnerability, *versus* the portrayal of more freedom to be individual; and (2) reporting of little emotion or ambiguous expression of cancer-related distress, *versus* open and clear emotional expressivity. I built a set of criteria under each heading from interview data and my knowledge of the literature, and listed what men had said under each (see Appendix 12).

The results are summarised in Table 7-2 below, which also specifies the criteria used to define each heading, and shows where the strong predominance of each man's talk fell. Note that the criteria for 'traditional masculine norms' on the table are restricted to the issue of masculine strength, and do not extend to other topics such as gender roles in marriage.

The criteria on the left half of the table reflect traditional masculine attitudes emphasising strength, self-reliance, status, emotional stoicism and aversion to emotional expression. A typical man whose interview fell predominantly under both of the left hand columns may have reported: never having been troubled by any significant illness before cancer; not being stressed by his disease or treatment other than perhaps being shocked upon diagnosis; taking prompt action to attend to family financial responsibilities in response to diagnosis; being profoundly impressed with the expertise of specialist doctors (e.g. to the point of believing there was no place for question or discussion of advice, or making excuses for doctors' failings); being expert or successful at his own vocation; being decisive about treatment decisions and making them during consultation rather than taking time to reflect and gather other information; discussing challenging details about the whole experience with no-one or only his wife, and even then restricting disclosure to physical matters (e.g. incontinence rather than fear); and having no use and/or little respect for emotionally supportive services, perhaps describing them in derogatory terms which suggest that to use them would indicate a lack of strength or competence and therefore would be inappropriate for a man.

The criteria on the right half of the table reflect a more individual approach characterised by freedom to express weakness and dependence on others, including balanced criticism and praise for the performance of others, together with the freedom to express a full range of emotional experience. A typical man whose interview fell predominantly under both of the right hand columns may have reported: being shocked and distressed upon diagnosis; suffering periods of low mood or self-pity or fear or anger; confiding feelings and needs in his wife or others and seeking out alternative support if family members were not readily available; criticism or affirmation of his doctors' performance in a balanced way; taking time to reflect on treatment advice and to seek further information, and then selecting a course of action which might be at variance with that advised by his doctor but is in accordance with his own assessment of

his best interests; and possibly having a metaphor (more than just a mechanical 'fix it' image) for his experience of cancer.

Table 7-2. *Masculine norms and emotional expression response styles*

	More traditional and restrictive		More free and expressive	
	Masculine norms	Emotions	Masculine norms	Emotions
Pseudonym	Emphasises strength/excellent health record ('bullet proof'), control, decisiveness, action ('get on with it'), fighting spirit, income earning, work competence, status claimed by association, deeply admiring of Dr's expert prowess (akin to reverence) and may consider it silly/insulting to resist Dr's advice, possibly also comparing it to the offense that he would take if his own work expertise was not recognised, excuses doctors'/refuses to blame them for significant errors, makes allusions to himself as a typical man.	Admits little emotion, denies need for emotional support, confides in few if any friends or family (perhaps only wife), private, denies anxiety, denies distress on diagnosis simultaneous denial and expression of vulnerability or distress, or socially acceptable rationalisation, has no use for/respect for counselling, if uses metaphor for cancer experience it is no more developed than mechanical 'fix-it' type of analogy	Comfortable with own and others' strengths and weaknesses, therefore does not speak of work or earning prowess except to extent appropriate to answer question, comfortable admitting pain and suffering and spheres of incompetence and dependence on others (aside from admitting dependence on / deference to women in care-giving roles). Free to critique Dr's advice and make independent treatment choices based on own analytical/rational thinking/priorities	Comfortable in expressing emotional experience and needs, admits distress and does so without discomfort / duplicity, may admit self-pity, names negative feelings, has metaphor for the emotional experience of cancer, admits need for emotional support
Jacko				
Hank				
Carl				
Freddie				
Harry				
Eddy				
Mike				
Brucie				
Rodney				

Peter				
Cameron				
Arthur				
Roger				
Lewis				
Roly				
Boxer				
David				
Bert				
Charlie				
Colin				
Paul				
Moko				
Monty				
Buck				
Tama				
Richard				
Jake				

Dark shading is used where the *strong* preponderance of the participant's talk fell under that head.
Light shading is used where the participant's talk is more spread between heads, although not necessarily evenly so.
White is left where very little if any of a participant's talk that fell under that head.

This table shows that 10 men spoke in ways that fell on the left side of the table (traditional and restrictive), 10 on the right (free and expressive), and seven with some mixed combination of responses, suggesting a fairly balanced continuum of positions in this sample of men. I note that five out of six Māori participants (Moko, Monty, Buck, Tama and Richard – the other was Paul) spoke predominantly in ways that were free and expressive. Although the methodology of this study does not permit any generalisation from this proportion, such expression may be regarded as consistent with the collective and spiritual norms of Māori culture. More open and direct expression of distress conveys deep and meaningful heart experiences which positions people to work collectively with others to address needs. Likewise, it could be said that the 10 Pākehā at the traditional and restrictive pole of the continuum spoke in ways consistent with 'strong and silent' traditional western masculine norms.

I illustrate the positions under consideration by describing one man's interview which, though mostly characterised by traditional masculine attitudes and restricted emotional expression, showed an interesting shift towards greater expressivity as a result of his experience of depression during cancer treatment, and comparing it with features of

another man's account. In keeping with traditional masculine norms about strength, much of Mike's talk emphasises his vocational success, his physical strength, and his emotional invulnerability. But he also discusses his brief encounter with depression which he attributed to his hormone therapy and to the triggering effect of losing a work-related driver's licence, which he experienced as a loss of control. This powerful emotional experience offered a glimpse of a whole new world to Mike, opening him up a little to emotionality and sensitising him to the plight of others.

Mike was a tradesman and then a businessman, was recently retired, 72 years old, Pākehā, and was treated for prostate cancer. He is married with adult children, and reported that previous to his cancer diagnosis he had no significant personal experience of physical illness, worked very long hours at a physically demanding job, and considered himself "bullet proof" and as fit as a man half his age. He was diagnosed after a workplace nurse, who checked his PSA level, recommended he see his doctor. However, when I asked whether he went to the doctor "fairly immediately" after this recommendation, he replied, "Oh, come on! The doctors! Men don't go to the doctors like that dear! Come on!" and said he would have made an appointment within a month. He often referred to his work expertise and success in business. He also referred to the "fast car" he owned, and the "very fast car" he used to own, stating its make. He emphasised that he had taken risks and been a decision-maker all his life and therefore wanted his doctors to inform him thoroughly. He referred to himself as "a typical man". He reported having no need for emotional support, even from his wife, and said he did not discuss treatment options with her or with any other personal supporters, other than to ask a friend who is a cancer specialist to confirm the standard treatment for his condition. Indeed, he said he did not understand the meaning of the term 'personal support' when asked where he received this support from, but, as the interview went on, realised that one way in which he received it was through the knowledge that many church acquaintances were praying for him. He noted that this gave him a calm feeling. He said that crying is an unacceptable "unmanly" response for him and consequently he is embarrassed if he cries while giving a eulogy at a friend's funeral and considers it evidence that he has an "emotional problem" stemming from deprivation in childhood. For him, the idea of going to counselling – say, had his depression continued – was "horrificing" and "frightening", but he could possibly be

"led down the garden path" to try it if a trusted senior woman, such as one of the radiation therapists he got to know, arranged it for him and met him there. This was "the only way that, as a man" he would go, because he was afraid of losing control in that situation. However, he recognised that it might be necessary to consider such an option in the circumstance of a prolonged period of depression, because he had found his own brief episode "a terrible frightening experience". Mike gained a great deal of respect for depression sufferers through his brief encounter with the condition. Whereas he said that he used to be one to say, "Oh, snap out of it! Snap out of it, girlie!" he now wondered how people coped with it, and advised people around them to, "Just give them plenty of room. Give them plenty of time." He could now understand why people could take their life, even though he hated the thought of it. He felt that the experience had made him a more empathetic, rounded and open person, even more inclined to help people in need than before, and also more inclined to "really explain things to [family] a bit better, instead of just saying, 'This is life - let's get on with it.' ". He also said that although he had previously thought he was "bullet proof", he now knew that life is fragile. He also said that he found the interview process fascinating, and quite different from the world he lived in, which was one of "pure facts": "It's so long, costs so much, weighs so much, it's going to take so much time." Like many men, he had undertaken the interview in order to help others.

While Mike emphasised his manly strength and capability repeatedly, and that he was very reluctant to place himself in a position where he might lose emotional control, men at the opposite pole did not talk about such things, but described their emotional experiences and their dependencies on others without suggestion of embarrassment. So, for example, Brucie told of how he explained his situation to his boss who offered him 'mental health days' if needed, and that he gratefully took one of those. Similarly he expressed his needs to a senior colleague who responded by lifting some work expectations from him, and, again, he was appreciative of the help. Brucie also spoke of his recognition that he was depressed, how it affected his thinking, and the various strategies he was using to deal with it, including accepting a prescription for Prozac from his doctor (although he was holding it in reserve), and participating in the research interview, which he saw as an opportunity to process the tumultuous events of the last year. Thus, Brucie was open about his emotional suffering and deliberately approached

strategies to manage it, in stark contrast to Mike who found both the experience of depression and the thought of counselling very frightening. Clearly, such differences have implications for means of coping with cancer-related distress, so the split of the sample along these lines is taken into account in discussing that topic below.

Distress: Summary.

I have attempted to portray the features of men's experience of distress in the diagram below (Figure 7-2). The diagram shows a circle for the distress that men reported and a circle for non-expression/the reporting of having experienced no distress, with an overlap area indicating ambiguous expression (i.e. an ostensible denial, with other indications to the contrary). In the 'no distress reported' circle are listed the circumstances found to associate with that response, and the nature of ambiguous expressions are listed separately. The circle indicating the clear reporting of distress contains three main groupings of emotions: anxiety or despondency related to loss; stress related to a lack of control; and a group which I will call 'the black feelings', i.e. self-pity, anger and feelings of degradation. The types of losses and types of stress associated with lack of control are noted in their respective circles. (Note that the size of the circles does not carry any substantive meaning, and that although the position of circles is used to suggest some association of meaning between them, the complexity of such associations cannot be shown on such a simplified diagram.)

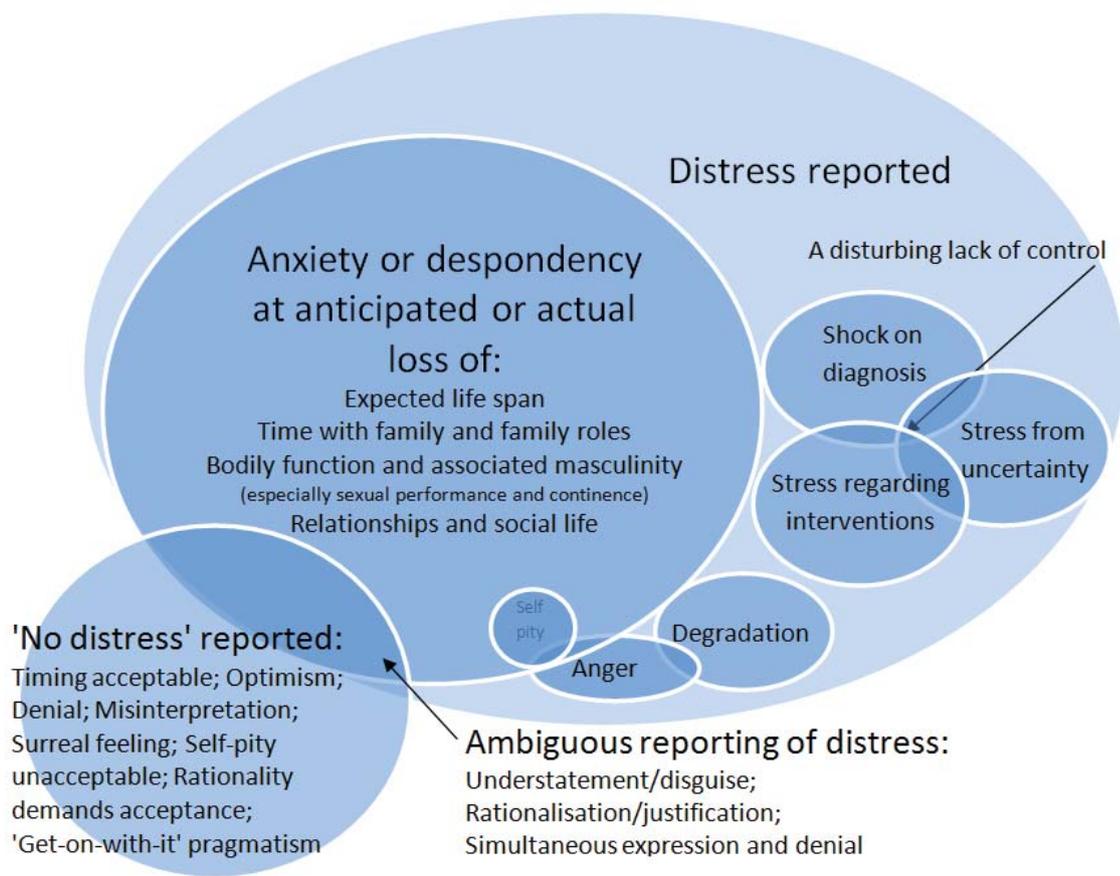


Figure 7-2. Distress themes

The structural findings are that some men report distress, some report none - but some of those do so ambiguously – and that the distress that is reported is largely to do with lack of control and loss, but involves some 'black feelings' also. Importantly, the distinction between those men who reported no experience of distress and those who expressed their distress freely was found to associate generally with a distinction between those men who displayed more traditional masculine attitudes regarding strength, and those who did not. This difference in expressiveness has implications for coping, as will be seen in the next section.

I have also explicated a 'wave' metaphor for the process of experiencing and resolving cancer-related distress. Disorientation and lack of control is highlighted and likened to being 'dumped' by a rogue wave, and then the process of re-orientation and recovery is likened to 'finding one's footing' again and 'dusting oneself off' so as to be able to face the future with a measure of confidence. The coping resources used in this process are now explored.

Coping themes

In this section I report the themes related to means of coping that I identified, and explore some differences in these according to whether men showed traditional masculine attitudes and restricted emotional expression or the opposite tendencies. The specific codes related to coping and their frequency of application are detailed in the appendices (Appendix 13).

Men used a range of attitudes, strategies, and resources for coping with the stresses of cancer, its treatment and its death threat. Four widely used and frequently mentioned themes were apparent, along with several less prominent ones (Figure 7-3, below). Each of the 'main' themes encompassed many facets. The main themes were: (1) a positive attitude; (2) an active and practical orientation; (3) being rational and exercising control; and (4) social support. I expand each of these in turn and then briefly discuss the smaller themes. Note that there is much conceptual overlap between these themes, and they are presented diagrammatically as a list only for simplicity.



Figure 7-3. Coping themes

A positive attitude.

The importance of taking a positive attitude to the challenge of cancer was emphasised by many men. For some, that meant taking a fighting 'don't-let-it-beat-you' stance (e.g. Jacko and Hank, quoted earlier) or never giving up (like Jake, also mentioned earlier), while others were conscious that the disease would "beat" them in the end, but they

were still determined not to "give in" to it (Monty), in the sense that they wanted to live a full "normal" life to the greatest extent possible. Even Brucie (also quoted earlier), who had a history of depression and who had to be talked around by his wife, eventually agreed that he needed to be positive and make the most of the rest of his life. A number of men said words to the effect that they were not the kind of people who "let negativity play" (Paul) in their lives. Also, as already mentioned, some men shunned any form of negativity seemingly to avoid self-pity, which was seen as unproductive and unacceptable. After Paul's extensive bowel surgery and arduous chemotherapy, and despite his contemporaneous divorce and modest financial circumstances, he was bursting with renewed value for life and the enthusiasm to make the most of it (668):

P: I look at the world in a different... so I get up every morning and look outside and I'm, 'Shit, I'm still here!' () I don't care if it's raining, the sun's shining, or whatever. () I'm here!

The positivity of some men had its darker side, however. I noted earlier that Lewis seemed to be reassuring himself by misinterpreting his doctor's calm tone as meaning that his cancer was not life threatening. Indeed, Lewis was expecting his surgeon to tell him, at his next visit, that he was cured, although the treatment regime he told me about was not a curative one. I asked him what would happen if, instead, his surgeon expressed concern, and it was interesting to note Lewis's quick fend and return to positivity (641):

P: Well, that'd be conjecture anyway, () wouldn't it? So, uh, I, I'm just going to have to wait and see what he says. () But I'm quite optimistic in what he, what he... () I mean, I dance twice a week, ah, very often three times a week () and I believe that that keeps me reasonably fit...[Lewis listed a number of other activities he pursued and then moved to another topic].

Lewis seemed determined to avoid contemplating any life threat from his illness. Hank had taken optimism and confidence in his own strength to a similar extreme before he was diagnosed with prostate cancer, and it resulted in his late presentation and terminal prognosis (19):

I: So what raised your initial concerns that you might have cancer?

P: Ahhh... probably a couple of things. One was having trouble urinating; one was urgency when I did () and the other one that I was getting quite swollen in my groin

- I: So just having raised that concern with yourself, ahhm, how how did that, ahhh , cause you to feel at the time? Do you remember?
- P: Ahhh... no, it... I was just a little bit concerned. But for a little while I did nothing about it because I thought, 'Oh, it will get better', 'I can handle it', you know, 'I will overcome anything'. Ahhh... eventually I told my wife about my problems with ahh, my bladder () and then we decided to have a check ().
- I: So what prompted you to tell her, do you know?
- P: Ahhh ... because a couple of times there I was in such a rush for the loo I didn't quite make it (). I was getting a bit worried about wetting my pants, () so to speak.

Although Hank's positivity and self confidence seem to have let him down at the beginning of his cancer experience, they served him well in forging his determination to significantly outlive his doctor's predictions – which he had done – and to continue to enjoy life while living with cancer. The impression conveyed, however, is that Hank achieves this powerful level of positivity at the expense of fully engaging with reality. Recall the quote cited earlier where he said his "biggest shock was looking at the bone scan results the other day " and how that "probably made me realise that I wasn't infallible. You know I wasn't gonna... ummm.... ummm... it wasn't gonna go away, yeah, I was going to have to keep battling (), and... it might beat me one day" (375). Hank seems to be only now recognising that his condition is terminal, despite the clear and consistent indications from his doctors for nearly a decade. Like Lewis, he seems to have strenuously avoided confronting reality in the service of positivity.

This delayed recognition (or denial) of terminal prognosis may be seen as a strategy that has been effective in allowing both men significant periods of time with minimal anxiety regarding the death threat associated with their diagnoses. However, as the end of their lives approach, if recognition of their prognoses is further delayed, both risk running out of time and energy to process the associated emotional and practical issues, which could be additionally distressing for them and for those who depend upon them. How men addressed this matter is discussed further in Chapter 12 (under Strength and inflexibility).

An active and practical orientation.

The majority of men noted the practical support they had enjoyed and were themselves determined to keep busy and keep living a normal active life. Several commented to the

effect that they were not prepared to "sit around and mope" (Monty) or "curl up" and "rot" (Buck), and such an active and positive approach seemed to be the norm. Other than immediately putting financial affairs in order or arranging to see family members who lived at a distance by way of preparation for death, the oft repeated aim was to "get on with it" in the sense of accepting the situation promptly (Freddie, 113: "You've got to accept it, girl! () You know its there! Its there! What can you do? Its there!") and attempting to live as normally possible. This was the way to be happiest in the situation. For example, Monty (817) said:

P: ...no use kidding yourself. () Um, you know, it's like [his surgeon] says there: 'It's going to catch up with you, () sooner or later.' () Ahh... and.... yeah. So enjoy yourself while you can, I suppose. () And, and, you know, really enjoying yourself is, its doing your normal things. () I mean, your normal things is what makes you happy. Ah () you know, the kids are saying, 'Oh, sell the house, and go on a cruise, and...', but I'm not...

Not only did men take practical steps which would assist their families in the event of their deaths, but they also greatly appreciated the practical gestures of others towards them. Those who were married almost invariably extolled their wives for all the practical assistance they provided, in the form of making special meals, assisting with personal cares, seeking out information on treatments, and being generally attentive. Men also frequently mentioned their appreciation for the practical gestures of others. For example, Roger appreciated his neighbour insisting he would cut the lawn after Roger's surgery, his club proprietor offering to stock special beverages for him while his treatment did not allow him to drink alcohol, and his club mates purchasing a book voucher as a gift for him.

For some men, there was again a darker side to the active orientation. When the phrase "get on with it" was used in relation to their treatment process, which was common, it usually referred to a decisiveness in treatment decision making that by-passed the opportunity for reflection on options and the gathering of other information and advice for consideration. The irrationality of this is attention catching given that treatment decisions could have life-determining consequences, as well as important lifestyle consequences. I elaborate this issue when discussing exercising and ceding control, below, but it is mentioned here as a manifestation of a decisive action taking approach.

Rationality and control.

Men used rational thinking a great deal, both to approach treatment decision making, and to deal with distress. The men who were more emotionally expressive told of strategies that they consciously selected to pre-empt or treat their distress, including: self talk of a positive coaching nature, reading the stories of survivors, playing a musical instrument, singing to himself, having a favourite meal, distracting himself, taking on a task or project, talking with a confidant, or having a cry. Rational thinking, such as weighing cost and benefit, was also used to make treatment decisions which would result in lifestyle outcomes which were the most emotionally tolerable, such as choosing whether to trade off sexual potency in favour of longevity.

Men frequently reported using opportunities to take control – in terms of their cancer treatment or addressing their own emotional needs (noted above) – and may have been distressed when that opportunity was not available to them. The exercise of control can thus be considered a coping tool used to prevent or treat distress. For example, Freddie had smoked all his life and he "knew", deep inside, that he had terminal lung cancer immediately that he was phoned by his doctor to come in and discuss a chest x-ray which had been taken to monitor his heart condition. He asked his doctor directly whether the shadow on his lung was cancer, and when his doctor said it looked likely but that Freddie would need to have a CAT scan to confirm this, Freddie said "No". He exercised his control to spend his energy and time on what was important to him, and declined to travel a long distance to have the scan "to tell me what I already know". He accepted his condition immediately and determined to enjoy the time he had left with his daughters and "go laughing".

However, for many men, the exercise of rationality and control ironically produced a relinquishing of control over treatment decisions to medical professionals. These men reasoned that the doctors were the experts, that they themselves were amateurs, and so the prudent course of action was to unquestioningly follow the doctors' advice. Colin (476) illustrated this:

- I: ...who was in the driver's seat here? Who was in control of that situation at that time?
- P: Well, he was. () Well, he was. My life was at stake, so he was, he was in the... and I was quite happy. It's a bit like the pilot and the plane, isn't it? So I, I had no qualms with that whatsoever.

I: Right. You were happy because he's the expert.

P: Yeah, straight away, because I had a good rapport with him, straight away, I was... I had all my trust in him.

I: Right. OK. And that's because, 'A' his rapport, 'B'...?

P: He's been recommend... and he'd be highly... people I've spoken to said how good he was.

This approach meant that Colin was able to rest assured that the best was being done for him, without having the stress of trying to "get [his] head around" the medical "gooble de gook" that some people advised him to research on the computer. So recognition of his knowledge limits was a factor that contributed to Colin's choice to completely entrust his treatment decisions to his surgeon, along with recognition of his surgeon's expertise, and the good rapport they had. A notable and important factor in that rapport was that the surgeon constantly initiating explained matters to Colin in plain language, and repeatedly invited questions, so that, although Colin did not exercise decision making control, he nonetheless felt that he was very well informed about what was happening to him. The stress that accompanies uncertainty was minimised and he had "no qualms" about relinquishing that control.

For other men, however, this relinquishing of control was accompanied by an apparent reverence for medical expertise that seemed to me irrationally excessive in their circumstances, putting their specialists' advice beyond discussion, and exposing themselves to risk – another coping strategy with a 'dark side'. Most of the university-educated men did not do this, but researched on the internet, read printed material, or obtained a second opinion, while taking time out to consider important decisions. However Charlie did relinquish control completely, even to the point of not understanding the purpose of the medications he showed me and not having a precise understanding of his disease status. He did this notwithstanding his high education and that advocacy and analysis had been central to his career. Another man who did similarly, though not highly educated, ran his own business and held public office (Jacko).

I puzzled over why men with such abilities would so completely relinquish decision making control at a time when their very lives were at stake. Of the five men who ceded control in this way (Jacko, Carl, Cameron, Lewis, and Charlie), all displayed

extreme allegiance to traditional masculine norms regarding strength and were also extreme in their emotional non-expressiveness, and all were Pākehā. I hypothesised that allegiance to hegemonic masculine norms, coupled with the need to alleviate the stress that accompanies overwhelming uncertainty, were at play. Medical expertise, at the level symbolised by cancer specialists, encapsulates masculine hegemonic norms, even when the doctor is a woman. Here are examples of these men's reports:

Jacko (096, 361, 424):

- P: As I said to [surgeon] later, 'I would have been real pissed off if you had of come back to me and said, "Oh, we stopped because of this but now we have to go and do it again" '. () I said, as I told him in the first place, 'Whatever you gotta do, you do'. () I'm not second-guessing a man that's spent his lifetime, spent a lifetime ah, working on all this stuff. () And some idiot [occupation] from [small rural area] starts telling him how to do his job. () That's not on. [...]
- I: Um, you've accepted your doctor's advice at each stage?
- P: Yeah.
- I: Um, and that's been voluntary from you. Does that leave you feeling in control of your situation? of your treatment?
- P: Um, no: it's a team effort. () And if you're, if you're not prepared to work as a team, well you might as well give up before you start. [...]. You know, if they tell you to put a fried egg on your chest, to, to do it.
- I: Right. Talking about the doctors here?
- P: Yeah. Um, but to, to take, to make sure you've got the good advi-, um, but let... don't try and second guess them. Don't try and, you know, the old saying was, 'Don't te-, tell your grandmother how to suck eggs'. [...]. ...when you get that diagnosis – whether it's good or bad – you've then got to be able to make good decisions. () And those good decisions you've got to make um, you gotta listen to what the doctor turns around and says to you. () You know, it's a bit like me and [my business]... () ...and I can, say, I get real jumpy about [amateurs] telling me how to [run my business]. () You know, and I look at it the same way. I'm [an amateur] when it comes down to [medical oncologist]. So you don't have to start being [an amateur] telling her how to, to run, to do what she does.

Jacko considered it "not on" to "teach his grandmother how to suck eggs" by "second guessing" a specialist's advice, and likened it to the offence of an amateur trying to tell him how to run his business. Charlie provided the same reasoning and the same analogy with his work when he explained why he took the same position. Jacko did not

perceive any personal responsibility, or constructive opportunity, to contribute to the strategic planning of his treatment. He continued to play no role even though he also acknowledged that his specialists made a mistake by planning radiation therapy before chemotherapy, causing the loss of time while he had teeth removed in preparation for the radiation. The lost time cost him in lifespan, yet, interestingly, he avoids blaming his specialists and continues to laud them (112, 180):

P: ...on the Friday we went to see [radiation oncologist] and I knew when they were calling me in there it wasn't going to be helluva good news. () And when [radiation oncologist] sat down, I could tell by the look on her face. () I said, 'It's shit, isn't it?' She said, 'Yeah, it is'. It's um, it had moved. () Um, and that um, she said putting me through to radiation would have been a waste of time, to do that. And um, I was then, she said I'll get [medical oncologist] down who's the oncologist. () Absolutely brilliant lady. () And [she] came down and said, 'Right, this is what we can do. Do you think we give it a go?' And I said, 'Well, you're the expert, not me. You know, I can walk out of here and say there's no problem but that's a load of crap. () Um but if you think that's the best thing we can do at the moment, we'll do it'. And so I... that day, that was Friday, the next day, I started on the chemo tablets. [.....] The only problem was, the only other step I would say – and it's easy in hindsight – that I might have been better to go on the chemo for a start off () rather than wait, because, with the radiation, they have to get, they have to get your teeth out, and then they have to make a mask, and all of those sort of things. () Um, and that all takes time, () um, and maybe with, it's all very well with 20/20 hindsight, () maybe with people that have got a nasty, um, a quick growing nasty, that they may be better starting on the chemo first, even if they only do two or three rounds () to knock it, [unclear word] to knock it, um, and then do all those other things they've got to do, () so that they can then start the...

The play to hegemonic masculine norms and status symbols is more evident in how Charlie speaks of his male specialists. Note also how he states that he did not want to discuss treatment options, and saw no need to research further about his condition once he was past the initial crisis, defaulting completely to his specialists (268, 595):

P: Yeah, it was a weekend that [my breathing crisis] happened. It was the next Monday, I think, I went over there, and I very quickly went onto [medical oncologist's] programme of chemo. And I found, I found both of those men superb () in their treatment. Ah, I liked [medical oncologist's] [article of attire] as well! () (little laugh) I used to, I used to wear () them myself. I, I used to be a bit of a flash Harry (little laugh) in that sense.

[.....] But there's no option when it's presented to you like that. You accept the advice of the experts. () And I did so willingly.

- I: Right. Ok. So it wasn't couched in terms of, 'Let's discuss the options.' – it was couched in terms of...
- P: No.
- I: 'This is what we do, can we have your permission?'
- P: I don't want that. I want treatment. I want to be fixed. And they are the people who know the best way to do it. () I put my faith in them.
- I: Right. So you're quite happy to, to do what the experts said is best?
- P: Of course! () Of course! As a [professional] if somebody asked me what to do, I'd say, 'Do this rather than that', and I'd expect my advice to be taken () – by someone who knows nothing () – as you would!
- I: Oh, I don't know about what I'd do, I tell you! I'll tell you what I did later! (both laugh)
- P: I was in no condition to debate the pros and cons of anything.
- I: Mmm. Yeah. So you didn't, um, ever seek a second opinion, or look up the net, or anything like that?
- P: No. No. () No. No. No need.
- I: And if, if there was someone else you knew – a family member, or friend – who had been recently diagnosed and was just going to move into discussing treatment, would there be a particular philosophy or strategy that you would suggest they take in terms of making those decisions?
- P: If they're in the same condition I was in, I'd say, 'Do what I did'.
- I: Yeah, but if... it would be.... You know, not looking at the specifics of their medical condition,
- P: Mhmm. Yeah.
- I: in terms of the general approach
- P: General approach
- I: to making treatment decisions, what would you suggest?
- P: Always act on the best advice possible. And in my case, that was these two oncologists. And my brother, I think, at the time, he was still [high up in health administration]: he had great faith in the management, all the top doctors there. () Knew them all, so () I was happy to go with the flow.

Charlie's report is distinctive from Colin's in its excessiveness and its allusion to masculine ideals: his faith in his specialists is not only unreserved but superlative and beyond question, and any suggestion of taking a different approach is seen as both

foolish and offensive, with the assumption being made that I too would take that approach. It was interesting that after the interview Charlie asked me how I had approached treatment decision making, and after I told him of my independent analysis of options and the consequences that followed, together with the story of another man who had been proactive in taking responsibility for his treatment research and decision making, he was shocked by the errors that were evident in the specialists' advice in these stories, and urgently wanted to know how he could start researching his own treatment options. It was as if a veil of aura surrounding his specialists – these masculine hegemonic icons – had been breached by the revelation of their mortality, and Charlie suddenly realised the importance of taking responsibility for these critical decisions.

The decision to relinquish control to medical experts may be a strategy to reduce the stress of uncertainty inherent in the cancer experience (which was noted as one of the main sources of distress earlier). Where it seems irrationally excessive, it may be that an element of masculine imagery, attributing super-human wisdom to doctors as icons of masculine rationality and expertise, has influenced that choice. The complacency that Charlie showed about his level of ignorance concerning his disease status and treatment may reflect the strength of the illusion of control and competence that were associated with these masculine iconic figures. I note that none of the men who took this excessive approach were Māori, despite their lack of education, and it may be that this is because they did not share the same imagery of medical experts as masculine hegemonic icons or that their collectivist norms make them less likely to put any individual on so high a pedestal.

Social support.

Men appreciated the understanding, encouragement, informational and practical support of other people, most frequently and importantly, wives, other women in the family, and doctors (GPs or oncologists), and, for Māori, whānau, notably women and mokopuna. This social support was used in different forms, to different degrees, and from different sources, by different men.

In its narrowest form, only practical support, and from only a few people, might be utilised. Mike exemplifies this (more detail of his story is provided under the subheading Splitting the sample, above). Mike (Pākehā and married) did not feel he

needed any emotional support despite experiencing a brief episode of acute depression. Indeed, as noted earlier, he said he never needed emotional support and did not even know what I meant by "personal support". He did not confide his feelings or thoughts in his wife or in anyone else at that or any other stage. He simply told his wife and family what his treatment decisions were, and carried on. He said that his wife, "made the world tick around. If it was without that there, and you had to do, get your meals and do this, and that, and the other thing, yeah, it would have been more difficult, but I would have done it"(945). Mike and his wife were given unsolicited support in the form of meals and prayer by church members, and he sometimes used one of his business staff to drive him to radiation therapy. While Mike was extreme in that he did not even discuss practical matters with his wife, there were many other men who reported speaking only with their wives – or with their wives and those who their wives brought into confidence – and limiting their discussion to practical matters. These were men who were also non-expressive about distress during their interviews.

Harry (Pākehā and in a *de facto* relationship) is an example of a man who was more expressive and consequently mobilised more support. He was in a long term intimate relationship which he found very supportive in a variety of practical and emotional ways. However, Harry was deeply distressed about the loss of his ability to enjoy normal sexual relations as a result of his treatment for prostate cancer, and this frustration interfered with his intimate relationship significantly, yet he had not been able to talk the issue through constructively with his partner. Incontinence after treatment had posed difficulties for an extended period also. Harry mostly used a strategy of keeping busy, active, and challenged with his work to distract himself from this distress and also to give him the creative satisfaction he wanted to cope with the knowledge that he had an uncertain life expectancy. However, he also talked with several long standing male friends, and told members of his hobby club (also men) about the incontinence problem since it affected his ability to perform his role in the club. He was encouraged by the number of men who came and talked to him about their own experiences as a result of his disclosure. Harry also noted how helpful a senior radiation therapist had been in talking him through his incontinence. Although he had adult children, he did not mention them as a source of support, and although he was open to the idea of counselling, he had not sought it to assist with his intimate

relationship.

Buck (Māori and divorced) was at the extreme expressive end of the emotional continuum, and he received the practical and emotional support of many people. Although he was not physically disabled by his prostate cancer and treatment, he was frank that he experienced distress and that he had little knowledge about the health system. He confided in both his sister-in-law and the Māori Cancer Coordinator, and learned from them a great deal of helpful information about the health system. He told his whānau what was happening even before he was diagnosed, and received emotional support from his adult children and his mokopuna, his male sporting friends, and his Church leaders. At work, his employer gave practical support, and he received the support of many of the clients who had also experienced cancer. In fact, Buck raised the topic of his cancer with them and got them talking about it to him and to each other, gaining the satisfaction of seeing that he was helping them as well as himself. Because Buck discussed his situation and feelings with others, he was able to receive the support of many people from a wide variety of positions in his life.

The above vignettes imply that men who are at either extreme of emotional expressivity are likely to make very different use of social support. To investigate whether this was so, I collated data detailing the support each man received from his wife or intimate partner, other family members, friends and other community based supporters, and professionals (medical and psycho-social). I collated into the same table a description of any support the man gave to his various supporters also (not applicable in relation to professionals). For this I selected only those men who were at the extremes of the emotional expressivity continuum as shown on Table 7-2. Most Māori fell at the expressive pole of the continuum, and I separated their data from those of the Pākehā at the expressive pole to control for the potentially confounding effect of cultural difference. I also excluded data from the one young participant because his social circumstances were quite different from those of the others. This left data from comparison groups of 12 emotionally non-expressive Pākehā men, five emotionally expressive Pākehā men, and five emotionally expressive Māori men. I then summarised this data into a series of tables which, being too long to reproduce here, are relegated to the appendices (Appendix 14).

A number of important differences are shown on these tables as to how emotionally expressive and non-expressive Pākehā and emotionally expressive Māori men engaged with social support:

- Wives were usually the main supporter of those men who had them, regardless of emotional expressivity. The specific nature of their support will be elaborated below. However, none of the Māori men had wives, and the one who had a partner had suffered relationship breakdown as a consequence of his cancer and lived separately from her, so no comment regarding the emotional support of wives can be made regarding the Māori men.
- The emotionally expressive Pākehā men tended to discuss their physical and/or emotional wellbeing with their wives, and receive direct emotional support as well as practical support from their wives. The non-expressive Pākehā tended not to discuss their wellbeing with their wives, who kept informed through attending medical consultations, and these men emphasised the practical care their wives showed them.
- Some wives of emotionally non-expressive Pākehā unilaterally assumed responsibility to inform others of their husband's health status and/or to take steps to protect their husband's health. None of the wives of emotionally expressive men did this, and some urged or even chided their husbands to act in particular ways that they felt were more adaptive, conveying the impression to me that these wives did not feel that they needed to be as protective of their husbands. This matter will also be elaborated below.
- Both emotionally expressive and non-expressive Pākehā men supported their children by taking such action as addressing financial and legal affairs and withholding details of their illness to spare their children's feelings. Expressive Māori men supported their families differently: informing wider whānau; withholding information from a wider range of people to spare feelings; and making efforts which displayed a sense of responsibility for grandchildren (e.g. concern about their future, or making great effort to see them before death) which might be more akin to the responsibility felt by fathers for their children in either of the Pākehā groups.
- The children of both emotionally expressive and non-expressive Pākehā men

generally had very secondary supportive roles compared with men's wives, in cases where men had wives. However, some daughters of non-expressive Pākehā were unilateral and directive in taking initiatives to support their father's health, and this was accepted gratefully. Again, this form of support will be elaborated upon below.

- Two Māori men (including one who, for the purposes of this point, I include although he did not meet 'expressive' criteria) submitted to extensive female supervision and direction of their treatment and another submitted to the directive of his former wife to accept her practical support. The tone of such protective and unilateral action taken by these women was comparable to that shown by some wives and daughters towards their non-expressive Pākehā men.
- Māori men tended to have a larger number of whānau supporters who showed their support in person.
- Emotionally non-expressive Pākehā men engaged very little with friends for support, but expressive Pākehā and expressive Māori men tended to engage with them and received both emotional and practical support from them.
- Neither Pākehā group engaged with other sources of community support to any significant degree, but some emotionally expressive Māori did so, notably with the church.
- Both Pākehā groups felt some personal support from professionals – the more so for emotionally expressive men. This took the nature of protectiveness and/or reassurance.
- Expressive Māori referred little to support from their specialists (although they were happy with their care), but both of those who made use of the services of the Māori Cancer Coordinator felt emotionally and practically supported by her.

As expected, the survey of this data showed that non-expressive Pākehā men had a relatively narrow range of supporters, and the support they received was mostly practical in nature. Expressive Pākehā had a greater range, in number and in type of supporter, and in the type of support (both practical and emotional). Emotionally expressive Māori had the greatest range of support and showed concern for the mokopuna generation to an extent similar to the concern shown by Pākehā for their children. These differences are consistent with Māori cultural values and practices emphasising whānaungatanga (the importance of intergenerational family), collectivity,

and wairua (spirituality).

The special role of women.

Women played critically important roles in the support of all three groups of men throughout their cancer experiences. All but two of the married men stated their strong appreciation for the support of their wives who typically reassured them, discussed treatment options with them, accompanied them to consultations and treatments, organised their complex medication and dietary requirements, bore with any negative moods, and were generally helpful and constantly attentive. When asked how they would cope without their wife's support, men usually took pause before responding with words to the effect that it would be "just too hard" (Bruce).

The protective and directive role that some of the wives and daughters of emotionally non-expressive Pākehā men took is fascinating. Men reported that these wives unilaterally took responsibility to act protectively of their interests, pressing them with 'alternative' treatments (usually dietary supplements), and becoming the conduit for communicating their state of wellbeing to family and community, and sometimes even to doctors. For example, Boxer accepted the fish oil and other "alternative expensive things you eat" that his wife pressed him to take, joking that he was not convinced of their efficacy but that he had learned to do as he was told. He also joked about how information concerning his illness had leaked out to his sporting friends through his wife, not himself. He had told no-one about his illness, not even his adult children, discussing it only with his wife.

In speaking for them, it seemed that these wives were assuming that their husbands were vulnerable or incapable. Indeed, Eddy said that when his wife and his doctor spoke over him, he sometimes felt "like a little boy", although he was not offended because he recognised that in order to do this his wife must have given his condition a lot of thought, which showed how much she loved him.

By contrast, two wives of emotionally expressive Pākehā men chided their husbands for not showing more emotional strength, and the wife of another who had terminal diagnosis persisted in urging him to think positively about what life he had left despite his initial annoyance at this. Thus these wives engaged with their husbands with the

expectation that they were as emotionally capable as themselves, and goaded or urged them to do better.

Some daughters of non-expressive Pākehā also acted unilaterally in what they considered to be their father's best interests. They gave directions as to aspects of their father's treatment, and, again, were deeply appreciated for it. For example, Boxer's daughter made arrangements for him to undergo expensive vitamin C therapy, which she had seen on television was successful in treating a man who was dangerously ill with swine 'flu. He happily accepted the *fait accompli* and paid for it. By ironic contrast, Boxer was quick to disparage his son's suggestion of an alternative therapy, saying that it was a "cure all" lacking credibility. The unilateral action taken by such daughters suggests that they felt the need to wrest decision making power from a man who did not have the competence to exercise it. But their fathers did not feel insulted by this implication. Far from it: they showed a little amusement at being bossed about, but they clearly felt loved, and their respect and appreciation for the efforts of both their wives and their daughters were singular and manifest.

As mentioned in the summary above, the reports of three Māori men (two emotionally expressive plus the one who was not) show similar deference to the assuming of authority by key women: a sister-in law who guided and assumed authority over treatment, a caregiver who enforced standards of care at home with both the man and with his visitors, and a former wife, who insisted that her practical help, in terms of meals and organising whānau members to do chores, was accepted. And the tone of these interactions was similar to the Pākehā ones as well: an element of jocularly at being bossed about perhaps, but, regardless, respect and gratitude for the care received. One of the men also expressed feeling like a child as his sister-in-law coached him through his treatment journey, which he knew so little about. He happily accepted this state of affairs except that he felt guilty that he had had to ask for her help when she was working through her own terminal cancer illness at the same time. (A fourth Māori man also enjoyed the close support of his intimate partner and sister at consultations, but did not mention whether they assumed authority.)

Perhaps this phenomenon was manifest for Māori men and emotionally non-expressive Pākehā, but not the emotionally expressive Pākehā, because the cultures of the former

two groups delineated a clearer distinction between the roles of men and women. This might be the case for Māori, regardless of emotional expressivity, and for non-expressive Pākehā men, because non-expressivity amongst Pākehā also tended to associate with allegiance to more traditional masculine norms about strength. In both cases, accepting this nurturing role from women does not demean the self-determination of the men, but reinforces their distinctive masculine position: perhaps part of being strong and manly is to have limited skill and experience in dealing with health weakness, because traditional norms about strength may tend to associate with traditional norms about gender roles.

Other coping themes.

Withdrawal.

A few men withdrew socially to cope with their cancer. While Peter withdrew from some community and family involvements in order to conserve physical energy, Moko wanted to isolate himself as part of his emotional response to his diagnosis (380):

P: I was... just wanted to stay away from people. I wanted to isolate myself. I watch a bit of TV and go to sleep out on my lounge. Then when I went... did go to bed, I couldn't sleep, I was four, five hours, just laying there: 'What's happening? What am I going to do?' () Ah, you know.

As noted earlier, Richard withdrew altogether from his intimate relationship because of his sexual impotence and Harry withdrew to the lounge and watched television to try to distract himself from his sexual impotence and accompanying despondency. Richard's wish to withdraw was reinforced by his misunderstanding that cancer was contagious and his fear of infecting his partner with a deadly disease.

Crying.

Five men reported crying. For some, it was an expression of despondency or depression associated with loss, e.g. for Bruce it as an expression of depression due to his terminal diagnosis at a relatively young age. For another two men, the issue was loneliness and/or loss of intimate relationship.

For one man, who was anxious about many things, crying was a deliberate cathartic strategy used to "get it [stress] off your system". Arthur was unashamed to tell me how he used it to cope with his wife being rushed to hospital at the same time as he was in treatment (1172):

I: ...how did you cope emotionally? How did you manage to cope through that time?

P: Oh, I had my... the odd break down. () You know... (indistinct word)... you know, have a damn good cry. () You know. Get up tight. I knew that, if I didn't get... didn't have a bloody good blubber, () I would explode () mentally. () I had to let something go. () It was easiest was... was to let it go. And then, you know, () once you let it go, you, you start feeling a bit better.

It appeared that for the fifth man crying may have been a cathartic expression of anger or regret at having caused his cancer by smoking, but he did not see crying as a positive way of coping. Thus, only one man referred to crying as a deliberate means of coping.

Spiritual beliefs and support.

More than one third of the participants said they were 'not religious', but more than a third reported or showed that spiritual/mysterious meaning in some form was significant in dealing with their cancer, including two who had said they were not religious. For most, spirituality took the form of Christian faith, either as an active personal, or as a constant in the background of their thinking that enabled them to accept their situation, trusting that God would look after their future. Cameron (1090) made use of the latter kind of faith:

I: So do you, did you draw on your Catholic faith at all?

P: Oh you do in some ways, yes. () Yes, you've got to. Yes, I think it's there and you, you never lose it.

For a few men their Christian faith was centrally important to how they dealt with the life threat associated with their diagnosis. For these men, God was involved with the particular challenges they were facing, which helped them release specific concerns by leaving them "in His hands" (Peter). Two had quite profound stories about God's intervention on their behalf. In Peter's case, the story involved the release of funding for his very expensive life-preserving treatment. In Tama's case, the story involved God telling him directly in advance, or through people who did not know him, specific messages relating to his terminal prognosis and to his value to God, which left him feeling loved and secure as he faced his last days. (These stories are too lengthy to present as quotes.)

The ministry of church leaders (I include the Mormon Church in this) was comforting to some men. Some (all Māori) found comfort in blessings and prayers by church leaders,

and the reassurance leaders gave that God was with them. At the other end of the Christian spectrum, there were two Catholic men (both Pākehā) whose practice was limited and who did not intend to inform their church leadership about their illness. Between these positions there were two men who felt encouraged or peaceful knowing that friends or church people were praying for them.

Other spiritual beliefs shown by a few men were a form of fatalism ("when my number's up, I go": Lewis), and the belief that on death the man would go to be with a loved one.

Proportionately, spirituality was important to more Māori men, consistent with Māori cultural emphasis on wairua. Three of the six Māori (two mainstream Christian, one Mormon) actively used their church for support. Two of these re-engaged with the church because of their cancer after a time of lapse, and one of these, who had no children, also drew much support from old people at his Marae. And Monty was comforted by his Māori traditional beliefs, saying that he had no fear of dying because of the way Māori handle it ("it's the acceptable thing") and noting that he was going to see his mother.

Personal growth.

Many men noted that their experience of cancer made them grow as a person, and in some cases this growth became a source of satisfaction and opportunity. For most, the growth was in empathy for the suffering of others, increased appreciation of the value of life and insights to re-order priorities, and satisfaction at having conquered the disease and/or a fear of cancer. Others became more aware and appreciative of the goodness and support of family or medical professionals. The experience made some realise that they were loved and wanted. Two thirds of participants specified that they had learned or gained something significant of this nature. Presumably such gains worked to off-set losses caused by cancer to some degree.

Buck felt that his growth in empathy made him a better man. Some men said they would be pleased to help others with their cancer if they had the opportunity, and some did this as part of their involvement with cancer support groups. Two (Buck and Paul) were taking satisfaction from their own initiatives: getting cancer survivors/patients who were work clients talking with each other, and providing personal encouragement

to patients who were in difficult straights. One man felt that he was a better father and grandfather for becoming more emotionally open, another said his family had become all the more "tight" because of cancer, and another that he now made special efforts to be the best grandfather he could be.

Paul also felt that he had grown in his manly mana as a result of his improved health from ceasing marijuana and alcohol use, rather than losing mana due to the sexual implications of his stoma and bag following extensive surgery for bowel cancer. Several men felt that their masculinity and confidence had been enhanced for having faced and overcome their fear of cancer, perhaps by "conquering" the disease (Moko, Arthur), thereby achieving something that many others had not, or by coming to understand and adjust to it, so that it was no longer the "bogey" (Harry) it used to be. The young participant felt cancer made him more of a man in that he had become calmer and more grown up for his experience of dealing with it. In these ways cancer opened or clarified new aspects of strength and insight for many men.

Note also that several of the men (all Māori) mentioned deliberately avoiding the use of alcohol as a coping tool. For these men alcohol abuse had been a problem in earlier life, they had since given it up, and they consciously chose not to 'go there' again. Richard was the only one who reported turning to a substance (marijuana), and this was a deliberate strategy used only briefly during his most acute distress. He then chose to work on his guitar skills instead.

Psycho-social service use.

The emotional and practical support of the Māori Cancer Coordinator was deeply appreciated by the two Māori participants who used that service. No participant had used the Cancer Psychology Service associated with the main treatment hospital, and many men were unconvinced of the value of services of a counselling nature, either for themselves personally or in general. Some of these conceded that they knew little about how such services worked and said they would be open to persuasion. Few men had attended support groups run by CSNZ and the majority could not imagine that they would do so. The image of support groups amongst Pākehā men was often negative: inward looking and self-pitying support for needy people. Clearly, this image runs counter to the action orientation and positivity which are noted above as characteristics of the coping style of men. However, Māori men were more positive about support

groups, consistent with their collective cultural norms. Perhaps beneath the negative perception of many Pākehā to supportive services there is a deep fear of exposing emotional vulnerability and appearing unmanly, as Mike felt about counselling (discussed above).

Coping: Summary.

As a whole sample, men coped with the pressures and distress of cancer by approaching their circumstances with positivity, practicality, action, rationality, taking control, and making use of social support from a variety of sources. There were also some who coped by withdrawing, one who used crying, and some who leaned on their spiritual beliefs and church leaders. Most men reported personal growth through the experience. The engagement of men with social support differed in extent and nature according to emotional expressivity, and ethnicity. Little use was made of services in the nature of counselling or support groups, except that appreciable interest in groups was shown by Māori men, and two Māori men also used and greatly appreciated the services of the Māori Cancer Coordinator. Although men generally took opportunities to control their circumstances, an intriguing ceding of control was evidenced in relation to particular trusted women and medical specialists. This affected emotionally expressive and non-expressive men differentially, and an ethnic difference was also apparent. A 'darker' – sometimes dangerous – side to positivity, decisive action-taking, and control appeared in how some men, paradoxically, relinquished control. The finding of most practical significance may be the extent to which emotional expressivity affected the nature and quantity of social support available to men.

8 METHOD: DISCUSSION PHASE

The second phase of the project involved discussions with small teams of men selected from those who had participated in the first phase (interviews). The purposes of these discussions were to (1) critique/validate preliminary findings from analysis of first phase data, and (2) discuss the suitability of intervention suggestions that I proposed to help lower men's cancer-related distress. It was important to discuss findings and suggestions with participants to ensure their validity and relevance as a matter of recognising and taking advantage of their expertise regarding the social worlds of the CRG, in accordance with PAR method and values. Most of the interventions discussed arose by implication out of the 'low level theory' which had been developed from analysis of interview data (I kept a list of ideas while performing the analysis). Others were consistent with this theory but arose out of direct suggestions by men or were from other sources that I was aware of.

Participant eligibility

Eligibility criteria for the second phase were designed to privilege the voices of men from particular vulnerable demographic groups further, and also men who may have had difficulty in taking advantage of the psycho-social services provided for cancer patients. To be invited to participate in team discussions a participant had to:

- Be single *or* Maori *or* have lower income (under NZ\$35,000 gross household income per annum), AND
- Have *not* made significant use of psycho-social services (other than transport), *or* have accessed them due to the initiative of someone else, rather than after seeking them out himself, AND
- Seemed to me to be in sufficiently robust health to attend and participate in the meetings.

Procedure

I gave eligible participants an information sheet about the team discussion phase at the end of their interview, or else posted it to them. In the case of two men with limited literacy, I phoned them first and explained what the information sheet would convey. With the information sheet was a form for indicating interest and a stamped addressed

reply envelope. I also accepted the verbal expression of interest from the two men with limited literacy.

Meetings were held in November and December 2012, in local CSNZ venues. I asked permission of participants to record the meetings for the purposes of ensuring the accuracy of my meeting notes, assuring them I would write up my notes promptly and then delete the recording. They were all happy with this, and that is the procedure I followed.

Using my laptop computer, I showed the men a powerpoint presentation of my preliminary findings. I explained each component of the descriptions of distress and coping and the process metaphor, using the graphical portrayals, and sought and noted their comments, which were readily forthcoming. I asked for any suggestions for improving services to reduce the stress men suffered, but there were no original and direct suggestions from any team. I then put forward the suggestions which I had compiled and obtained the men's comments on them. Also, when men described particular inadequacies in hospital or psycho-social services or particular needs, I converted these into intervention suggestions which I put to the teams for comment.

Participants in these discussions were thanked for their assistance with a \$50 service station gift card, and their travel costs were also reimbursed. Meetings took between 90 and 150 minutes, and refreshments (morning or afternoon tea, or lunch) were provided.

Additional consultation

While these meetings provided good feedback on my tentative theoretical findings and on the ideas I had for improving services, I was concerned that the limited education and non-managerial work experience of the men who participated in them may have hampered them from making their own suggestions for improving services. The theory that PRs in PAR have the expertise to generate answers to research problems (McNiff & Whitehead, 2006) assumes that they have an understanding of the relevant systems. In the present case, the analysis of interview data showed that a major factor in the distress of men was 'a disturbing lack of control' and that lack of knowledge and information about the disease, its treatment, hospital systems, and psycho-social issues and services was central to this stressor. Thus a lack of understanding about 'the system' both caused

distress and prevented men from being able to work out solutions. Their position was characterised by Richard's comment that medical staff were very kind to him and often asked whether he had any questions, but he did not have enough understanding to know what to ask, which troubled him. In this circumstance, the assistance of people who can translate the expressed needs of the PRs into solution suggestions is required. This was the role that I performed as I put suggestions to the teams for their comment. However, although I was pleased that team members were quick to express disagreement with any suggestions I made that they thought would not work, I felt uncomfortable about the amount of power I had in initiating suggestions.

I decided that I wanted the suggestion list critiqued by participants with more education and managerial experience, and who may also therefore have some original suggestions to offer. I therefore sought the assistance of three interview participants who were articulate and had tertiary degrees and managerial experience. However, the privileging of the views of men with more vulnerable demographic characteristics was protected by (1) their critique and validation of the distress and coping findings, which was not open for review by the more educated men, and (2) their prior and considerable involvement in shaping the list of intervention suggestions.

Unfortunately one of the more educated men could not be contacted, and though the other two were keen to assist, one had recently been very ill. I therefore arranged to meet each of these two men individually in their homes, rather than as a team. Using the powerpoint presentation, I briefly described my distress and coping models, but only to bring them up-to-date with progress and to provide context for the substantive discussion. I then asked for any ideas for intervention, pointing out (as I had in the team discussions) that the distress and coping findings highlighted both men's needs and their strengths for addressing them. Neither man offered any fresh ideas. We then discussed the intervention suggestions already compiled, and each man confirmed the great majority of them but provided a significant idea for refining one. Only one meeting of approximately 150 minutes was required with each man, and they were recorded on the same terms as were the team discussions. The men were thanked with \$25 service station gift cards.

Materials

The information sheet provided to men eligible for team discussions is presented as Appendix 15 and the consent form as Appendix 16. The powerpoint presentation used during the discussions is presented as Appendix 17. Slides depicted the distress, coping, and process models I had tentatively drawn from analysis of the interview data, and included pictures as memory aides for those men with poor literacy. The same digital recorders were used as for the first phase.

Analysis

The team discussions and the talks with the two educated men were not transcribed and thematically analysed because the purposes of these discussions did not involve significant theory development. I followed up each meeting by typing up notes and quotations from my handwritten notes and the audio recording of the meeting, ordering them according to their relevance to each part of the theoretical models and to the list of intervention suggestions. I then modified or elaborated the models and list accordingly.

9 FINDINGS: DISCUSSION PHASE

During team discussions, men generally affirmed the three sets of findings – distress, processing, and coping – as fairly reflecting their experience, with the exception of a few themes omitted with regard to distress and coping. Team participants also contributed various minor points of elaboration and demonstrated the potential utility of the process metaphor by their engagement with it. Discussion also revealed the potential of lower education and more traditional marriage roles to increase distress burden.

In this chapter I describe the refinements to each of the sets of findings in turn, drawing out relevant passages from the interview data to integrate with the team discussion material. I conclude the discussion of each with a revised graphical portrayal and a bulleted summary, both of which integrate features from the interview and team discussion phases. But first I provide detail regarding team participation.

Participants

Of the 12 men who were eligible for team discussions, two indicated their discomfort with participating in group discussions generally, and three did not reply. Six responded positively and remained willing and able to assist when I contacted them a year later when I was ready to proceed. The remaining man was one of those who had not replied originally but I contacted him when I was seeking a second man in his geographical area, and he had no hesitation in agreeing to assist. There were therefore only two eligible men who were not available for reasons which were unknown, and which could have had relevance to research sampling, process or substance. However, since all participants in the interview phase conveyed to me (usually explicitly) that they were pleased they had participated, I think it likely that these participants' reasons for failing to respond were not relevant to the substance of the research, as was so for the two who were not happy to speak in a group and the one who had simply failed to respond but was delighted to be asked again.

Three small teams were drawn from these seven men, comprising: two Pākehā men from the Horowhenua who both had low income and low education, and were both retired and married (Arthur and Roger, who had three meetings with me in Levin over

morning tea); three Māori men from the Horowhenua who all had low income and low education, and were all single and either recently retired or on welfare benefits (Paul, Buck and Richard, two meetings in Foxton with lunch); and two Pākehā men from Whanganui, who both had low education, while one had low income from part time work and a welfare benefit and was married, and the other was employed full time on medium income and was divorced (Rodney and Colin, two meetings with afternoon tea).

The more educated men who I consulted regarding interview suggestions were Bert and Harry. Their comments are taken into account in the 'practical products' described in Chapter 11.

Distress themes

Concern for wives and dependents

The men in the Levin team (Roger and Arthur) pointed out that the description of expressions of distress was deficient in that it did not explicitly note their considerable distress for their wives, which involved a number of aspects.

Worry about the well-being of wives and dependents.

First, they were worried about how their wives would cope – both emotionally, with the news of their diagnosis and/or prognosis, and financially, if they were to die. These men described their feelings of responsibility as provider and protector, and their perception of their wives' dependence upon them, in accordance with traditional Western marital roles:

Arthur: ... we've always been the 'leader of the pack', you know, and possibly in our case, we've been handling the finances...

Roger: And the breadwinners.

Arthur: Yeah. And all of a sudden you're wondering, 'Well, what's going to happen?', you know. 'How's she going to cope?', you know.

[.....]

Arthur: I think the most stressful part about it was finding the tumour, and how she [wife] was going to take it, because in the back of a woman's mind, a tumour is 'the deadly weapon' if you can understand what I mean... I wasn't too sure how to approach her... Getting back to it, the 'leader of the pack' type of thing.

Roger: Yeah, yeah.

Arthur: She's your mate – you don't want to...

Me: Drop her in it.

Arthur: Exactly. That's the word: 'Drop her in it.' That's what I mean, yeah.

In his earlier interview, Roger had also described that his concern for his wife's distress, at the time that he was diagnosed, was the main reason he accepted treatment. He said he did not recognise the threat to his life at that time so the diagnosis did not concern him in the least, but he was concerned that treatment could have severe effects on his quality of life. Nonetheless, he went ahead with treatment for his wife's sake. This is what he said earlier, during his interview (265):

P: If, if it had been left totally up to me, I probably wouldn't have had anything done. () It was only [my wife]... um, I mean once they'd said, ah, you know, that it [the biopsy] was positive and, ah.... We went outside and she was sobbing. Um. () Ah, so, you know, there was no way I could not have it treated. She was...

I: She had you cornered, eh? (laughs)

P: Oh, yeah! (little laugh) She, she was shocking!

In the team discussion, Arthur also described his wife's distress as difficult to bear. He said, "She was making me, us, up tight... so, sort of, putting extra pressure on, on the problem we had."

For Arthur and Roger, concern for their wives' emotional well-being was of pre-eminent importance: For Arthur, worrying about how his wife would take the news of his diagnosis was "the most stressful part about it"; and for Roger, the desire to assuage his wife's distress led him to accept prostate treatment which would leave him sexually impotent (which was "not what you want") and involved a course of hormone therapy administered with an exceptionally large needle ("quite a nasty one") even though he was needle phobic, and none of which he recognised the need for at the time.

Both men also worried about their wife's future financial well-being. The one interview participant who had dependent children – Peter – reported feeling similar pre-eminent concern for the financial well-being of his wife and children when he was diagnosed. These were his initial thoughts when he received the "bomb shell" news of his diagnosis (reported in his interview, 207, 211):

P: I have faith... well, I accept things as they are. () Um. I suppose I was more worried about [wife]... I mean, I've got kids and family and everything. I sort of thought, well, you know, () I thought I've got to get that... () perhaps not particularly under control, but I sort of thought I had a few more years to, ah, () provide for them properly ...

[.....]

P: Yeah, I suppose it makes you feel, like, your responsibilities, doesn't it? Takes, takes you, takes... well... put things in order, and... Still had loans to pay off, and still got kids to look after, and... () so...

I: How did you deal with those worries? Or responsibilities?

P: How did I deal with it? I suppose, I really looked to prayer. () And I just sensed that we would be given time to sort things out, so...well, I just felt relaxed about that.

Although the Levin team and Peter shared pre-eminent concern for the welfare of their dependents, there were notable differences in their stances towards their wives which carried implications for their experience of distress: (1) Unlike in Roger and Arthur's accounts, nowhere in Peter's interview did he express feeling guilty or concerned about causing his wife distress (other than to say that his wife probably found his complaints about his aches and pains "a little bit boring"); (2) Peter saw his wife as sharing responsibility for resolving his financial concerns ("we would... sort things out" – my emphasis), whereas Roger and Arthur – as "breadwinner", and "leader of the pack" who had had sole responsibility for "handling the finances" – were anxious as to how their wives would cope if they died; (3) In their interviews, Peter noted a number of initiatives taken by his wife regarding his treatment, and indicated his respect for them, whereas Roger and Arthur noted no such initiatives taken by either of their wives, who seemed only to respond to what the doctor or their husband said, notwithstanding that both were clearly very concerned about their husband's health. In each of these instances, Peter's stance towards his wife was that of a fellow team member, rather than of a leader who is responsible for a needy dependent, and he consequently carried less distress burden. He may have also felt more strongly supported, since his wife took a lot of initiative investigating treatment possibilities and sharing his financial responsibilities, while also providing similar personal support to that provided by Roger and Arthur's wives.

It is notable that Peter (52 years of age) was nearly a generation younger than Roger (74) and Arthur (68). He was also a professional with a tertiary education whereas Roger and Arthur both had minimal education and, before their retirements, had physical jobs which did not require formal qualification (although Roger was self-employed). It appears that these older, less educated men had more traditional marriages which meant they carried more responsibility for their wives, and consequently more guilt and worry when their ability to carry out their roles of provider and protector were threatened by cancer. Such men may also be more likely to have traditional restrictive masculine norms regarding emotional expression (although this was not, in fact, the case for Arthur). This implies that they may carry more distress burden while being more restricted in their expression of it, and therefore less able to receive the support of others – a double bind.

Concern for their wives' emotional and financial well-being can be conceptualised under both of the main types of distress found earlier: distress at men's loss of expected life span and of family roles; and stress associated with uncertainty. However, since it can be such a pre-eminent concern, it deserves to be noted as a distinct form of loss of control, and this is done in the revised graphical portrayal of distress themes, below Figure 9-1).

Empathic distress, guilt and regret.

The second and third aspects of concern for their wives that the Levin team described were empathic distress and guilt or regret. Roger said that when he was first diagnosed, and did not understand how serious his illness was, the only distress he felt was empathic concern for his wife's distress, but once he understood the seriousness of his illness, he then felt guilty that he was "putting this on her". (Arthur said he felt "much the same".) Thus Roger's initial distress was purely empathic as a result of seeing his wife's distress, whereas later he also felt guilty for causing that distress, recognising then that she had good cause to feel as she did. His guilt stemmed from his perception that he had let his wife down in his marital role as her protector and provider. Providing another example of pure empathic distress, Roger told of how a doctor spoke to him coldly about his prostate cancer, leaving him feeling inadequate, and that although this didn't upset him directly, it distressed him that his wife was upset by it. Other than in

relation to his wife, Roger reported feeling 'no distress' from his cancer. Feeling/expressing no distress for oneself, but being distressed as a part of one's protective role for one's wife, is a response consistent with traditional masculine norms about strength.

Expressing his similar feeling that he had failed in his family roles, interview participant Charlie expressed regret and anger at himself for continuing to smoke, against the advice of friends and family, causing his lung cancer. He said his "primary regret" was that he was not going to "be around" for his young granddaughter, and he clearly felt blameworthy. Charlie did not use the word 'guilty' however, and the distinction might be that he felt that he was going to be the bigger loser, rather than his granddaughter.

Empathic distress is distinctive, in that it connects only indirectly (through another person's distress) with issues about loss or about lack of control. *Per se*, it does not derive from oneself, through blame, as guilt and regret do. Therefore, in the revised graphical portrayal of distress themes (Figure 9-1, below), I have represented it with its own circle, and situated it in the overlap of the large circles relating to loss and to lack of control. Guilt and regret involve an element of self-blame and are more associated with loss or anticipated loss, so I have placed the circle for them mostly on the loss side of that overlap. Guilt, in particular, is heightened by empathic distress, since both are about concern for the other person, and I represent this by overlapping their two circles. Regret at not having taken earlier or more effective action also co-occurs with anger at oneself, so I overlap the regret and anger circles as a reminder of this.

Shock

The factors found, from analysis of interview data, to be associated with the shock men felt upon diagnosis included realisation of life threat, suddenness/unpreparedness, uncertainty about the future, and blunt/cold delivery by the diagnosing doctor. In team discussions, Arthur offered two experiences which expand the meaning of the 'suddenness' factor. One was the sharp contrast between his normal "fighting fit" working lifestyle, and the medical drama and hospital stays that began one evening when he suddenly experienced a major and explosive haemorrhage while urinating ("Blood everywhere!"). The other was the sense of urgency and emergency associated with the speed at which events unfolded leading up to his diagnosis, including the use of an ambulance. A further shock factor for Arthur was the distress that his wife showed

at all the blood. His empathy and feelings of protective responsibility for his wife meant that her shock and distress compounded his.

Stress from uncertainty

Uncertainty about the nature of their cancer and of treatment side-effects was noted in team discussions as particularly stressful. Roger said, "The worst thing, I think, is not to be told", and Richard, of the Foxton team, repeatedly said that he wanted to be sure he was "being told the whole story" about his cancer.

An account from Rodney, of the Whanganui team, also demonstrated how disruptive uncertainty can be to important daily arrangements, resulting in further stress. Despite being diagnosed very early, he suffered delays in his treatment planning process totalling nearly a year. Consequently, his cancer became invasive and he could not make plans regarding his small business. This process coincided with the death of his best friend. At the time of his interview, Rodney was disturbed by his lack of motivation and energy – which continued even though his radiation therapy was more than three months behind him – and by his lack of finances. During his team discussion he described the period of uncertainty after his diagnosis:

Rodney: I was getting chucked from one guy [specialist] to another and then back [.....] You'd think they would... work together... Not knowing... you couldn't plan anything. [.....] I had my own little business, was self-employed, and that just (indicates 'down the drain') because in the middle of it, this guy who helped me out, he died of a heart attack, just before I got diagnosed – I knew I had cancer at his funeral – and from then on it was just downhill. I tried to work but it just sort of... I thought, 'Well, I'm going to have at least three or four months off after the op', and then you've got to try to work out your customer... how you're going to... and I thought I was going to... 'Oh another month and I'll be back in the saddle again.' It was more than that! (little laugh)

Rodney was also one of the men, discussed below, who seemed not to have recognised that the truncated manner in which their diagnosis was delivered was sub-standard until they heard from me, at team discussions, that other men had complained about this. I suspect that his limited education left him unable to advocate for better treatment on either score, or even to recognise that the system was failing him. It is disturbing to think that Rodney's business, physical health, and mental health may have all suffered significantly as a result.

Loss of work/business

Rodney's account also highlights the threat cancer poses to work/business and associated income and identity for men who have not retired. Paul and Richard also lost the ability to work because their previous jobs relied heavily on their physical strength. The fact that both of these men are Māori highlights the reality that a far greater proportion of Māori men do rely upon unskilled labouring work because of their generally poorer level of education. This loss of income, and the associated stress, was another omission from the preliminary set of findings.

Loss of bodily function

Roger, of the Levin team, said it was the *loss of control* of his sexual function and continence that were the worst aspects of these side effects of his treatment, rather than the losses of function (permanent and temporary, respectively) themselves. Richard, from the Foxton team, echoed this sentiment. All three Foxton team members had their capacity for normal sexual relations curtailed by prostate and/or stoma surgery. When the other two men said they were content with having only platonic relationships, Richard reacted sharply saying, "I'd rather have the choice!" In the Whanganui discussion, Rodney said the loss of the physical abilities and the loss of control were closely associated with each other.

I have added 'Loss of control of bodily functions' to the 'Loss of control' circle in the revised graphical portrayal of themes to denote this feature. I have also relabelled 'Stress regarding interventions' to 'Anxiety regarding interventions' to clarify that that theme is about fear of a treatment or its side-effects rather than the kind of ongoing stress, post treatment, that Roger, Richard and Rodney were referring to.

Feelings of degradation or disregard

Elaborating on 'feelings of degradation', the Levin men described feeling "inadequate" because of the cold and dismissive way their specialists spoke to them:

Roger: Funnily enough, I think it [his doctor's communication style] sort of made me feel inadequate, for some, for some reason. He said the options and the likely effects and all that, but he said it in a way that it...

Arthur: It was an everyday occurrence...

Roger: Yeah, yeah. () 'You shouldn't even be here' sort of thing..... you know, 'I'm busy and I haven't got a lot of time to spend with you!'

Me: I'm trying to get, to really nail this word 'inadequate'..... as if you just weren't significant or important?

Arthur: Sort of 'belittled'.

Roger: Yeah.

Arthur: 'Inadequate' or 'belittled', you know what I mean?

Roger: Yeah.

Arthur: Then after that you never saw him – you only saw his understudies.

Roger: Oh yeah – that's right! [.....] When we came away from him, my wife was *really* upset".

Consistent with what some other interview participants had said about their male specialists, Roger and Arthur conveyed that these doctors – all of them male – made them feel like unimportant nuisances to be brushed aside as quickly as possible. They contrasted this with the warm and caring way that the radiation therapists (who were women) and a woman doctor spoke to them. Arthur said it was like going "from one extreme to the other" as these women placed their patients at the centre of their practice and explained everything in detail: "They took time out, you know, and they wouldn't commence the radiation until they thought *you* were ready". They also dignified the men by being friendly and personal. Arthur was most impressed when a woman doctor who was not his own stopped and spoke to him while she was seeing other men in his ward cubicle, and by a woman 'understudy' to his surgeon who invited him to ask her questions to fill the 10 minutes she had available.

It is notable that neither Roger nor Arthur mentioned this maltreatment by their male doctors during their interviews, but only at the team discussion after I explained the degradation circle on the distress diagram. Rodney, of the Whanganui team, was the same, saying that he hadn't thought about it at the time, but that his diagnosis delivery was "pretty blunt and short", with, "'We'll see you in surgery' all in one hit". I wondered whether these poorly educated, low income men actually expected to be spoken to disrespectfully by senior medical professionals, and therefore did not think it worth mentioning until they learned that other men had (notably Bert, Harry, and Brucie – all educated and with higher incomes). If this is so, then there was probably an even

greater frequency of this bad experience amongst the men of this sample than was apparent after the interviews, which is quite disturbing notwithstanding the non-representative nature of the sample.

Arthur described further experience of degradation involving young men at work, who had limited experience of illness. He had to wear a catheter for nearly three months while he awaited surgery, and felt "a bit apprehensive" about having to tell male management and the younger men, fearful of their reaction and that they would look at him differently in future. He was concerned about feeling "degraded – it's a filthy subject, type of thing", and thought that they didn't want to hear about it. Arthur explained how the young men reacted, and Roger could relate:

Arthur: ...and when they [the young men] found out, they were sort of, oh, you know, 'Eeewww', you know.

Roger: Yeah. Yeah.

Arthur: 'You've got, like, rabies' or something like that, type of thing, you know – until they started asking questions... You're treated like a leper.

Arthur was also concerned about what the male managers would think, saying that, in his experience, men did not talk about such things much (Roger confirmed this). But Arthur felt confident about one of the younger male managers, aware that his father had died of cancer, and also about the women workers, because they were older and he knew that they had experienced cancer in their families too. His confidence proved well founded.

Anger

Like other interviewees, Rodney said he had been angry at himself for failing to immediately follow-up on an opportunity that may have enabled him to obtain a better health outcome. In his case, he wished he had taken up a suggestion that he attend the CSNZ men's group earlier, because there he belatedly learned about the availability of second opinions: "The surgeon said, 'This is how I do it [prostate surgery]', but I wasn't given, um, a choice on whether to go and see another one who did it another way, type of thing, which some of the other guys had been through."

Rodney's talk is interesting in that it relieves his surgeon of the responsibility to have provided him with choice. Once again it appears that this poorly educated man was not

aware of his doctor's poor performance, nor of other action he could take, and the consequences for him were significant and both physical and emotional.

Self pity

Foxton team members elaborated on the topic of self-pity. Paul said he would "become depressed and upset – really frustrated – because you can't do anything" and Buck described self-pity coming in "spasms" early on, when he thought, "Why me?". The men discussed how they thought their way out of this emotion, choosing to re-focus on doing something active and to think of others' needs (refer Helping others and Being active sections, below).

The unacceptability of self-pity and pity from others was confirmed in team discussions also. Men were quick to explain how they overcame their self-pity, and Roger explained that his public silence about his illness was a strategy to avoid being pitied. He did not want to be treated like an invalid: "I didn't want people to know, and my wife thought that was awful, but I didn't want people coming up and saying, 'Oh, are you alright? Have my chair', you know". On the other hand, he was pleased to have the offer of lawn mowing from a neighbour who was aware. He said that when that neighbour later was diagnosed with cancer, they talked about it, "and he did not want people to know for the same reasons".

Reporting 'No distress' and ambiguous expression of distress

Richard doubted the accuracy of the reports of men who said they did not feel any distress: "You've gotta feel *some* distress." His view may have been coloured, however, by the particularly severe relationship and lifestyle losses that he suffered as a consequence of cancer. Colin, of the Whanganui team, said he thought that men probably knew they had issues but that masculine norms meant that some did not feel allowed to express negative feelings. He elaborated on the social dynamics he saw at play:

Colin: Yeah, most probably being able to express it, you know.

Rodney: Mmmm.

Colin: Because I found it quite good in that interview with you [the researcher] that day, being able to talk like that one-one-one... Like you talk to all these other

people, but to actually sit down and talk. I found it actually quite 'therapeutic' – would that be the word? You know, I came away from that feeling really good.... And you asked questions no-one else would have asked, you know... Being in the right environment to let yourself... that was a biggie for me... () And coming to do that with you – I would never do that in a group of men. Like, you talk about the male group they have [CSNZ men's group] but I wouldn't feel comfortable there doing that because I'm the only one there with it [breast cancer], and its most probably just something I've got in my head () but I'd... Talking to you that day... yeah.

Me: So it did come down to a sort of masculine acceptability issue, eh?

Colin: More than likely. You most probably hit it on the head there.

Colin repeated the observation he made during his interview that he had no problem talking with the men at his very masculine workplace. There were a number of factors which he attributed this to:

Colin: Its surprising the number of men [workmates] who check under their arms and that. Guys would come up and ask me what the symptoms were and that, and I'd think, 'Well that's cool'.

Me: You've never had any trouble from them eh?

Colin: No, they've been more than encouraging. Asked me how my treatment was and...

Me: The [masculine work place] context – you'd think that if there was going to be a bloke put his foot in it, that would be where he'd do it.

Colin: Not at all. Not at all.

Me: Why was that? Because they knew you as a person, so they had respect straight off?

Colin: Oh I think, a little bit. And I'm a [more senior role than most workers] there so we have a bit of a professional relationship. And I've been here six or seven years now. But I think, yeah, they've got a bit of respect for me, and the men's health thing – I think a lot of them are a lot more aware now than what they were 10, 15 years ago. () And we're all an aging workforce, and people have health issues as they get older. There's a group of us now all about the same age and we all have our issues or whatever and we all go off to the doctor.

Me: So a combination of having a bit of respect for you, having more awareness these days, and perhaps being old enough to not be so 'gung ho'?

Colin: Yeah.

Colin identified four circumstances that he felt made it acceptable for him to talk: respect for him as a known person; respect for him in his professional role; increasing

general awareness about men's health issues; and more mature age, which brought with it personal experience of health issues. With all of these factors aligned, he was not afraid to speak to men in his very masculine workplace even though his type of cancer – breast cancer – was a particularly sensitive topic in terms of masculine norms... and he received only positive feedback. By contrast, he was not willing to join the CSNZ men's group, where he did not know the men. Interestingly, when Rodney first heard that Colin had breast cancer during the team discussion, he let out a short nervous laugh/snort before collecting himself and saying, "I've read about it." Rodney was a member of the CSNZ men's group, of a mature age, and aware of cancer issues through his own experience. His reaction therefore suggests that perhaps the personal and professional respect that Colin's workmates had for him were the most important factors in creating safety for him to discuss his cancer.

Revised graphical portrayal

A revised graphical portrayal of distress themes, which takes into account comments made in the team discussion phase of the research, is presented below (Figure 9-1). Having more themes to add to the three featuring a loss of control, I removed the three individual circles and the item in their overlap, and put all four in one list under 'Distress featuring loss of control', together with the items added after team discussions, in a large circle to the right. I then overlapped the loss of control circle on the right with the substantive loss circle on the left to better signify the commonality amongst these themes. The other significant additions to the diagram are the small circles for 'Empathic distress' and 'Guilt and regret', and the listing of 'Work/business and associated income' in the loss circle.

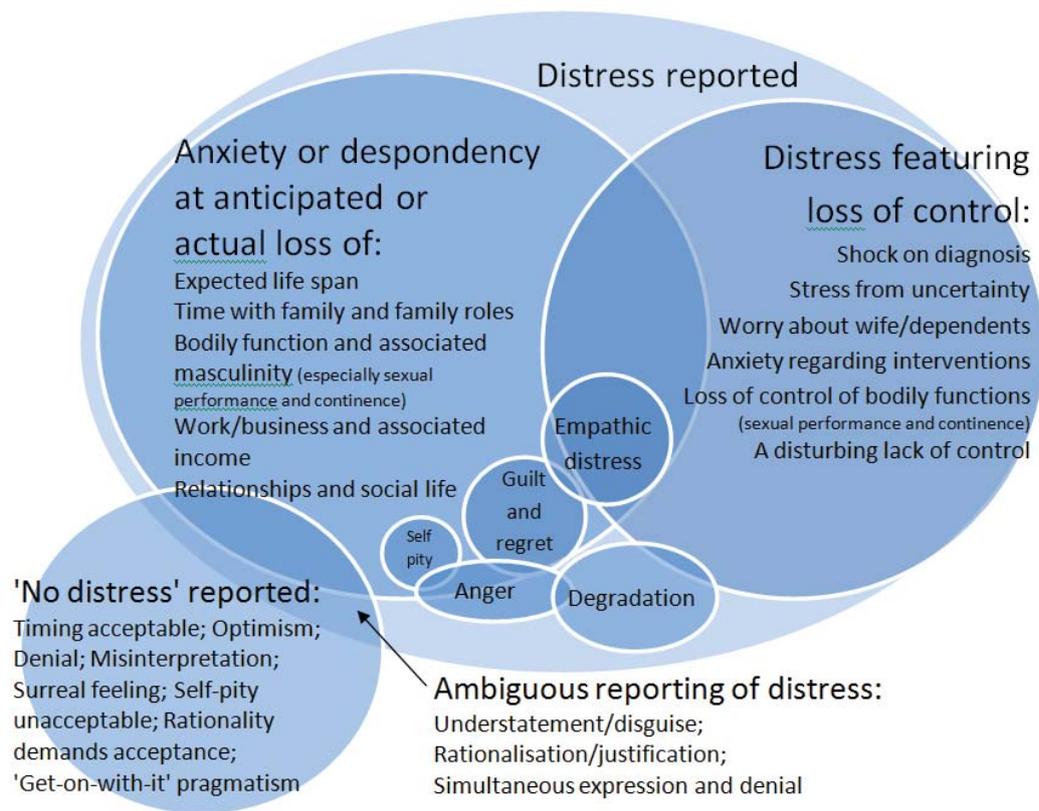


Figure 9-1. Revised distress themes

Although a very much simplified representation of the associations between themes, the diagram is intended to convey the sense that: there were men who expressed distress and men who did not; some of those who did not were ambiguous in that; there were several main groupings of distressed feelings, namely those associated with loss of control, those associated with loss, the 'black feelings', and those which were an empathic response to the distress of wives; and that there is much association between these groupings, particularly between loss and the black feelings, and between substantive loss and loss of control.

Summary of distress characteristics

I conclude this subsection with findings presented as a more detailed bulleted summary of features, integrating those arising out the interview phase with those arising out of the team discussion phase.

Summary of distress themes and features

Superordinate theme: Distress featuring lack of control:

Usually anxiety, and a transitory processing phase

- Shock on diagnosis
 - Associated with:
 - Suddenness/unpreparedness, perhaps no family history of cancer
 - Little health knowledge
 - "Death sentence" image of cancer and/or family deaths
 - Blunt/matter-of-fact/truncated/misleading/cold diagnosis delivery
 - Uncertainty about prognosis
 - Contrast between normal life and medical drama
 - Speed of events
 - Expressed by 'non-expressive' men too.
- Stress from uncertainty and waiting
 - Desire to know 'the whole story' about the cancer and treatment side-effects
 - Loss of ability to plan, including for business, causing confusion and loss
 - Worry:
 - about the outcome of tests and procedures (prognosis and side effects)
 - about the meaning of the behavioural cues of medical professionals
 - about a feared intervention
 - Worry resolved when outcome known or plan made
- Worry about wife/dependents
 - 'How will she cope emotionally with diagnosis/loss/prognosis?'
 - 'How will she cope financially if I die, since she has no experience handling finances?'
 - Concern regarding support of family, payment of debts
- Anxiety regarding interventions
 - Anticipated or experienced inconvenience, discomfort, pain or fright associated with unpleasant diagnostic tests or treatment side-effects
 - Resolved after intervention experienced and found not as bad as expected
- Side effects impacting bodily function (continence and sexual potency)
 - Creates ongoing stress from a lack of control/choice
- A disturbing lack of control
 - Over health and/or treatment-related decision-making, and, consequently, life in general
 - Includes alarm, annoyance, alienation, resistance, and resigned capitulation

- Associated with lack of information about/inclusion in decision-making, regarding the disease, procedures, treatments, side-effects, or after-care
- Can be associated with feeling degraded

Superordinate theme: Anxiety or despondency at anticipated or actual loss

Anxiety related to threat of loss, and frustration and despondency related to realisation of loss, when severe aspects of loss cannot be mitigated. Involves in-depth and lengthy contemplation

- Loss of expected life span
 - Where 'no distress' reported, usually there are signs of ambiguity around this loss. May involve a struggle to avoid the issue.
- Loss of time with family and family roles
 - Includes loss of opportunity to support family financially or morally
- Loss of bodily function and associated masculinity
 - Rational trade-off for survival
 - Temporary loss of strength and energy
 - Permanent loss of body image, sexual performance and continence
 - Worst implications include loss of: sexual activity; intimate relationship; physical lifestyle (work and recreation) and associated social contacts; enjoyment and life purpose in life; dignity and sense of adequacy
 - Loss of sexual performance acceptable to some (stage in life, loss of libido, wife's support) but severely distressing to others and difficult to express.
 - Loss/crisis may trigger personal growth/transition to new roles/stage in life
- Loss of work/business and associated income
- Loss of relationships and social life
 - Due to disease or treatment side-effects
 - Loneliness

Superordinate theme: The 'black' feelings

- Guilt and regret
 - For causing illness (smoking or failing to take prudent medical steps)
 - For imposing distress on wife
 - That will not be around to support/enjoy family/grandchildren
- Feelings of degradation or disregard, including feeling inadequate or belittled
 - From distasteful medical interventions and side effects
 - From interactions with medical professionals (notably diagnosing doctors)
 - Treated as unimportant/a lesser person/a nuisance to a busy doctor

- Blunt/truncated discussion, lacking warmth, information and choice
 - From interactions with members of the public:
 - Fear they will look at man differently in future
 - Treated 'like a leper' or invalid
- Anger
 - A transitory processing stage
 - Can be an expression of depression/frustration due to loss of life expectancy, bodily functions, roles
 - Can be associated with self-pity, self-blame or blame of others (notably 'the system') for health status
 - Can be a response to unreasonable, disrespectful, thoughtless, or degrading treatment by medical professionals
 - Expressed by 'non-expressive' men too
- Self-pity
 - Comes in 'spasms' early in process
 - If regarding 'fairness' then may be associated with anger
 - Generally regarded as unacceptable/pointless

Distinctive theme: Empathic distress:

- For wife's shock and ongoing distress
- May associate with guilt

Superordinate theme: 'No distress' reported

Pragmatic 'get-on-with-it' acceptance of each stage in the process reported, perhaps with the assertion that one is 'not an emotional person'. Associated with:

- Acceptable time to die (elderly or has been seriously and chronically ill)
- Optimistic 'we-will-beat-it' attitude, or determination to always make the most of what time is available
- Denial of life threat
- Misinterpretation of health status expressed by doctor
- Diagnosis felt surreal
- Self-pity unacceptable and perceived as the dichotomous alternative to positivity/acceptance
- Rationality demands acceptance or ignoring of dismal prognosis
- **Ambiguous reporting of distress:**
 - Understatement (including humorous or clichéd expression)
 - Disguised as the report of a coping strategy or by the use of euphemisms
 - Justified or rationalised as inevitable (the only possible human reaction, or attributable to medication)

- Simultaneous expression and denial (contradictions, non-lexicon utterances and pauses), possibly evidencing a struggle to accept an overwhelming loss, or the perceived unmanliness of expressing vulnerability
- Taking action to 'put affairs in order' while denying life threat
- Experiencing low mood and hallucination of comfort while denying life threat
- Need safe social situation to express distress
- Expression can be 'therapeutic'

Greater distress burden for particular groups of men

Data indicated that men who adhered to more traditional marital roles and men with less knowledge of how the health system worked could be exposed to greater distress burden. Men who adhered to traditional marital roles could feel constrained from sharing their cancer-related burdens fully with their wives because of their protective role in the marriage, and could experience the added burdens of feeling guilty for their wives' distress about their cancer, and worried for their wives' future emotional and financial wellbeing. This concern regarding wives' present and future wellbeing could exceed concern for their own. Men of lower education and less knowledge about cancer and how 'the system' works could suffer as a result of their ignorance of the standard of performance they should expect from specialist doctors, and a lack of the confidence and knowledge required to advocate for a better standard of performance when appropriate standards were not being met. Examples of this experience were: men being spoken to by specialists in a degrading manner though seemingly not realising that this was unacceptable until hearing how other men had complained about it; the damage to Rodney's business and physical and emotional wellbeing that resulted from prolonged uncertainty about what treatment he would have; and Rodney's self-blame for not knowing that he could obtain a second opinion regarding his treatment options, and the possibility that a second opinion might have led to a less seriously impacting treatment.

While the first of these dynamics is heavily embedded in masculine hegemonic culture and may therefore be very difficult to address, the latter two include a significant component of ignorance, which is a simple – if not easy – matter to address. The provision of information could be important in empowering poorly educated men to

avoid or address a number of potential sources of distress and is therefore central to the intervention suggestions arising out of this research, as discussed in Chapter 11.

The distress processing metaphor

The 'wave' metaphor of distress processing met with universal interest and approval during team discussions (as it required no modification the graphical representation of it is not reproduced in this section). Men were interested to locate themselves in the process depicted, and to consider whether they might go through the process again in the event of a cancer recurrence.

These spontaneous applications of the metaphor suggest that it could be a useful tool for explaining to men the nature of the emotional trajectory that they might experience. I suggested this possible use to the Foxton team and Richard recognised the metaphor's potential power to bring hope to men who were in the initial overwhelming 'washing machine' stage of the process: "That's a pretty strong word eh? Hope. Otherwise you give up." And Buck said the experience of having come through the process 'armed' men to help other people who were just beginning.

However, I found Rodney's engagement with the metaphor most fascinating. Rodney had expressed distress ambiguously during his interview in that he verbally denied any distress but his pauses and false starts while responding to probing questions suggested discomfort. His style comprised a strong preponderance of illusions to traditional masculine norms regarding strength and emotional non-expressiveness. Also, as noted earlier, Rodney reported that he was unable to relate to the written accounts of other cancer patients' shock and distress, saying that for others cancer seemed to be "a big thing" but that he didn't know about that personally because he "didn't feel anything emotional about it". When I explained the process metaphor to the Whanganui team, however, Rodney became uncharacteristically animated and immediately located himself in the process: "Yeah, (little laugh) I quite like that one. For the first part of it... to me, I think I'm still in that wave, even though I've got my feet in the sand..." He described his ongoing worry about recurrence and his (mistaken) concern that if that happened, it could be pancreatic cancer with a very short prognosis, as had been the case for a friend. This suggested that a lack of knowledge as to the natural course of his prostate cancer may have contributed to stalling Rodney's progress through the

processing of his cancer-related distress towards 'equilibrium'. I suspect that his emotional non-expressiveness may have contributed as well, e.g. it may have impeded his ability to identify the nub of his concern, preventing him from obtaining the information needed to free himself from worry.

Most importantly though, it seemed possible that the abstract metaphor of a wave provided Rodney with the 'language' and/or safety he required to allow him to consider and discuss his cancer-related vulnerability. If so, this metaphor could also be a powerful tool to assist other men who do not recognise and/or report distress or concerns openly. It was exciting to see the enthusiasm Rodney had for engaging with the metaphor, and his preference for it ("I quite like that one") over the descriptions of distress and coping themes which used direct language regarding emotion rather than the language of control and an abstract image.

The Māori team offered an interesting refinement to the process metaphor. They noted that gaining a new equilibrium to them meant finding "another gear" (Paul) which involved both a refreshed appreciation of life and loved ones, and addressing their physical limitations by making the transition into a mentoring and organising role, which is appropriate to a more mature stage in life in Māori culture. This new role is described below, as a means of coping.

Summary of processing metaphor

I conclude this subsection with a bulleted summary of the features of the 'wave' processing metaphor integrating points from both phases of investigation.

Summary of processing metaphor features

Overall process: Cataclysmic loss of control followed by gradual regain to a point of equilibrium

Shock / loss of control and Overwhelm / disorientation: 'In the washing machine'

Like being suddenly 'dumped' by a rogue wave at the beach, and disoriented as in a 'washing machine' not knowing 'which way is out'. May coincide with diagnosis and treatment planning phases.

- Unexpectedness
- Busyness

- Huge array of unknowns, regarding the disease, the systems for dealing with it, and the effects it will have on oneself and one's family
- Anxiety relating to various aspects of lost control may be felt, including concern for dependents and anxieties or despondency regarding death threat
- Empathic distress and some of the 'black' emotions may begin to be felt, e.g. degradation, self-pity and anger
- May begin to become despondent about anticipated or actual losses, and may begin to process them

Realisation of hope and Engagement with the challenge: 'Finding your footing'

Like finding one's footing and dusting oneself off. May coincide with treatment planning / early treatment phases

- Realisation that there is still hope and a future to be lived
- Realisation of agency and reassertion of control, determining to make the most of what opportunities are available
- Realisation of the social support available
- Beginning to settle the myriad unknowns and form priorities
- Beginning to understand the physical and social implications, feeling and processing the losses that will occur
- Beginning to strategise as to how to move forward, including pulling together human and other resources
- May settle into depression rather than temporary despondency about anticipated or actual losses or 'black' feelings if adjustment processes do not progress, i.e. sadness from loss not recognised or loss not grieved, hope not realised, coping strategy not engaged with

Persisting through trials: 'Never give up'

A 'hard slog'. May coincide with treatment and post-treatment phases, including adjustment to treatment side-effects

- More understanding and settling of unknowns and strategies, involving high and low points as good and bad news comes to light (e.g. test results and treatment options)
- Hard work and endurance required as treatments and implications regarding losses continue to be worked through.
- Adjustment to very significant losses may involve the adoption/learning of new strategies/roles and new self-image. Flexibility and social support are required
- May settle into depression if adjustment processes do not progress
- Deep appreciation of social support

Equilibrium / achievement: A 'new gear' is found

May coincide with post treatment phase

- Renewed appreciation of life and loved ones
- Adjustment achieved in relation to major losses, self-image and role transitions
- Relief and/or satisfaction at having 'beaten the bogey', i.e. cancer or the dread of it
- Regained an acceptable level of control of life, including awareness of possible future threats

Coping themes

The description of coping was found wanting in one important respect, and men elaborated on other points.

Helping others

The importance of helping others was previously understated (mentioned under 'Personal growth' as a minor theme). However, the Foxton team talked about forging whole new roles around helping young people when their cancers forced change from men's previous lifestyle, and I realised that this powerful means of coping ought to be listed with the other four 'main' ones, as the reciprocal aspect of social support. These Māori men took advantage of their cultural resources – large informal whānau-based networks and the expectation that they would become mentors and organisers as they grew older – to overcome their loss of physical lifestyle (both wore ostomy bags which precluded most of their previous work and leisure activities, and both had also been forced to curtail sexual relations), defend against self-pity, and become active and purposeful again:

Paul: Yeah I just keep active, even if I can't do... I still keep my mind going... Yeah, I've got people coming, I've got people fishing, I've got all that happening. So it gives me an interest. () ...I get the younger fellas to do the job.

Me: So you've got, like, an organiser role now?

Paul: Yeah, I can organise everything and I can use all I know. () Yeah, yeah – to up-skill other people. Because I can't lift, know what I mean?

Me: You've got a real role in terms of passing that on, right?

Paul: Yeah, you've got your knowledge...

Me: So would it be fair to say that its quite a natural transition? ... to say, 'Well, ok, I can't do the straight muscle job now, but I can...' Its actually the right time in life anyway to be talking to other people?

Paul: Yeah, it is.

Richard: Mmmm.

Paul: It is for me anyway. And all the young fellas listen.

Richard: Yeah.

Buck: Of course.

Paul: Yeah. They're all there to learn. But I teach them how to weld, how to paint, how to panel beat cars... something that you can save money with for your family... fishing... at least at the end of the day you've got a feed you can take home, you know, food is there. And I've got all these skills and I've got all the equipment, which I had before I had the cancer, and instead of just selling everything off and just sitting there looking out the window, () I'm using it with anyone who wants to come around and learn. Or you want a feed of fish or....

Richard: I'm the same on the guitar. I've got drums now. And now I've taken back the old harmonica...

Me: Right, so you're expanding on that front. [.....] So it sounds like you've got a real mentoring role going on?

Buck: Yeah. You have good input at the other end.

Paul: Yeah. And I get a reward out of just seeing... Well, a young fella came from college yesterday and [Paul is teaching him how to weld].

I note that none of the Pākehā men spoke of taking up new roles due to cancer, though some said they had taken up minor community roles following retirement. However, nearly all interviewees said that they participated in the research with the motivation of helping others.

Social support

In team discussions men elaborated on the nature of some of the social support that they particularly valued.

Colin elaborated on his surgeon's support in keeping him positive as he went through treatment: the concern and empathy he showed by reducing his fees to an amount Colin could afford, advocating to other specialists for Colin to get optimal treatment, and delighting in telling Colin the good news of his test results; the encouragement he gave

Colin by expressing his confidence that he was a patient who would do the full treatment and get a good outcome, and by repeatedly reassuring him that he was doing well; and the fact that he spoke to Colin 'on the level' – "He'd talk to you like we are talking now, you know, it was not like a professional and patient thing" – always concerned to inform Colin of information that might interest him, without waiting to be asked. All of this contrasted starkly with the treatment some men received from their doctors which left them feeling diminished and distressed rather than encouraged and assured. Colin's surgeon's approach promoted a number of the coping factors identified in this research: positivity, rationality and control (through the provision of information), and the emotional aspects of social support.

In similar vein the Levin team emphasised the support of radiation therapists. Arthur had been afraid of radiation therapy but the therapists "made you feel relaxed" by their caring and friendly chattiness. Reiterating the oft heard appreciation of professionals who treated men 'on the level', Arthur said, "they weren't authoritative, if that's the word – bossy".

Arthur also described some of the support he received from people at work who had themselves "been through the mill" and had a good understanding of what he was experiencing. Some such women were particularly supportive:

Arthur: And some days I was on a real downer before I had the op, because I was wearing a catheter, and I was having bad days, and they were, you know, trying to chirp me up a bit, you know. They could tell by the tone of my voice that I was 'blah', but by the end of the day they'd have me in fits of laughter.

The Foxton Māori team emphasised the importance of their families, and how their children and mokos "just turned up" and put mattresses on the floor, expecting to stay, whether they were needed, or asked, or whether the timing was convenient, or not.

Buck had retired since his interview the year before and said he saw so much of his family that he was "living alone, but not". Richard said, "My mokos, even when they're naughty I appreciate them being around now", and, "When they leave, its cold!"

These men were amazed when I told them that Pākehā men might refrain from telling their children the seriousness of their condition in order to prevent them from being burdened by it and rushing to see them, and that they might see their grandchildren once every week or fortnight at an arranged time. Buck suggested that with such a

"regimented lifestyle" he could see a role for social services to step in and organise visits or a cup of tea!

A positive attitude

An aspect of positivity that I failed to explicate earlier was humour. As mentioned above, Arthur found humour very useful to keep him positive through the more difficult phases of treatment. He also recounted men in the cancer ward who were "more or less at the tail end of it" using humour to get them through. Freddie was at that stage with his lung cancer, and in his interview said he would not be interested in attending a men's group unless they were like him, i.e. 'going laughing'. Richard also spoke of how the naughtiness of his mokos amused him and kept him going when they visited him *en masse* while he was in hospital dealing with serious complications from his major surgery which left him feeling very low and degraded. Thus humour seemed to have particular value for coping with some of the most difficult aspects of cancer – terminal stage experience and particularly difficult and degrading aspects of treatment.

Being active

The men in the Foxton team, two of whom had limited literacy, emphasised how important keeping active was to their well-being:

Paul: There's got to be something out there for me every day. I told me doctor, I said, 'If I'm going to die, doc, I'm going to die outside.'

Richard and Buck: Yeah.

Paul: I'm not going to be lying here, reading books and watching TV.

Richard: Not me either.

In particular, stepping out and doing something for others (as discussed above) was a vital strategy against self-pity. But the decision to do that came down to a battle of the mind:

Richard: That's just got to be clickin' eh? (tapping head) That's got to click over, eh? That's got to click over. ()

Buck: Yeah, know your goals, know...

Richard: I have been to this place where... 'Ahh, fuck it! Fuck it!' Of course. Just plays with your head. Messes you up. But then you just get off your arse and go and do something. Its not so bad.

[Richard and Paul then discussed their mentoring of young people.....]

Paul: ...But you've got to be confident, you've got to have... mentally. Its only in your head, you know?

Revised graphical portrayal

I revised the graphical portrayal of the coping themes to highlight 'Helping others' as a reciprocal aspect of social support (Figure 9-2, below). As noted earlier, although the themes are drawn discretely for simplicity, the reader should remember that there is a great deal of association between them.



Figure 9-2. Revised coping themes

Summary of coping characteristics

Once again I conclude the subsection with a bulleted summary integrating material from both interview and discussion phases. The extensive association between themes is evident. For example, being active was seen as a means of maintaining a positive attitude, and having a positive attitude promoted activity and helping other people.

Note also the 'dark' or 'ironic' side to some of the means of coping, which could prove counterproductive to maintaining optimum physical and/or emotional wellbeing.

Summary of coping themes and features

Superordinate theme: A positive attitude:

- 'Don't let it beat you' / 'Never give up' / live as normally as possible
- Shun all negativity / self-pity
- Humour useful against the most difficult and degrading aspects of disease and treatment
- Possible 'dark' side: some men deny seriousness of illness in favour of positivity at possible cost of lost opportunities

Superordinate theme: An active and practical orientation:

- Keeping busy seen as vital to enjoying life generally and to keeping negativity and self-pity at bay
- Accept reality and 'get on with it', i.e. be decisive, take necessary action (treatment, putting affairs in order) and then live as normally as possible
- Practical support appreciated
- Possible 'dark' side: some men by-pass opportunity to investigate alternative treatment options in favour of decisiveness

Superordinate theme: Rationality and control:

- Think through treatment decisions coolly and rationally, including cost-benefit analysis
- Conscious strategising to control distress and keep negativity at bay
- Take control of treatment process when possible to minimise distress
- Irony: could involve ceding control of treatment to 'expert' specialists, with varying levels of understanding, and varying complacent faith in, and 'reverence' for, their knowledge and status

Superordinate theme: Social support / helping others:

- Appreciate understanding, encouragement, information and practical support offered by other people
- Great range in the amount of emotional support received, associated with level of emotional expression and ethnicity
- Vital supporters were wives / other women in the family.
- Protective / unilateral tone to the care of women associated with non-expressive Pākehā and with Māori ethnicity, and was appreciated

- Men supported their families both practically (putting affairs in order) and emotionally (differing by ethnicity)
- Next most important supporters included doctors (for Pākehā), friends, and, for Māori in particular, wider whānau (notably mokopuna) and church leaders.
- Medical professional communication that was 'on the level' and warm was most appreciated
- Community members who had experience of illness were 'safe' to disclose to and understanding
- Some Māori transitioned to rewarding new role as mentor of young people and organiser
- Helping others a strategy against self-pity
- Desire to help others widely expressed

Other themes:

- **Withdrawal:**
 - A brief adjustment mechanism, or
 - An ongoing retreat from emotional or physical pressure
- **Crying:**
 - A cathartic release of tension or disappointment, or
 - An expression of despondency associated with loss or loneliness
 - May not be acceptable to the man himself
- **Spiritual beliefs and support:**
 - Variety of levels of engagement with Christian faith including comforting trust and confidence, appreciation of the ministry of church leaders, and personal engagement with God regarding emotional and practical cancer-related issues
 - Other beliefs included fatalism, the belief that one goes to be with a loved one after death, and traditional Māori beliefs
 - Beliefs were usually reassuring and brought peace
- **Personal growth:**
 - Growth in empathy for others
 - Increase in appreciation of life and of family
 - Growth in personal maturity and physical health possible
 - Satisfaction from how handled the challenge of cancer
 - Generally alcohol and drugs were avoided
- **Psycho-social service use:**
 - Little use of counselling or support groups
 - Māori Cancer Coordinator especially appreciated
 - Māori may particularly appreciate support groups

10 INTEGRATION WITH MASCULINITY LITERATURE

The analysis approach and findings I have discussed so far have been grounded very much in the reported experience of participants, in accordance with phenomenological and PAR theory (Dick, Stringer, & Huxham, 2009). In this chapter I provide a further analysis, this time in the light of theory in the masculinity literature discussed earlier (Chapters 3 and 4). Then, in the two remaining chapters, I explain the central role of information in men's distress and coping, and the practical implications of the findings for intervention, and their overall value.

The masculinity literature suggests that some of the distress felt by men in the context of cancer is distinctive to them, as men: Gender Role Strain Theory emphasises 'strain' as a product of perceived disparity between a man's performance and his internalised social norms regarding manhood (Pleck, 1995), while Connell's relational model of masculinities predicts stress as a man perceives threat to his position in the gender hierarchy (Connell, 1995, 2005). Means of expressing and coping with distress are also constrained, shaped, and enabled by social constructions of 'what men do' and pressure to maintain masculine status (Courtenay, 2000; Levant et al., 1992). Thus, cultural norms of masculinity are important to any discussion of how men feel about, and cope with, their cancer.

To structure this discussion I select four sets of norms associated with traditional or hegemonic masculine behaviour, then discuss the relevance of each to my findings regarding the nature of the distress shown by participants, their (four main) ways of coping, and the trajectory indicated by the distress processing metaphor. This exercise is intended to locate cancer-related issues which were of particular significance to the participants as men.

The first set of norms is 'avoid feminisation/emasculatation'. Anti-feminisation has been long established as fundamental of traditional (Western) masculine norms (David & Brannon, 1976; Levant, 1992; Thompson & Pleck, 1986). Emasculation is by definition anathema to masculinity, and may be associated with feminisation because of the traditional tendency to dichotomise gender (Levant, 1992).

The second set is 'provide for and protect your wife and family'. Levant (2011) relies on ethnographic scholarship to say that masculine roles of provider and protector are characteristic in most of the world's societies.

The third set is 'be positive, strong, and active'. Strength is the focus of this set, and carries connotations of toughness and self-reliance. It is, again, a well recognised masculine norm (David & Brannon, 1976; Levant, 1992; Thompson & Pleck, 1986) and carries the expectation that the body will be able and active to facilitate its performance (Connell, 1995, 2005). I have added positivity to this set because its importance was very widely affirmed by the present sample of men, because of its natural association with activity (Teychenne, Ball, & Salmon, 2008), and since it opposes the indulgence of fear, self-pity, or despondency, which are anathema to hegemonic masculine norms.

The fourth set is 'restrict emotionality, maintain control, and be rational'. Again these masculine characteristics are well recognised, and are also important to hegemonic status, since they convey an air of calm appropriate to leadership (Connell, 2005; David & Brannon, 1976; Levant, 1992; Thompson & Pleck, 1986).

Whilst there are other norms that may be considered 'core' to traditional masculinity (e.g. risk taking), I have selected these four sets for their high relevance in the cancer context.

Avoid feminisation/emasculation

An element of the distress felt by some participants was due to aspects of their cancer diagnosis and treatment that were experienced as feminising or emasculating and therefore diminishing or degrading. While some of this experience was inherent in the nature of medical procedures or their side effects, much of it was associated with a loss of control or a subjection to the power of another, both of which are remediable.

Medical procedures and their side effects

Emasculisation can be thought of as a feeling of loss – or theft – of manly power, potency or essence. It may be most clearly exemplified in the diminishment felt by some participants as a result of their loss of sexual potency as a side-effect of prostate

cancer treatment, or in their loss of control over bodily functions (erectile and continence).

I observed three aspects of loss associated with treatment-induced impotence: loss of personal pleasure and fulfilment, damage to intimate relationship, and diminishment of masculine self-image and status. The relative and absolute gravity of each of these losses, and their importance to masculine self-image, varied greatly between men, and produced a wide range of reported distress experience.

Some literature places sexual potency at the centre of masculine identity. Connell (1995, 2005) does this, Robertson (2007) affirms it in the context of health and disability, and Abel (2002) affirms it further in the context of his sample of African American men with prostate cancer, calling sexual potency the "cornerstone" of their masculinity (p.26). But only one of the present participants clearly expressed concurring sentiments: Harry said he felt "inadequate, cheated, or um... not a whole man" because of the discontinuation of his sex life. He also said that he felt diminished in the eyes of other men, because (534),

...we [men] think that we're bullet proof and, um, can go flat tack every day, and can bang off anybody they see, and for hours on end, and anybody that can't is not with it. () Mmm. You know, if, if you're not in that league, you're a sissy or not worth dealing with.

It may be that some other men felt similarly to Harry but were too embarrassed to put their loss into words. Rodney felt disturbed when told he had "old man's disease" by an acquaintance (a reference to his prostate cancer), and Richard said, during team discussions, that he essentially hid at home because he felt whakamā (shy, embarrassed) after surgery removing his prostate and bladder, although the loss of his long 'muso' hair was an important factor in this (as discussed further below). Both were unhappy with their loss of potency.

However, I noted no other indications that participants felt diminished as men in the eyes of others, and none were prepared to say that they had become 'less of a man' in their own eyes either. Several denied any significant stress from losing their sexual potency, citing compensating or mitigating factors including extended lifespan, loss of libido as another side-effect of treatment, staunch spousal support, age-related family roles (with grandchildren or whānau of that generation), and aspects of their cancer

experience that had enriched them (e.g. learning greater empathy for others or gaining better overall health). Often these men normalised and accepted the loss of erectile function saying it was 'a sign of getting older' (as was the reaction of part of the sample of prostate cancer patients in Maliski, Rivera, Connor, Lopez, & Litwin, 2008).

Charmaz (1995) called it 'awakening to death' when the seriously ill participants she interviewed were confronted with the need to modify their lifestyle to such a great extent that their identities were threatened in order to survive. However, all the men in the present study who were confronted with the loss of sexual potency as the price of survival chose that option (as was usual in the Maliski et al. study also), and generally they asserted that they remained 'the same man' that they were before treatment. Two even claimed that they were 'more of a man' due to what they had learned through cancer.

None of the three men I have mentioned (Harry, Rodney and Richard) could console themselves with the thought that impotence was normal and therefore acceptable due to their age. Both Rodney and Richard were still in their fifties, and although Harry was in his seventies he saw no reason why age should alter his expectation of a normal sex life. These men's expectations differed from those of the men who considered sexual impotence a normal part of growing old. This difference in expectation is significant in terms of gender role strain theory, as 'discrepancy strain' only occurs when a man's expectation of his masculinity is not matched by his self-perception. Thus, for men who considered it normal that sexual performance would be curtailed by age, an adjustment may have been required concerning stage of life, but not concerning masculine identity, and adjusting to aging would be relatively easy since it was to be expected as a natural process.

In terms of the relational model of masculinities, it could be argued that all participants who lost potency should have felt stress relating to recognition that they had lost masculine status. However many of the men appeared to already regard themselves as far from the hegemonic ideal, so another signal of marginalisation meant little if anything. For example, when I asked Buck whether his masculinity had been affected by his prostate treatment, he said that he had never considered himself "much of a man" anyway, and that what he had learned about other people's suffering made him "more of a man". Buck was a Māori of Mormon faith, who had little education, a modest paying

job, was heavily involved with his family, and enjoyed his sport and his many friendships. His concept of manhood reflected Māori cultural and spiritual values – he tangata, he tangata, he tangata (it is people who are important) – and his concept of his own masculine status also reflected those values – don't be whakahihi (conceited)! In the Māori world it is appropriate that a man becomes more knowledgeable about people as he gets older and may assume kaumātua status. The young are honoured for their physical strength, while seniors are honoured for their human and spiritual wisdom. Buck could see that perhaps he was not "much of a man" by the hegemonic standards of broader New Zealand society, but by the standards of his own social world, he had actually grown through cancer.

But Harry raged against his loss of sexual potency. Compared with most of the sample, and, indeed, compared with most men in the provincial regions from which the sample was drawn, he had been a 'high flyer' during his working life. He was tertiary educated and had held significant management roles before entering semi-retirement working for himself. His work had also always demanded a manly degree of physical skill and strength and had a 'rugged' image. Furthermore, sex had always been very important to him. Thus both Harry's self image and his outward image fitted New Zealand masculine 'hegemonic' ideals of strength, competence, and virility quite well, and during Harry's years in senior employment positions he would have been accustomed to having his presence and opinions recognised. The loss of his sexual potency, coupled with his unreliable continence, may have been the sharpest blow to both his self image and his public image since his retirement. From the quotes above it appears that he felt both were threatened. However, of the three types of loss associated with sexual impotence, the one that distressed him most was his loss of personal pleasure and fulfilment. Harry is a bold and confident character who talked to male friends and hobby club acquaintances about his illness and treatment side-effects. This is not how a man behaves when he is fearful of losing social status. The loss that was most important to Harry was about personal fulfilment, not social status. And in Richard's case status was never intimated. His losses were clearly about personal fulfilment and intimate relationship.

My findings suggest that the factors which were most strongly associated with distress concerning loss of sexual potency had little to do with masculine status. They were:

whether the loss was congruent with the man's age-related expectations of sexual performance; whether the loss of sexual pleasure was cushioned by an accompanying drop in libido; and whether his intimate partner's response also cushioned the loss and supported the man's dignity. Where intimate relationships had been based strongly on sex, libido had not diminished, and expectations had been dashed, distress was felt from loss of both personal pleasure and relationship quality.

There were other particular medical procedures and side-effects that men found distasteful and sometimes distressing as well, namely, prostate biopsies, prostate digital examinations, wearing a catheter, incontinence, and wearing an ostomy bag. The degradation felt likely had connotations of sexual invasion (feminisation or homosexuality) or of having a senile/childlike lack of control. Both of these connotations could be regarded as symbols in terms of Connell's (1995, 2005) relational model of gender relations, and their implication is severe – if temporary – diminishment in masculine self-image and possibly status. In many cases, however, men mentioned no discomfort around such procedures, and in some (notably, prostate biopsy) they said their distress could have been largely or completely mitigated by the provision of more information beforehand about what to expect the procedure would feel like. The real cause of the degradation/emasculatation felt in such cases was therefore the approach of the administering medical professional, which is a matter discussed further below.

It is interesting that when men experienced temporary 'feminine characteristics' as a result of treatment, such as hot flushes and emotional fragility or depression from hormone treatment, they were often laughed off or seen as 'an education' (e.g. 'power surges' were noted as a point of solidarity with men's wives), but appeared to pose no threat to their masculine identity. However, in the case of Colin's breast cancer diagnosis, which could not be attributed to a medication or some other external and temporary force, the feminine connotation clearly left him feeling vulnerable to ridicule or diminishment in the eyes of other men. Colin consequently avoided disclosing to men who did not already know and respect him – even the men's cancer support group.

Loss of control and subjection to the power of another

The data suggest that emasculation or disempowerment was an aspect of the 'disturbing lack of control' noted by men, and was sometimes due to the approach of particular

helping professionals. Men had strong adverse reactions to perceiving that a helping professional (usually a male specialist doctor) was wresting control from them, for example, by withholding information or by being too directive. Men felt alarmed, annoyed, affronted, angry, alienated, and/or degraded and sometimes actively resisted, curtailing cooperation or seeking alternative assistance. Other times men capitulated resignedly, feeling powerless to take any action because of their lack of social status or knowledge of health matters. These are the reactions of men who feel an insult to their person.

For example, the three Māori men comprising the Foxton team adamantly expressed their desire to be told "the whole story" about their disease status, and were clearly uncomfortable with the awareness that they may not be in possession of that understanding despite having had extensive treatment. One of this group, Richard, earlier described a "pretty invasive" lack of control when a home helper (who could "take over your house, and your stuff") was assigned to help him after his surgery without his knowledge, and said he eventually told her to leave. David's specialist repeatedly urged him to have prostate surgery, without presenting any other options to him. Deeply afraid of any medical intervention, David resisted this pressure and, after significant time lapse and disease progression, eventually found his own way to a specialist who, with explanation and gentle warm encouragement, persuaded him to have radiation. David said that he might have been persuaded to have surgery at the outset had his first specialist taken the same approach. However, he was surprised to learn, during the interview, that he may lose his sexual potency eventually as a side-effect of the radiation.

The 'disturbing' qualities of these interactions may include both the diminishing feeling of emasculation – a theft of control over one's own body and life by the subtle or openly coercive action of a powerful other – and an element of betrayal of trust. In some instances this combination may perhaps feel like a rape by stealth. I wonder how David felt as he contemplated the implications of not being told that he may become impotent, both regarding his life and self-image, and regarding the confidence he had placed in his second specialist. He was not the only man who was not told of this side-effect.¹

¹ Could men have been told of the likelihood that they would suffer erectile dysfunction as a side effect of treatment, but, in the pressures of the moment, failed to 'hear' this? There were men who provided

Poorly educated men are the most exposed to such poor treatment since they are not familiar with what standards of communication and autonomy are to be expected and are less capable of advocating on their own behalf.

Similarly men could feel emasculated – "inadequate" or "belittled" (Levin team) – when their doctors treated them in ways they perceived to be cold, dismissive, arrogant or "authoritative" (Arthur). Although men who had more education or higher level vocational experience also found such treatment distressing or distasteful, they may not have been so vulnerable to feeling diminished by it, since they knew the behaviour was substandard and that other options for assistance were available. In terms of the relational model of masculinities, medical experts are icons of hegemonic masculinity. Cancer places male patients in a position of dependency upon them, heightening the visibility of any extant status differential, and creating a differential where there wasn't one before. While men are 'under' specialists' care, they are very vulnerable to being degraded by words or attitudes that are insensitive to, or disrespectful of, their position. Such unsatisfactory interactions with medical experts seemed to be the forms of emasculation that were most widely felt.

Provide for and protect your wife and family

Regardless of whether men reported being distressed on their own account, they readily expressed their worry about how their wife and family would cope financially, and their sadness that they would not be able to continue to support them personally, in the event of death. These concerns were often pre-eminent, in the sense that they were the first thing men thought of when diagnosed. They appear to be associated with a broadly felt manly responsibility to provide for and protect one's family. Acknowledging distress or concern about the prospect of being unable to continue to fulfil these roles therefore

evidence to the contrary or to the effect that what was conveyed was cloaked in obscure language, and certainly that the matter was not discussed with the thoroughness and clarity its importance warranted. Harry said that although he could not be sure that he was not told, he thought he would have heard if anything had been said because the matter was so important to him. Also he said his partner, who attended consultations, did not recall anything being said about sexual dysfunction either. Arthur said that he was informed by way of a paper which said he could experience "problems" with sexual activity. He felt that professionals were "ducking" discussing the matter openly. Given the vital importance of the matter to men, and their embarrassment at raising it, it is surely incumbent upon medical professionals to inform men and engage them in discussion of the issue in the clearest terms as a part of obtaining informed consent to treatment. If this had been done, there would be no doubt that the matter had been raised.

affirmed, rather than negated, one's masculine status, and consequently did not pose a problem for men.

However, a distinction appeared in that only men with a more traditional view of their marital roles felt guilty and distressed at having burdened their wives with distress about their cancer. This can be read as an example of gender role strain in that these men were feeling the 'discrepancy' between their traditional expectation of protecting their wives and their perception that, on the contrary, they had 'dropped her in it'. Other men did not indicate experiencing such guilt, and their talk suggested that they fully expected to share the load of their predicament with their wives.

It was interesting to observe that where men had been to some significant degree dependant on their wives/partners or daughters for their personal care, they invariably lavished high praise upon them. This affirmed women in their role as expert caregivers, highlighting a gendered role distinction, and thus by implication affirming their own masculinity despite their dependence and, perhaps, reduced ability to fulfil their provider and protector roles (as described also by Charmaz, 1995). The same dynamic was apparent when the Pākehā men with more traditional views submitted to the assertion of authority by their daughters regarding their treatment, and when Māori men submitted to the assertion of authority by women of their own generation from their whānau (remember that none of this sample of Māori men had wives).

Be positive, strong, and active

The expectation of being strong and active – to live life as normally as possible – was normative to this group, and is characteristic of masculinity (Connell, 1995, 2005). This expectation was apparent in dissatisfaction expressed about any ongoing experience of lost energy. The degradation of this state was apparent in the way two men chided themselves as "lazy" for the ongoing loss of energy and motivation they continued to suffer some time after treatment.

Maintaining a strong, active and positive masculine identity is indeed problematic in the face of terminal prognosis, physically disabling, or socially embarrassing side-effects of treatment (Maliski et al., 2008; Robertson, 2007). In the subsections below, I first

discuss how men experienced visible physical deformity, and then issues of denial and flexibility raised by how they conceptualised strength.

Visible physical deformity

Whether or not visible physical deformity resulting from treatment was a source of reported discomfort or distress appeared to be influenced by masculine norms regarding body image, included here under the general rubric of 'strength'. The two men who suffered facial disfigurement from parotid gland surgery both denied feeling distressed by it. Jacko seemed to be indicating that this was a matter of masculine ruggedness and character when he responded to my enquiry as to whether it concerned him like this (468):

P: No. I've, I've never been a vain person. You know, I like being tidy and all that sort of thing, but I'm not a, not one of these guys running around preening themselves in front of the girls. Ahhh, my attitude to that has always been [...] 'A guy's nature is much more important than his looks. You can't live with an asshole'.

An interesting characteristic of Jacko's response was the dichotomies it drew. He leapt to the extreme contrast of vanity when merely asked if his appearance concerned him. He then made a further leap to contrast a concern about facial disfigurement to poor character. This tendency towards polarisation or narrow definition in the context of masculine strength will be discussed further below. Suffice it here to say that 'tidyness' seemed to be Jacko's standard for manly appearance, so surgical facial disfigurement was not damaging to his masculine self-image.

Richard, on the other hand, lost his confidence to appear in public when his long hair fell out as a side-effect of chemotherapy. He had lost the visible sign of his highly valued masculine identity as a 'muso', and, despite the fact that he retained all his musical skill and the hair loss was only temporary, it affected him deeply. Having low education and income, it may be that Richard felt he had limited alternative resources from which to exhibit a strong or competent masculine image (Courtenay, 2000). He later drew upon his musical skills to develop a new role for himself mentoring young people. This was vital because by then he had also lost his previous identity and lifestyle based on his physical strength due to stoma surgery. Charmaz (1995) speaks of

the importance of men developing such new valued masculine identities when past ones are lost due to illness.

Colin also experienced sensitivity regarding his visible appearance which seemed to be associated with masculine norms. In his case the threat came from the feminine connotations associated with his scar from surgery for breast cancer. He said he wore a tee-shirt to cover it when swimming in some contexts, but grew less sensitive to the issue over time.

Strength and denial

The ambiguity in some men's denials of distress betrayed the pressure they were under to always present themselves as strong, positive, and fearless in accordance with masculine norms. Dismal prognosis and sexual dysfunction were the issues that sometimes proved sufficiently overwhelming to expose their discomfort in signals at variance with their words. And some men appeared to feel obliged to deny the life threat posed by cancer in the cause of remaining 'positive'.

Men who denied distress, either ambiguously or not, usually displayed their allegiance to masculine norms regarding strength throughout their interviews. Some explicitly declared themselves 'not an emotional person'. In (only) two instances such men surprised themselves with new experiences of emotion or expression, as cancer expanded their life experience. It was interesting to observe them interpret these instances in an acceptably 'strong' way. For example, Mike attributed his brush with depression solely to a side-effect of medication, despite both his doctor's contrary opinion and his own awareness that loss of control in relation to work triggered the episode. The threat that 'mental weakness' posed to his self-image was exposed in his reaction to his doctor's opinion: "I actually blew my stack" (547).

Some of the apparent reasons for reporting no experience of distress were characteristically masculine. Those reasons were: a masculine discomfort with admitting a lack of strength, either to someone else, or even, perhaps, to oneself; an expression of the masculine obligation to 'remain positive', as mentioned above; Levant's 'normative masculine alexithymia' (Levant, 1992), i.e. men did not recognise their own distress or were not able to put it into words; what Charmaz (1995) calls

'bracketing' of illness, i.e. compartmentalising it away from the rest of one's life, as a discrete event, in order to avoid having to confront and integrate its massive implications for lifestyle, future, and self-image (I suspect that Lewis was doing this in his apparent determination to focus on how active he was rather than consider the life threat posed by his illness); and lack of awareness of the seriousness of one's disease.

Strength and inflexibility

Continuing to live an active normal lifestyle was very important to men. Keeping busy was recognised by some as a strategy against self-pity, and activity also appeared essential to men's self-image. As Paul said in team discussions, "There's got to be something out there for me every day" and, he wanted to "die outside". Paul was not capable of the physical work that he previously did, but was happy with his new roles organising and mentoring others, and continuing with his participation in community causes. Richard handled his loss of physical capabilities similarly, keeping busy and productive by mentoring young people in musical skills.

This strategy of developing new masculine roles/identities in order to recover from damage to other identities was noted by Charmaz (1995). She also noted, however, that not every man has the flexibility to make such a 'gear shift': a man needs the ability to make meaning out of the situation and the willingness to grieve his losses. Paul and Richard were the only men who reported inventing whole new roles and identities in order to cope with lost lifestyle and occupation. As noted earlier, their capacity for flexibility may have been enhanced by their Māori culture which offers an extended range of ways to prove one's masculine worth as one ages, and which included engagement with wide whānau networks.

However, when it came to sexual impotence, Richard had not conceived of how to reinvent his way of relating to his intimate partner, and he lost that important relationship as a result of his own discomfort. Bruce was the only man who, after losing sexual potency, oriented himself towards rebuilding the sexual aspect of his relationship as "a challenge" to be met in partnership with his wife. For other men, the loss of sexual function was a dead end which they could either accept or could not, but there were no other options.

Brucie's flexibility may have been enabled by a number of factors: he was an educated man, he was relatively young (55), he was emotionally expressive, and he was not traditional in his attitude towards masculine strength. He was able to state frankly that he had been depressed about his prognosis and that his wife had been helping coach him through it, and he did not seem embarrassed to shed a few tears during his interview. In the relational model of masculinities Brucie might be regarded as 'complicit' rather than 'hegemonic' on account of his egalitarian attitude towards his wife. This expression of masculinity offers a much broader range of options, both for the reshaping of a man's own masculine self-image, and for his wife's role in assisting. Indeed, both gender role strain theory and the relational model recognise that a hallmark of traditional/hegemonic masculinity is the narrowness and unattainability of its standards, which effectively set men up to fail. Brucie's broader definition of masculine strength and marital roles opened up options not available to men with more traditional expectations.

For some men, their narrow definition of strength seemed to constrain them to play out contradictory behaviour. These men had more traditional views of masculine strength and were emotionally non-expressive. They seemed either to recognise only physical strength, or else to additionally define emotional strength as restraint of emotional expression. Some repeatedly used rhetoric like 'I won't let it (cancer) beat me', in a context which suggested they meant that they would physically overcome it, despite a clearly communicated prognosis of imminent death. This narrow definition of strength constrained such men to verbally deny reality rather than to 'be beaten' as a man – both in respect of their self-image, and in their role as family protector. Hank and Jacko were prime examples. Yet Jacko was only a few weeks from death at the time of his interview, and he was well into the time period that his doctors had predicted, while Hank's prostate cancer was riddled through his bones and he had already well exceeded his predicted lifespan.

The denial of imminent death carries a heavy opportunity cost, leaving men in a peculiarly masculine dilemma: be 'strong' and 'positive' by denying imminent death and all associated emotional concerns, but at the cost of failing to put one's affairs in order in accordance with one's manly responsibilities to protect and provide for wife and family; or, be 'weak' and 'admit defeat' in order to discharge those responsibilities. Robertson (2007) noted complexity and balance in how men handled their health in

order to avoid damage to their sense of masculinity, and it was interesting to see how Jacko and Hank manoeuvred through this dilemma: they simply acted one way and spoke the other! They carefully avoided enunciating their prognoses even though this was the driver of their actions, without any hint of recognition or excuse for the contradiction! Both men were farmers and family men, and both had diligently put both business and family matters in order after being told of their prognoses, yet both spoke optimistically and determinedly of 'beating it'. Thus, for lack of a definition of 'strength' which could accommodate physical demise and emotional openness, these men were forced to use a rhetoric which their actions showed they knew to be false.

Jacko's interview showed how the need to protect a masculine self-image of strength and self-reliance affects the behaviour of supporters as well. His wife and her female friends (he had no daughters) found ways to comfort him which showed an understanding of his dilemma and did not press him to speak the unspeakable, e.g. his wife's friends sat by his bed and held his hand while chatting and gave him lots of hugs. Thus they also entered into the 'complex balancing' (Robertson, 2007) needed to protect his masculine identity. However, Jacko's male friends appeared to be left with no way to approach the topic of his terminal illness. Notice their avoidance in the following passage, despite Jacko's obvious preference for the women's approach (244):

P:one of the things that happened, just from my observations, is that women have much better empathy: if a woman gets cancer, generally all her mates will just rally round () and do those sort of things. () Ah, a lot of guys have a problem: they don't know what to do. () They would, they would like to do something, but they don't really know what to do. () And kind of, [male friend] made the comment, () when I... when he found out I had what I had... that he said to [my wife], 'I don't know what to say to him. () And I'm just giving him shit, like I always did'. And she just said, 'Well that's the best thing that you can do'. But women seem to have a far better network than what guys do, for that sort of thing. () Maybe its the way they are.

I: Yes, well this is actually a big part of the reason why we're doing this research. Because we find that men can become much more distressed by cancer, because they do have trouble discussing it sometimes. You know.

P: Yeah. Not only that, but I think they, ah, um, their mates and that don't.... they, they'd like to do something, but they feel uncomfortable. () So therefore they don't.

I: Yeah. What.... can you put your finger on what exactly it is that they're uncomfortable about?

- P: They don't really - if somebody's sick, I think its generally even if somebody's sick, or... its just not necessarily cancer - they just don't know what to do. () They find it hard to deal with. () Ah, maybe its showing up their own mortality, sort of thing? () And they don't really want to see that. () So. And it's showing that maybe they might actually need somebody at some stage.
- I: Yeah. So it's hitting on this independence thing?
- P: Yeah. And it's... it's probably the way guys have been brought up, over thousands of years. () It's probably more... something you wouldn't change in five minutes. It's probably, I'd kind of even say it's probably genetic. () That's how they are.
- I: OK. Um. And yet, you've got a lot of friends that are... like we just met [another male friend] at the gate, and whatever...
- P: Yeah
- I: ...and they are just touching base with you.
- P: Oh yeah. If I see them around and that sort of thing, they do, yeah.
- I: Yeah. So they're certainly not ignoring you at all, are they?
- P: No, no, no, no, no, nothing like that.
- I: Yeah
- P: Nothing like that. Um. Um. I think probably where the difference is, that guys if they see you'll they'll stop and they'll talk and whatever. But women will more tend to um, if one of their mates is sick, they'll tend to go and just call in on them. () Whereas guys don't kind of do that. ()
- I: Yeah. Because of that discomfort thing, you're talking about?
- P: Yeah.

Jacko is clear in attributing his friends' avoidance to 'the way men are' rather than to any lack of concern. His case demonstrates how others in a man's social proximity must manoeuvre around issues relating to masculine strength. It also demonstrates that in doing this, women supporters may have more options available.

A narrow definition of masculine norms was displayed across various contexts, and often appeared as dichotomous polarisation. For example, men generally interpreted my enquiry as to whether they had experienced any cancer-related distress as an enquiry as to whether they had indulged in self-pity, which then led to a denial and an indication that self-pity was unacceptable, i.e. men interpreted distress in one narrow and unacceptable form. Dichotomous thinking was seen again in the assumption that action

and emotion were mutually exclusive: recall Carl saying that his priority was to "get on with it" and therefore he had no time for emotion-targeted services. Other instances of narrow interpretation that I have mentioned earlier relate to: perceiving limited options of sexual expression; defining strength as physical robustness and emotional positivity (only); and purporting that concern about facial disfigurement would be vanity. Thus narrowness or tendency towards dichotomy was common in the conceptualisation of the physical, sexual and emotional strength of many men.

As Charmaz (1995) points out, such rigidity sets the stage for despondency or depression for men who exhaust their few attainable options and recognise that their masculine status is becoming marginalised, i.e. that they are losing status in the hierarchy of masculinities (Connell, 1995, 2005). Using the gender role strain paradigm, it sets the stage for discrepancy strain. It also leaves men with fewer social support options.

Restrict emotionality, maintain control, and be rational

'Keeping a cool head' while making decisions under pressure is a classic Western hegemonic masculine ideal. The many treatment and lifestyle decisions that have to be made in the context of coping with cancer put a man's capacity (or willingness) to live up to that ideal repeatedly to the test. The participants in this sample consistently valued a controlled and rational approach to their treatment decision-making, in accordance with masculine norms. But only some of them, like Jacko, regarded emotional restriction an essential element of that: 'to make a good decision, you have to get a bit ice-cold about it' (438). Other participants managed to integrate information from various sources and weigh up pros and cons while also being emotionally expressive. Jacko's approach may be considered another example of the dichotomous thinking associated with traditional masculine norms about strength.

I noticed that Mike, who was emotionally non-expressive and had traditional masculine norms about strength, used the phrase 'losing control' as a euphemism for feeling or expressing distress, and especially for crying (some detail about Mike was given under Splitting the sample in Chapter 7). He spoke of how frightening he found the thought of seeing a cancer counsellor because of the possibility that he might "lose control" which would be "unmanly". This is a fear of feminisation, of being a 'sissy', and I suspect that

the disparaging way in which many men spoke of counselling and men's support groups disguised a deep fear of being 'reduced to feminine emotionality' in these contexts as well.

It may also have disguised a fear of exposing points of vulnerability to other men. In contexts influenced by hegemonic masculine norms, such exposure is risky since competition is strong between men. I was surprised at how often men told me that one of the important things they learned through cancer was that 'there are some good people out there'. This was intended as an expression of admiration and appreciation for the competence and compassion shown by the majority of helping professionals that they encountered. But it implied that many men's life experience before cancer had not built an expectation of 'good' treatment from strangers, i.e. men perceived their worlds to be normally unsafe. In such a context, the link between the otherwise unconnected terms 'emotional expression' and 'losing control' is clear: emotionality means exposing vulnerability to others which transfers to them points of control and potential advantage, which is dangerous and frightening.

An important feature of the loss of control experienced by some men in this study was that it felt 'disturbing'. This suggests to me an insult upon previously taken-for-granted assumptions about a man's self and his position of power relative to his world. Men experienced a taste of powerlessness – inherently emasculating – at the hands of overwhelming forces. This was likely a rare or foreign experience, felt as an attack on masculine control and self-image. Richard exemplified how destructive such an overwhelming loss of control can be: he seriously contemplated suicide twice while he was so disoriented by the 'avalanche' of decision making and lifestyle and identity change required following his diagnosis that he 'didn't even know which way to spit'. In such circumstances, men can turn to suicide as a means of retaking control (Heifner, 1997), and Richard contemplated it twice.

The choice some men took to divest themselves of control over treatment decision making in favour of their doctors appears to be another counterproductive action taken as a response to overwhelming loss of control. Men rationalised this as a bow to expertise, making their own feeling of inadequacy in the face of medical matters clear. When in the turmoil of the 'washing machine' phase of the experience, one way to

regain a sense of control is to reduce the size of the task by delegating some of it to a trusted other. But, as noted earlier, the wholesale divestment of this responsibility is both inappropriate, given that only a patient knows his own life priorities, and dangerous, given the stakes.

Conclusion

The material traversed in this chapter confirms that serious illness such as cancer renders the maintenance of traditional masculine self image problematic, since it is characterised by such qualities as strength, action, control, and virility (Robertson, 2007) – identity management dilemmas arise when 'bullet proof' meets radical prostatectomy. However, data from this sample has shown that the extent to which a man feels diminished or distressed by such dilemmas, for how long, and the coping strategies and resources he brings to bear, vary greatly.

Men who are not heavily invested in hegemonic ideals and roles have less to lose and more coping options open to them. In Connell's (1995, 2005) terms, they may already be 'marginalised' by minority ethnicity, or they may be 'complicit' rather than 'hegemonic', in that they hold more gender-equal values. Their non-hegemonic norms may offer a range of coping and self-redefinition options which could be regarded as 'feminine' or 'weak' in terms of hegemonic norms, but are highly adaptive in the circumstance, such as emotional expression or remaining active by adopting a new role.

Men who have more traditional/hegemonic norms find themselves with fewer options. This rigidity forces them, and those close to them, to perform convoluted and sometimes dangerously counterproductive manoeuvres in order to avoid confronting diminishment in their masculine self-image. Alternatively, they can find themselves in a despondent stall, unable to figure a way forward (Charmaz, 1995). However, those men who are strongly supported by the care of women in their families are buffered from the sharpness of such dilemmas by the opportunity to continue to define themselves against this perceived expression of femininity (Charmaz, 1995). Even worrying about how a wife will manage financially once he, the 'leader of the pack', has died, defines the man as a man. And those whose expectations of their physical (notably, sexual) strength are age-related suffer little challenge to their masculinity if

their experience fits that expectation. Thus it is the narrow range of options associated with hegemonic norms that is the true cause of masculine identity related distress.

A universally felt affront to masculinity, however, was ill-treatment by medical professionals which was felt as degrading. The nub of the affront was the perceived diminishment of a man's dignity, in the context of a relationship where the professional was entrusted with the man's vulnerability. This is an issue of power, which is of the essence of masculinity in a patriarchal society. It is interesting that another form of loss of power – complete overwhelm from loss of control – was demonstrated to be particularly dangerous by Richard's brush with suicide. Furthermore, such overwhelm was posited to be the cause of inappropriate and dangerous ceding of treatment decision-making control to doctors. Power and control are thus vital issues both to men's self image and to their ability to function adaptively.

11 THE CENTRAL IMPORTANCE OF INFORMATION

Having collected data, then theorised from it, the next step in the PAR cycle is to 'plan', i.e. to apply theoretical findings to the research problem to generate intervention ideas. In the present case, this means applying what has emerged from analysis of interview data to the problem of reducing men's cancer-related distress, with the aim of generating suggestions for service providers regarding how their services might be modified to better meet the needs of men. Such application requires identifying the nub of causation: what are the main factors – amenable to practicable psycho-social intervention – that cause and relieve men's distress? My examination of the nature of men's distress and coping, together with my discussion of findings in the light of masculinity issues and literature, provide a clear lead, namely, that men need accessible, relevant, and timely information about cancer, its treatment, the doctor-patient relationship and treatment process, and support services, in order to allow them to take greater control, which will reduce their cancer-related distress.

In this chapter I survey the main findings (from the descriptions of distress and coping, the metaphor of processing, and my integration of findings with the masculinity literature) to explicate the relevance of such information/education to men's distress and coping. I comment also on the type of delivery format that might be appropriate. I then briefly summarise the intervention suggestions that I have prepared for the consideration of service providers. Note that although the discussion below refers only to men, since they are the target group for this research, many of the suggestions offered are likely to benefit women also.

The nub of distress and coping

Distress themes

The distress reported by men fell into several main thematic groupings: that associated with a lack of control, that associated with anticipated or realised substantive loss, the 'black feelings', and empathic distress in response to the distress of wives. It was noted also that men who had lower education or more traditional beliefs about marital roles were exposed to greater distress burden. Most of these factors are underpinned or exacerbated by a lack of information or knowledge.

Under the theme of distress associated with lack of control were subordinate themes of shock on diagnosis, stress from uncertainty and waiting, worry about wife/dependants, anxiety regarding interventions, side effects impacting on bodily function, and 'a disturbing lack of control'. Shock on diagnosis was heightened by, amongst other things, unpreparedness and lack of health knowledge. This suggests that greater health knowledge generally and greater understanding of the purpose of cancer-related tests should help reduce the shock associated with these factors. The first of these matters is one of health promotion, and beyond the scope of the present project. The second, however, is about the communication style of doctors, which is a recurring theme in men's distress throughout their treatment, including worry caused by wondering about the meaning of doctors' behavioural cues. Remediation requires the improvement of professional skills regarding the importance of information to men, empathy, and communication, and possibly the improvement of the training techniques used to teach them.

Stress from uncertainty included the desire to 'know the whole story' about one's cancer status and the inability to plan matters regarding treatment or other aspects of life (such as business). Orienting information regarding how cancer and treatments work, the way that tests and treatments are conducted, and typical treatment pathways, should help resolve these concerns by enabling men to better understand the specific information medical professionals provide them with about their own particular cancer, tests, and treatment, and to know what questions to ask or what to research for themselves. Information about procedures should also assist with anxiety regarding interventions. Much of such orienting information is generic and could be conveyed efficiently using modern technology, such as DVD. Likewise, information regarding the management of troubling treatment side-effects is largely generic and could also be conveyed using DVD. I suggest this audio-visual format because it is accessible to men (and family members) of limited literacy, to Māori (and people of other Pacific cultures) who prefer face-to-face communication, and it is also inexpensive once initial production costs are met.

Worry about how dependants will cope emotionally and financially in the event of a man's death should also be amenable to at least partial relief by the provision of information to the man and his family. In this case information about supportive

community resources and assistance with problem solving is required, and, again, could be conveyed in an inexpensive generic DVD format, which could include reference to the role of oncology social workers and other relevant support services. Knowing that wives and families are equipped with the knowledge and support required to cope with the future without them should also help resolve the guilt or empathic distress felt by some men.

Under the theme of anxiety or despondency associated with anticipated or realised substantive loss were subordinate themes of loss of expected lifespan, loss of time with family and family roles, loss of bodily function and associated masculinity, loss of work/business and associated income, and loss of relationships and social life. Some of these losses are not avoidable, but, with information, some are, or can be mitigated, and tips can be provided as to how to cope and find extra support.

For those losses that are unavoidable, distress can be relieved by working through a process of grief and then consideration (or creation) of future options (Charmaz, 1995). The data suggested that these processes were foreign to some men, who may have insufficient emotion processing skills or be trapped in narrow dichotomous thinking about available options (e.g. many may not conceive of a sex life in any other form than the 'normal' one they had previously). Some tips and modelling regarding how to process losses (grieve) and then generate options to consider for the future could be part of a generic information package. Information could also be provided regarding community counselling and other support services and resources (e.g. helpful books and websites) to help with such processing.

Some losses are too deep, personal and complex to fully address in a generic format. Facing terminal prognosis or managing sexual impotence may be of this nature for many men, and individual or group intervention may be required to address these issues. However, generic information about support services or of a substantive nature is still a significant component of what is required. For example, Kristeller, Rhodes, Cripe, and Sheets (2005) describe an effective intervention addressing depression in terminally ill cancer patients which simply involves a patient's oncologist making a brief enquiry as to whether the patient's spiritual needs are being met and offering to make a referral to an appropriate spiritual professional if desired. For addressing sexual impotence, a

possibility is a seminar or brief course, for men and their intimate partners, incorporated into standard treatment pathways (D. Baken, pers. com. December 2012). Such a course could be valuable for men affected by ostomy surgery also. The course would cover medical issues and options as well as psycho-social ones, and would normalise the issue for further discussion between men and their intimate partners or with medical or psycho-social professionals. Men with a traditional or physical approach to intimate relationship may particularly benefit from learning of a broader range of possibilities. Men in the team phase of the present study were very keen on this suggestion, both for its substantive content – none had discussed sexual rehabilitation with their doctors – and for its normalisation of it.

Some of the losses that distressed men in this study are actually avoidable – again, with the provision of generic orienting information. For example, had Rodney understood how the doctor-patient relationship worked, he may have obtained a second opinion with a view to avoiding his loss of sexual potency. If he had understood how the decision-making and treatment pathway typically worked, he may have asserted his entitlement to a prompt decision and earlier treatment, thereby improving his prognosis, or putting him in a better position to plan for his business. All of these issues were serious with far reaching implications, yet the information Rodney needed could easily have been presented to him on an orienting DVD. Men of limited education, in particular, could be spared a good deal of distress by such an intervention.

In the grouping of 'black' feelings, prominent themes were anger or degradation from cold, blunt, overly directive, belittling or otherwise disrespectful or uninformative communications from doctors. Power imbalance is an important aspect of these unsatisfactory interactions, and can be expected to particularly impact men of limited education. While this matter can be addressed as a matter of professional training, another approach is to empower men with the knowledge of what standard they should expect from their doctors, and what options they have should those standards not be met. This is another topic that could be addressed efficiently with a generic information package in DVD format.

The fourth type of distress in the found was empathic distress. There are two directions from which this can be approached: lower the distress of wives, or lower the distress of

men about their wives. Roger said he was upset by his wife's distress at the degrading way his doctor spoke to him. Wives could be assisted by receiving the same empowering information about the doctor-patient relationship that I have suggested for men. Wives are also, no doubt, distressed by many similar uncertainties and losses to those facing their husbands. They could also therefore benefit from access to the same information giving them a better understanding of the disease and its treatment as provided to their husbands. A generic information package could also contain information of support services available in the community suitable for spouses and family members, e.g. services provided by CSNZ.

The other approach was to lower the distress of men about their wives. An information package could explain some of the emotional processes that family members might experience, and how to support them in this. Men are likely to feel less distressed for their wives if they understand the trajectory of the adjustment process that their wives are likely to experience and feel there is something they can do to help.

Coping themes

The four major coping themes were a positive attitude, an active and practical orientation, rationality and control, and social support/helping others. All of these means of coping are assisted by, or dependent upon, an understanding of what is happening to one's body, what the treatment process will involve, how to manage physical and psycho-social side effects, and what medical and psycho-social resources are available. So, for men to take advantage of their characteristic active and rational problem-solving approach, educational interventions are indicated (Helgeson, 1995; Tamres, Janicki, & Helgeson, 2002). Men with more traditional masculine attitudes – who may be more deprived of health related information or have a narrower range of coping options within their current repertoire, and may be suffering greatest distress – may gain the most from such interventions (Helgeson, 1995).

Psycho-oncological interventions educating patients about the disease, treatments, and services showed potential to produce moderate-strong effect sizes in my recent meta-analysis which used mixed gender trials (Heron-Speirs, Harvey, & Baken, *in press*; Heron, 2009). As noted above, given that men begin with less health knowledge, their potential for benefit from such education could be greater. Furthermore, men tend to

use avoidant coping strategies for dealing with cancer-related stress (Fife, Kennedy, & Robinson, 1994; Stanton & Courtenay, 2004) and these predict poorer psycho-social adjustment than approach strategies (Fife, et al., 1994; Roesch et al., 2005; Stanton, Revenson, & Tennen, 2007). A lack of knowledge, and of the freedom to seek help – including admitting ignorance – could explain this. The provision of useful information as a part of standard treatment could overcome both the lack of knowledge and the reticence to ask for it.

The transactional model of stress and coping by Lazarus and Folkman (1984) posits that appraisal of a stressor is key to the selection of a strategy for coping. Appraisal of a stressor as a challenge predicts approach coping, whereas appraisal of it as an overwhelming threat to a man's person and available resources predicts avoidance coping. Based on this theory, Roesch, et al. (2005) point out that men who interpret their cancer diagnosis as a challenge are likely to take action to give themselves increased control over it, e.g. by seeking more information, using that information to participate in treatment decisions with their medical professionals, complying with treatment regimes, and suppressing activities that draw away from their ability to attend to the challenge. Men who interpret their cancer diagnosis as an overwhelming threat are likely to use avoidance strategies, which are ultimately counterproductive. Indeed, the three aspects that I noted as a 'dark' or 'ironic' side of participants' means of coping could all be interpreted as avoidance strategies resulting from the need to fend off the threat of overwhelm. They were: denying the seriousness of a prognosis in favour of being positive ('We will beat it'); by-passing the opportunity to research and consider treatment options in favour of taking 'decisive' action; and ceding an inappropriate degree of control of treatment decision-making to medical experts.

If men are provided with sufficient, appropriately timed, and accessible, information which gives them an overview of the disease, its treatment, and 'the system', they should be less vulnerable to feeling overwhelmed. Rather, having been oriented to the overall picture, they should feel able to locate the specific issues they need to resolve, and ascertain how to seek their resolution. Any initial feeling of overwhelm should be reduced to a manageable challenge, promoting adaptive 'approach coping' and the re-taking of control (self-efficacy), and reducing distress.

Processing metaphor

Regaining or maintaining a sense of control is particularly important to men who are distressed (Cochran & Rabinowitz, 2000; Heifner, 1997; Watts, 2002) but this is very challenging in the sea of uncertainty that a cancer diagnosis presents. The 'wave' metaphor describes a process of losing and regaining of control. The crux of the process is the point at which men 'regain their footing' after the initial cataclysmic loss of control. This point is the realisation that there is hope of regaining control and a life worth living in the future, coupled with an orientation towards how to begin to achieve that. Vital to the realisation of hope is information that offers perspective on the psycho-social and medical processes that men are in. Vital to orienting men towards beginning the work of regaining control is information about useful resources and support. Once men have a sense of perspective and orientation, they can engage with the challenge before them, as a challenge, and can apply their coping strengths of positivity, action, practicality, rational problem-solving, and enlisting social support, to resolving each of the myriad of psycho-socio-spiritual, economic, practical, and medical issues that must be addressed.

The 'wave' metaphor itself should have utility in offering men perspective regarding the psycho-social process they are in. As noted earlier (Chapter 9), the metaphor met with universal approval and interest from participants and showed that it had potential to assist those men who report 'no distress' to discuss their feelings. Such concrete metaphors are commonly used in therapy for working with men who have difficulty identifying or expressing feelings (Sweet, 2012a). They not only provide an acceptable and understood language for describing vulnerable feelings, but can provide a bridge to the open use of emotional language (Steigmeier, 2012). Once discussion is opened using a safe metaphor, trust can be built, and men who do not usually express emotion may feel safe enough to do so. A particular social context would have been constructed allowing a man to behave in a way that he cannot in other contexts, consistent with the functional social learning gender theory of Addis, Mansfield, and Syzdek (2010).

Thus the metaphor offers two important potential uses: perspective on the process of losing and regaining control, including the imparting of hope and of an understanding of the work required to progress; and means for emotionally non-expressive men to

communicate vulnerability. The latter opens the possibility of eliciting needed social support for men who may otherwise receive very little.

Points from integration with the masculinity literature

Two potential causes of distress which were recognised in my integration of findings with the masculinity literature were rigidity associated with traditional masculine norms, which limits the range of options perceived as available for problem solving, and the power imbalance between men and specialist doctors due to the knowledge and status associated with medical expertise and the position of dependence of patients.

Rigid gender roles are recognised as a barrier to adjustment to chronic illness (Stanton et al., 2007) and rigid masculine roles are recognised as a common source of both personal and interpersonal stress for men by therapists who work with them.

Accordingly, encouraging broader redefinition of acceptable masculine behaviour is an established treatment strategy (Sweet, 2012b). It would therefore be appropriate to incorporate modelling and discussion of a greater range of masculine options for conceptualising and expressing cancer-related losses, distress, and ways of coping, into psycho-oncology interventions for men. The need is particularly clear in relation to losses which affront men's masculine sense of strength and control, such as those associated with terminal prognosis, sexual impotence, incapacity for work, and incontinence or the need to wear an ostomy bag. Feelings of diminishment associated with such affronts may be avoided or minimised by redefining what is masculine. Losses also may be mitigated by the suggestion of alternative options. For example, education that broadens the definition of sexual expression, and also broadens the definition of relational intimacy beyond sexual expression, could help men who are trapped in a narrow concept of both which is dependent upon the ability to have an erection.

Ignorance of their own position of power in the doctor-patient relationship, compounded by ignorance about health matters, leaves men disempowered in communications with their doctors. They are then vulnerable to accepting the degrading communication style of some doctors, and to ceding to doctors more control over treatment decision making than they may prefer. Education as to the parameters of responsibilities in the doctor-patient relationship should empower men to fulfil their

own decision-making responsibilities, and to take appropriate action to deal with any disrespectful or otherwise substandard performance from their doctors. The provision of background information regarding the disease and treatments will also position men to ask targeted questions and make strategic use of their consultation time, which should also be felt as a significant benefit by doctors.

A paradigm shift towards informing men

All of this discussion points to the central role of a lack of knowledge in the distress experience of men: There are many components of men's distress that can be mitigated by the provision of information; their main four means of coping can be strengthened by the provision of information; the process by which they resolve distress could be hastened by the provision of information; their options for defining themselves as men in the face of affronting losses could be broadened by the provision of information; and they could be empowered in the doctor-patient relationship by the provision of information. Furthermore, many of the men who stand to gain most from the provision of needed information belong to the vulnerable socio-economic groups of particular interest to this research. Men who have little education are likely to have particularly limited knowledge about the disease and its treatment, and poor researching capability. Men who have low income are likely to have a particular need to learn what government or community funded services are available to them. Men who are single may have particular need for help with navigating the treatment process and finding needed services. Māori (and other non-Pākehā) men may have particular need for orienting information arising out of the cultural foreignness of treatment and support services to them, and may well also have particular needs arising out of low education and income. Indeed, a recent investigation into the views of Maori men suffering chronic illness in the Waikato found that they wanted clear information in plain language, presented with warmth and respect, and were often too *whakamā* to ask when they did not understand (Kara et al., 2012).

Many psycho-social interventions for cancer patients (men and women) already focus on educating patients regarding a wide range of topics regarding the disease, its treatment, coping, and the challenges associated with long term survival (for detail see Heron, 2009). Meta-analyses are inconsistent as to the effectiveness of such

intervention at reducing cancer-related distress, and my own earlier meta-analysis found they produced only small effect sizes against anxiety. However, men were greatly under-represented in the trial samples, there were no trials of educational interventions that took into account baseline levels of distress, and there were two trials from developing countries (where the overall education of the population is low) that produced effect sizes of outlier proportions (Heron-Speirs et al., *in press*; Heron, 2009). My meta-analysis also demonstrated that greater benefit was obtained where baseline distress was elevated, i.e. people with greater need have more to gain (Heron-Speirs, Baken, & Harvey, 2013; Heron-Speirs, Harvey, & Baken, 2012). Given that men may generally suffer more cancer-related distress and have less cancer and health system knowledge than women (as discussed in Chapter 1), it could be expected that they would enjoy greater benefit from information targeted to their areas of need. It could further be expected that men of lower education would benefit more (as was found in relation to an intervention for prostate cancer patients by Lepore, Helgeson, Eton, & Schulz, 2003). However, (as also discussed earlier) it appears that men utilise psychosocial services at only about half the rate that women do. So although some very high quality, evidence-informed interventions have been designed for men (for an Australian example, see Boonzaier et al., 2008) engaging men in utilising these services remains problematic. Increasingly, the need to meet men literally where they are is recognised (e.g. regarding health promotion efforts, meeting them in the workplace, see Robertson and Williamson, 2005), thereby avoiding any reluctance to help-seek, difficulties associated with ignorance about the health system, or practical difficulties associated with mens' lifestyles.

My conclusion is that a paradigm shift is required regarding the delivery of information which emphasises the importance of communicating effectively in order to enable men to regain a sense of control, and implies the need to provide an orienting framework. This would comprise a move towards incorporating accessible, relevant, and timely information for men about cancer, its treatment, the doctor-patient relationship, and psycho-social services, into the standard pathways of patients' cancer diagnosis and treatment. The shift is thus from a paradigm of informing patients for the purposes of enabling them to feel they understand their diagnosis or feel comfortable with a forthcoming procedure and to obtain 'informed consent', to a paradigm of informing

patients for the purposes of placing them in a position to retake control over their lives in the face of the overwhelming unfamiliarity of the situation they now find themselves in. This requires a much broader and more comprehensive and deliberately planned effort at communication, in which orientation is a key component. For men this approach is important in addressing their particular needs to be empowered with the health-related knowledge they often lack, to retake control in their lives, and to ensure that they are not required to seek information to achieve these. Traditionally, medical practice objectified patients and constrained them towards dependence upon the expert knowledge of their doctors, conveying little understanding of the disease and treatments to patients, and failing to recognise the importance of non-medical aspects of the illness experience. Although this approach has changed very much in recent decades, much high quality information is now readily available, and many men in the present study felt well informed about their disease and treatment by their doctors, the full significance of enabling patients to have the information they need to optimise control over all aspects of their life whilst undergoing cancer treatment is not recognised in how treatment is delivered. Nor is the particular disadvantage that men have regarding health information, and their reluctance to appear ignorant or seek help. For men to be 'put back in the driver's seat' the importance of integrating information into cancer treatment must be recognised at a new level.

Practical products

The ultimate objective of a PAR project is to produce change in the field. Although the present research was not resourced to complete a full cycle of data collection, theorising, intervention, and further data collection, the theoretical results described above drove the conceptualisation of some intervention suggestions for service providers to consider for application in the field. While the substance of this thesis is in the theoretical results, I now briefly describe the practically oriented documents I wrote to convey those suggestions – the 'practical products' of this research.

Three 'product' documents were drafted and offered to service providers. Two are peripheral reports that arose tangentially to the main research question and drew from simple summaries of interview data. As such, they rely more heavily upon the theoretical expertise of those providers for whom they were written to assess the

validity and usefulness they may have to their application. The third is the main report of intervention suggestions, drafted after analysis of distress and coping themes was complete and validated by the participants, and taking into account their suggestions and feedback. I now describe these products and their utility.

Peripheral reports

The first was a report to the research funder, CSNZ, on some matters of particular interest to its health promotion and psycho-social service provision work (Appendix 18). The interview schedule was designed to include questions on these matters.

Of relevance to CSNZ's health promotion work, this report summarised the knowledge men had, and the processes they experienced, in becoming diagnosed and making treatment decisions. It included the trigger for diagnosis, barriers to earlier diagnosis, and factors taken into account in selecting treatments. It made suggestions arising from this data. I reported that men were largely ignorant of cancer facts, and that health promotion messages targeting vulnerability (i.e. 'Beware of these symptoms') could be regarded as irrelevant by men, who were busy and focussed on priorities of work and family. I suggested that a health promotion message that encouraged men to have a regular 'WOF' (Warrant of Fitness check, as for maintaining a vehicle) with their GP would circumvent men's symptom ignorance and may be better appreciated as relevant. A number of other findings and suggestions were provided, notably the observation that men were interested in, and respected, survivors' stories, which suggests an opportunity for cancer education, and that ignorance about cancer and systems related to its treatment were significant issues making effective information provision a priority.

Of relevance to CSNZ's psycho-social service provision work, the report summarised men's impressions and use of CSNZ services and also the psycho-social services of some other providers. Problems with the image of men's groups and counselling, and barriers to connecting with services were identified. Suggestions mostly revolved around connecting with men at various points while they were in treatment, rather than expecting men to reach out for information about services.

Some of the suggestions made in this document foreshadowed suggestions which progressed through the participant team discussion process and were ultimately included in the main product of this research described below. These include

informational DVDs, an orchestrated and comprehensive approach to connecting men with information about services which begins with screening questions on the hospital admission form, and the use of other men's stories to convey cancer information.

The second report was a learning resource for medical students (Appendix 19). This was drafted in response to a request from a lecturer in professional practice at Otago University Medical School. After providing some introductory material regarding masculinity and its interaction with health care utilisation, I set out ten 'tips' for making the most of a GP consultation to assist men, illustrating each with quotations from the research interviews. Most of the tips concern providing men with the information they want and need, for example, ensuring that no assumption is made that men understand health terms and ensuring that the relevance of information is made clear. The objective was to provide medical students with some memorable vivid real-life images of helpful and poor practice to inform their future work. My intention is to reduce this document to a brief practical publishable piece in due course.

Main report

The third and major practical product of this research was a discussion document listing suggestions for intervention to assist men with their cancer-related distress (Appendix 2) and an accompanying powerpoint slideshow presentation (Appendix 3 is the powerpoint and Appendix 4 is the accompanying notes). These were designed for presenting the research to stakeholders involved in service provision. The initial meeting was of select providers in Palmerston North, and was organised by the manager of the Central Cancer Network, Ms Jo Anson. Attendees at that meeting were affirming of the research. They expressed support for many of the suggested interventions and discussed possible implementation. They also recommended and facilitated the dissemination of similar presentations to other stakeholders. Detail of these meetings is tabulated by way of providing evidence of the validity of the research in the following chapter.

The list of intervention suggestions flowed, in large part, from the conclusion that information is vitally important to men's distress and coping. Two main issues were identified: (1) the need for relevant, timely and accessible information regarding the disease, treatment, systems (including the doctor-patient relationship), and support services; and (2) the need for coordinated connection of men to information and

services. Whilst at present a good deal of high quality information exists (e.g. CSNZ has many superb resources and recently some DHBs have begun to develop information on DVDs regarding their services) an overarching strategy for orienting patients to the cancer experience and for injecting relevant specific information at relevant times is wanting, and information resources are therefore typically underutilised. Six main strategies for achieving the identified issues were suggested:

- (1) **A local co-ordination role** to ensure that information is provided comprehensively and at appropriate points in the diagnosis and treatment journey. This is to address the present patchy and haphazard nature of both the substance of information currently provided and the timing of its delivery;
- (2) **A clause incorporated into the hospital admission form** to provide permission for CSNZ and Māori Cancer Coordinators to contact patients and explain their services, unless the patient elects to 'opt out'. This is to address men's ignorance of cancer support services and their reluctance to seek help and ask, by making it normal practice for the service providers to contact men rather than waiting for men (or a referral agency) to contact them;
- (3) **A set of informational DVDs** created and incorporated into standard hospital treatment pathways (detailed further below). This would provide patients with orientation concerning the disease, its treatment, 'the system' and support services;
- (4) **Other specific interventions** to (a) facilitate the obtaining of a **rapid response** to questions throughout a patient's treatment journey, and (b) **address the sexual implications** of some treatments. The first of these interventions would address patient-specific concerns, and the second would 'bring out into the open' and address an area of great loss and challenge to many men, including not only prostate patients, but patients with other cancers such as those required to wear an ostomy bag;
- (5) **Better utilisation of existing connection points** to provide men with information about services and their health (including CSNZ transport drivers and ward visitors, radiation therapists, oncology social workers) and the establishment of

new connection points (including an information pack about CSNZ services upon admission, and CSNZ volunteers connecting with men in radiation therapy waiting rooms and chemotherapy day wards). This again is to address the lack of comprehensive coverage presently and the need to reach out to men with information rather than waiting for them to seek it out; and

(6) **The connection of male survivor volunteers** with new male patients as 'buddies' through CSNZ men's groups and perhaps through a new type of men's group for Māori.

These suggestions are sensitive to the limited literacy of some men, the preference of Māori to receive information face to face, and the time pressures on hospital staff. They also take advantage of the respect that research participants expressed for both the advice of professionals and the experience of survivors.

The set of informational DVDs (item 3 above) is the single most important intervention suggested as it would equip men to understand what is happening to their bodies, how treatments work (including what the main medical and psycho-social side-effects are and how they can be managed, and including palliative treatments), how the process of treatment unfolds including what patients should expect of their relationship with their doctor, and what psycho-social services are available to support them. Orienting information would be provided on a DVD viewed at a special appointment scheduled after diagnosis but before treatment planning. The requirement that men attend a viewing appointment ensures that the DVD is actually viewed before treatment decisions are made, recognising the central importance of this information to holistic treatment (men may then be given the DVD and accompanying booklet to take home). More detailed information would be provided on treatment-specific DVDs (surgery, radiation, chemo- and hormone therapies, and palliative care) given to patients during or after treatment selection (by this time they will understand the importance of viewing the DVD so a viewing appointment is not as important). These treatment-specific DVDs would cover the nature of the treatment, troubling side-effects and how they are managed (including an introduction to sexual side effects and how to obtain more helpful information), and the support services relevant to that course of treatment (e.g. transport for daily radiation therapy, or spiritual services for palliative patients). I note

that the Foxton discussion team, who were all Māori and two of whom had limited literacy, found the presentation format of an extant DVD which explained radiation therapy very acceptable and useful.

12 VALUE AND LIMITATIONS

In this chapter I consider the value of this research project and its limitations. I return to the criteria Guba and Lincoln (1982) set out for evaluating the 'trustworthiness' of research findings and consider the present project in the light of each. I then consider the transferability of findings, the strengths of the project, its limitations and its implications for future research. I close the chapter – and the thesis – with thoughts that hark back to my opening reflection about deficits and contradictions.

Trustworthiness of findings

The first of Guba and Lincoln's (1982) trustworthiness criteria, as outlined in the Methodology chapter (Chapter 5), is credibility: Are the realities of participants represented and interpreted in a way that they find believable? The credibility of the descriptions of distress and coping and the metaphor of processing were thoroughly tested in hours of discussion with the small teams of men in the second phase of the project. Men found the preliminary form of the findings generally accurate but added a few significant points. They fully endorsed the process metaphor as it was. No ideas for intervention which were opposed in discussion were advanced into any 'practical product'. Thus I feel confident that findings do reflect the realities of participants in substance. However, I would not go so far as to assert that there is nothing more that could be added to them and nothing that could be construed differently, due to the subjective aspect inherent in the method, and the limitations of the participant sample, discussed below.

The second criterion relates to transferability: Is sufficient description of the sampling setting provided so that judgment can be made as to whether research products might be useful in other specific settings? I have provided detail regarding men's demographic characteristics (age, ethnicity, marital status, income, occupation, education, and domicile) and some information regarding their cancer status (primary site, together with spread and whether the disease is terminal, as was known from the account of the participant). This should provide sufficient information for readers to make an assessment of whether research products are likely to be of use in their settings. Appropriate breadth of transferability is discussed below.

The third criterion is dependability and confirmability: Could the process used and interpretation offered by this research be seen as reasonable and fair for its purpose by peers? I have largely addressed this point in the Methodology chapter, referring to the choice of PAR method and my approach to reflexivity including the assistance obtained from my 'critical friends' and Māori cultural advisor. I can now add that findings seem to fit well with the masculinity literature.

The fact that only one person coded interview transcripts could be raised as a possible weakness in my analysis procedure. Perhaps the assistance of a second coder would have brought more themes to light. However, effortful attention was applied to coding the transcripts thoroughly and consistently, and team discussions provided extensive opportunity for themes that were missed to be identified – and some were. There is never a 'perfect' or singular analysis in qualitative research, and never enough resource to do everything optimally, but I am satisfied that a diligent initial analysis was performed and that the views of those people whose views were most important were diligently sought and heard in refining it.

The ultimate test of the validity of a PAR project is the extent to which it is useful in catalysing change in the field (Gergen, 2009; Herr & Anderson, 2005). Effecting and testing change was beyond the scope of the present project, but some indication of the potential that the theoretical findings and practical products of this research have to catalyse change can be gauged from the interest shown by stakeholders working in the field.

Below I have detailed (Table 12-1) instances of presentations to, and other communications with, Cancer Networks and various medical and psycho-social providers, notably CSNZ, regarding the findings and suggestions for change arising out of this research as at the end of August 2013. I put considerable time and effort into arranging, preparing material for, presenting, and discussing material with these stakeholders, and will continue to do so for a few more months after the submission of this thesis, while I have the time to do so. The project's funders graciously gave permission to use surplus from the research grant towards this dissemination work. Some feedback from presentations and discussions was available, and where it was, I have tabled summaries of that also. The table includes two engagements that were

planned but not executed at time of writing, and there were other possibilities arising. In addition, the Clinical Oncology Society of Australia (COSA) conference, scheduled for November 2013, has accepted my abstract for a brief presentation and poster, and I have submitted abstracts for the Psychosocial Oncology New Zealand (PONZ) conference, also in November. I have also begun drafting three articles for publication addressing (1) men's distress, (2) men's coping and intervention suggestions (3) practical suggestions for medical professionals regarding communication with male patients.

Table 12-1. *Interest and feedback from stakeholders*

Date	Presentation/communication	Feedback
August 2012	Emailed peripheral report (summaries of responses and suggestions concerning CSNZ health promotion and psycho-social service provision) to CSNZ national office	
14 August 2012 and 20 February 2013	Discussion with Lis Latta, Professional Practice Fellow, School of Medicine, Otago University regarding men's needs. Followed up by email to Lis with peripheral report, "What men want: Being a good doctor to Kiwi blokes".	Email from Lis Latta saying she has sent the document to one of the school's teaching oncologists and will consider it as part of planning the teaching of end of life care also because she regards men's health an important area to cover
9 and 14 January 2013	Emailed draft main report (intervention suggestions) to Jo Anson, Manager, Central Cancer Network.	Return email from Jo Anson welcomed the paper noting that there were a number of initiatives afoot along lines which are similar to, or which could be utilised to promote, those suggested. Ms Anson volunteered to set up a meeting with some key service provider representatives to plan how the suggestions might be considered in substance. This was held on 18 February 2013
18 February 2013	Meeting with representatives from Central Cancer Network, CSNZ national office (Susan Sutcliffe) and Central Division, the supervisors of this research, and the new Cancer Care Coordinator service to present theoretical findings and main	Received enthusiastically and suggestions made regarding implementation of interventions and dissemination opportunities. Steve Kenny (CSNZ National Men's Health Coordinator) said he had already modified the CSNZ 'Get the Tools'

	product	website to make use of a suggestion I made in the peripheral product sent distributed in August (incorporating survivors telling their stories).
1 March 2013		Email from Susan Sutcliffe (CSNZ National Office Support Services Manager) reporting that she had discussed intervention suggestions (in both the earlier peripheral product and the main product) with regional support managers at a meeting on 28 February.
19 April 2013		Email from Steve Kenny (CSNZ National Men's Health Coordinator) reporting that the findings and suggestions presented on 18 February have been used to shaping the new CSNZ Men's Health policy.
16 May 2013	Email summary of suggestions for incorporation into CSNZ draft Men's Health Strategy to Marie Daly (CSNZ National Office Support Services Manager) and Steve Kenny (CSNZ National Men's Health Coordinator).	
22 May 2013	Present theoretical findings and intervention suggestions, and discuss practical applications for CSNZ support services at Support Coordinators meeting, CSNZ Central Division, Palmerston North.	
30 May 2013	Present theoretical findings and intervention suggestions to 'grand round' (hospital and community cancer/palliative doctors and nurses) at Taranaki Base Hospital, New Plymouth.	Large turnout. Positive feedback from people attending.
30 May 2013	Discuss practical applications with Tania Gecse, Support Services Manager, CSNZ Central Division, New Plymouth.	
30 May 2013	Present theoretical findings and intervention suggestions to Central Cancer Network meeting, New Plymouth.	Positive feedback from chair. Asked to submit an abstract to Public Health Association Conference in New Plymouth by Cancer Network equity manager.
5 June 2013	Present theoretical findings and intervention suggestions to Midland Cancer Network Māori Advisory	Positive feedback from prostate cancer researcher attending who wanted to link me to her team of

	Forum (Hei Paa Harakeke), Hamilton.	researchers including sexual dysfunction researcher
5 June 2013	Present theoretical findings and intervention suggestions, and discuss practical applications for CSNZ support services and health promotion with CSNZ liason nurses Waikato/Bay of Plenty Division CSNZ, and other cancer nurses, Hamilton.	Positive feedback from people attending. Asked to do a presentation to colorectal cancer nurses summit.
24 June 2013	Present theoretical findings and intervention suggestions, and discuss practical applications for CSNZ health promotion. Health promotion/community health Coordinators meeting, CSNZ Central Division, Palmerston North.	
8 August 2013	Present theoretical findings and intervention suggestions to colorectal nurses summit group, Wellington	
8 August 2013	Discuss intervention suggestions with Regional Oncology Social Work Director, Whanganui and MidCentral DHBs	
8 August 2013	Discuss implications of research for CSNZ draft Men's Health Strategy with two CSNZ/Movember men's health representatives, Wellington	Assured that the research recommendations had been incorporated into CSNZ men's programmes and that future strategies would seek their advancement beyond the organisation. Asked to state strategic importance of advocacy regarding integration of information into hospital systems in writing. Asked to accept a position on national directing body for CSNZ Men's Health Strategy
3 September 2013	Present to CSNZ men's support group, Palmerston North, with objective of then meeting with the group's leadership to discuss changes in the group's objectives/modus operandi	Yet to present at time of writing
November? 2013	Present to Central Cancer Network, Palmerston North district group meeting, including MidCentral DHB treatment area service manager and others with administrative roles from the DHB	Yet to present at time of writing. Individual meetings with the treatment area service manager and others involved with planning medical treatment paths are intended.

	Present to Te Ohu Rata o Aotearoa (Te ORA), Māori Medical Practitioners Association	Yet to finalise date and present at time of writing
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Overall, the research findings and the intervention suggestions (main report) have met with enthusiasm and considerable interest. Some service providers were found to be already delivering or planning interventions which resemble some aspects of my suggestions in part (e.g. three DVDs already exist which cover some aspects of the material I suggest) or in a different form. The fact that stakeholders have identified similar needs and solutions further indicates the 'dependability and confirmability' of the findings and intervention suggestions arising from the present research. However, the point that information is central to men's coping, and the consequent need for it to be integrated into medical treatment pathways in a planned, comprehensive and accessible way, emphasising effective communication – the paradigm shift – had not been recognised. My hope is that the theoretical framework and comprehensive nature of my suggestions will help rationalise the presentation of information to men into a coherent flow of (1) what they need (2) in a form and at times when they need it.

A further practical impact of the research is that it has impelled me to design and seek funding for a further three year research project to benefit prostate cancer patients, following the identification of an opportunity by one of the supervisors of the current project, Dr Don Baken. It seemed important to pursue this opportunity given the serious distress associated with the loss of sexual function experienced by some participants, and the lack of information and intervention that was provided for them to address this. At time of writing (August 2013) Movember and CSNZ had awarded funding to the project subject to finalisation of terms. The object is to gather evidence regarding the need of prostate patients for sexual rehabilitation intervention (medical and psycho-social), and the views of medical professionals, with a view to making a case for public funding of such intervention.

Transferability

The question of the transferability of conclusions to other population groups boils down to a consideration of the similarity of cultural, social, and medical factors between those of the target population and those of the present sample. Of most importance are the

similarity of masculine cultural norms regarding strength and family roles, health provision, and socio-economic characteristics.

Most participants in the present sample were domiciled in small provincial New Zealand towns and others lived on the surrounding farms. They were predominantly Pākehā (21 men) but with sufficient Māori to be heard as a distinctive voice (six men). The voices of poorer, less educated, and single men were privileged, as were the voices of Māori. However, the voices of more educated and wealthy men also came through clearly in the analysis of their interview data. Many men displayed fairly traditional norms regarding masculine strength and marital roles of provider and protector. The theoretical descriptions and metaphor should have relevance in much of provincial New Zealand where similar demographic emphases and masculine culture are found.

However, caution should be exercised in considering their transfer to large urban settings in New Zealand with markedly different socio-demographics, such as significant Asian/Eastern or Pasifika populations or significantly higher or lower overall levels of education or wealth. The availability of more social services together with significant cultural differences or significantly greater privilege or deprivation can be expected to produce different stressors and means of coping which could change the emphasis or alter the content of the theoretical descriptions and metaphor. By the same token, caution should also be exercised in considering transfer to remote rural areas of high Māori population where Māori culture is strong, health services are limited, and average incomes are low (such as the East Coast of the North Island or Northland). I also note that the present sample had its limitations (discussed below) which means that there may be some groups of men within otherwise similar provincial regions whose experiences are not thoroughly described by this research.

With those reservations noted, I have little doubt that wherever cultural norms disadvantage men in acquiring knowledge and support about health matters and place pressure upon them to 'be strong', and particularly wherever there are men with poor education, a lack of knowledge will be a considerable source of men's cancer-related distress, and the provision of accessible and useful information in various forms will be of significant assistance. Even for educated men, information that provides an orienting overview of the disease, its treatment, and 'the system', will be a priority need for many.

Asian/Eastern and Pasifika cultures may be quite traditional and patriarchal in the allocation of domestic roles, so there may well be considerable cancer-related distress amongst men from these backgrounds, and this may be compounded for recent immigrants who experience New Zealand's Westernised medical system and culture as foreign. Findings and intervention suggestions may have application in some contexts outside New Zealand, particularly in Australia, given the similar culture of white Australians to that of Pākehā in New Zealanders, and given the countries' similar stage of political and economic development and health systems.

My hope is that theoretical and practical conclusions from this research will be adapted and applied in various New Zealand cancer contexts around the country, and even adapted to benefit men with other serious and chronic illness. Although my focus throughout has been on men, many women could also gain significantly from these interventions, both as patients and as main supporters of the male patients in their families.

Strengths

The strengths of this study lie in its method, its unique contribution to the literature on masculinity and health, and its potential to catalyse practical change for men with cancer in New Zealand, and perhaps for men with other serious illness or in other countries. With a few reservations noted below (under Limitations) PAR method and the sampling strategy served the objectives of the project well. Participants represented the main socio-demographic characteristics in the regions they came from, and were enthusiastic, recognising their opportunity as participants to help 'make a difference' for men. The project was met with cooperation and assistance from a wide range of people in stakeholder groups who were also keen to make use of the opportunity to work towards change for men. This was evidenced by their willingness to assist with recruitment and their support of findings, as well as many instances of practical support for the project provided by CSNZ and the Central Cancer Network. The support the project enjoyed meant that a strong database could be produced and that validating discussions were also strong, providing a sound foundation for findings. It also meant that people working in the field were available to provide comment, assist with

reflexivity, and offer opportunities to raise interest in the project and promote the application of its findings.

The project has resulted in two main outcomes that are valuable and in keeping with the practical rationale of PAR. The first of these is the quality and nature of the theoretical findings. The descriptions of distress and coping and the process metaphor are simple and readily communicable in nature, in keeping with applied objectives. The description of distress is interesting in that it summarises, integrates, and explains a wide range of reporting about cancer-related distress. Features include the discussions of 'no distress' and ambiguous reporting, how each relate to traditional masculine norms, the discussion of varying levels of distress associated with loss of sexual function, and recognition of the role of lack of knowledge/information in causing or exacerbating distress. The detail summarised in this description should well inform the provision of information and other forms of psycho-social assistance for men. Furthermore, the discussion which relates the reporting of distress to masculine norms regarding strength should be valuable for informing the style of conveying such assistance. The process metaphor itself has potential to be a valuable communication tool for discussing distress with men who do not otherwise speak of it, and also for conveying hope. It explicates the central significance of control and, by implication, information, in addressing men's cancer-related distress. The description of coping summarises men's strengths clearly and succinctly, and as such has potential for use in workforce development as well as in the development of psycho-social intervention. Interesting features of this set of findings include the range in how men made use of social support, and the unilateral approach taken by women in supporting Māori men and those Pākehā with more traditional norms. Both findings have important implications for assisting men with their cancer-related distress.

The second valuable outcome is the clear direction that both theoretical descriptions and the metaphor indicate for intervention. It is significant that findings cohere around the significance of control to suggest the importance of being proactive and intentional about connecting men with information. The findings also provide detailed guidance regarding the 'whats' and 'hows' of the information that men need. This integration of theory and practical problem solving demonstrates the essence of Lewin's commendation of Action Research: "there is nothing so practical as good theory"

(1951, p.169, as cited by Friedman & Rogers, 2009). The affirmation of suggested information interventions provided by men in phase two of the study, and the interest shown by stakeholders since, give reason for some confidence that the practical suggestions for intervention should find sufficient support amongst service providers to be implemented, at least in part.

Limitations

I can identify three areas of limitation that require discussion, other than the limitations of its application to other populations discussed under Transferability, above. They are limitations regarding interview participant sample diversity, limitations regarding participation and format of phase two discussions, and limitations regarding PAR assumptions.

I have asserted that, generally speaking, the participant sample seems to have represented the diversity of men living in their regions of domicile well. However, there were several limitations to its diversity which mean that some features of men's experience of distress and coping may be missing from findings, and the participants who validated them in team discussions would not have been in a position to identify such features.

First, the age range of participants was limited. Only one man was under 52 years of age: Jake, who was 23. On reflection, I feel that it was an error of design to admit younger men in the eligibility criteria because younger men are likely to have different worldviews (including regarding gender-related issues), have different development-related issues, and their social worlds are also quite different from those of older cohorts. Since Jake was the only younger participant, my analysis could not explore the distinctive distress and coping of younger men, and so, in effect, my findings are relevant to older cohorts (over 50 years) only. (It was interesting, however, that Jake's data supported key features of the findings, notably the process metaphor.)

Furthermore, the lack of participants in the 30-50 year age group meant that relatively little data was available regarding distress related to work and to dependent children. These two domains are highly pertinent to a man's self image as protector and provider, and so can be a particular problem for men who are dependent on their physical strength for their livelihood (Maliski, Rivera, Connor, Lopez, & Litwin, 2008). Future research

could profitably distinguish between developmental stages, investigating the distress and coping of younger single men, whose main social support base may still be their family of origin and friends, separately from the distress and coping of men in the middle age group, who are likely to have the support of an intimate partner and responsibility for dependent children, separately again from the distress and coping of older men.

Second, the range of ethnicity was limited to Māori and Pākehā. Given the significant proportions of Eastern/Asian and Pacifika people living in New Zealand now, this raises significant issues regarding the validity of transferring findings, particularly to Auckland where their populations are greatest, as has been mentioned. However, the object of the present study was to focus on provincial regions. Even so, the absence of men of Chinese descent, given their long history of horticultural work in New Zealand, is a limiting factor to the transferability of conclusions.

Third, to my knowledge, no participant was homosexual. Although little is known about the psychological implications of sexual dysfunction and other side effects of prostate cancer treatments for gay men, the ability to have an erection is central to gay identity, so effects could be severe for both self-image and the ability to maintain or initiate an intimate relationship (Asencio, Blank, Descartes, & Crawford, 2009). Furthermore, gay men are twice as likely to be affected by prostate cancer since their intimate partners are also men. Clearly there is a need for research into the distress and coping of this highly exposed group (Asencio et al., 2009).

Fourth, none of the six Māori participants had an intimate partner at the time that interviews were conducted, although one did by the time team discussions were held. Since wives/intimate partners were so important in supporting Pākehā men, it would have been interesting to observe the variation in how Māori men were supported by them, and how that support interacted with support offered by other whānau members, particularly women.

Fifth, none of the men who had wives/intimate partners reported that they were unsupportive, and most could not speak too highly of their partner's support. The data therefore contained little description of dissatisfaction/distress and coping relating to lack of support from – and none regarding rejection by – an intimate partner. The

distress associated with such lack of support or rejection is likely to be particularly severe, given the dependence of many men on their wives/intimate partners as their only confidant (Cochran & Rabinowitz, 2003; Keller & Henrich, 1999). The distress that Richard suffered as the result of losing his ability to have an erection and the consequent loss of his intimate relationship was so severe it caused him to seriously contemplate suicide twice. However, in his case, his partner did not reject him – it was he who withdrew from the relationship because he could not function as he used to and wanted to. Presumably a man could suffer distress that was even more severe if his partner rejected him on account of his sexual dysfunction, and perhaps made the damage to his masculine self-image worse with degrading words. The analysis would have been richer for the inclusion of some reporting of this nature.

Finally, the sample was biased towards prostate patients. Though this was unplanned, I consider it advantageous in that it provided extra data regarding the highly salient topics of sexual function and continence. However, I would have preferred that the sample included more men with bladder and bowel cancers (it included only one of each) who face serious and similar challenges.

From this list of sample limitations it can be seen that the dataset did not reflect the full range of men's cancer-related distress and coping. However, for the age group, sexual orientation, and ethnicities included in the sample, most of the range of experience should have been represented.

Regarding the discussion phase of the research, it could be asked whether an alternative approach to validating interview findings and discussing intervention suggestions might have been preferable which would have involved a larger sample of participants. Alternative options might have included returning to interview participants individually a second time, or the use of formal and larger focus groups, perhaps with a new participant sample.

Practical considerations place significant constraints on research with cancer patients, on research with men, and on research which is dependent upon the voluntary recruitment assistance of health professionals working in the field, and all three conditions applied to this project. Obtaining a new participant sample would not have been possible as the pool simply 'dried up' – there was a period of many months after

the last participant was recruited during which no further recruits were forthcoming despite repeated requests made of recruiters. Since the project engaged a comprehensive range of cancer health professionals in recruitment, obtaining a new sample would have required moving the project to new geographical regions in order to engage a new set of recruiters, which would not only be time consuming and expensive, but would introduce complications regarding the demographic characteristics of the new participants, and may also be considered a breach of the PAR method which I interpret as requiring the honouring of the original participants' investment in the work by returning to them for validation and discussion of practical application of findings. Participation in phase two of the project was thus constrained by both significant practical reasons and a philosophical one relating to method. Although the resulting sample was not large, nor was it tiny, and I feel the quality of participation in group discussions was high, since participants had already built rapport with the researcher and commitment to the research project through their earlier interview.

Team discussion format was considered advantageous over another round of individual interviews for phase two because it potentiated the creativity of multi-party discussion, which was considered important to the critique of preliminary findings and the generation of intervention ideas. In the event, however, such intervention ideas were not forthcoming regardless. Would larger groups have assisted? I do not think so. The group of three men did not come up with more intervention suggestions (zero) than the groups of two (also zero), notwithstanding that the participants in that group, being Maori and from the same district, had some small familiarity with each other before meeting, and we had three (compared with two) of the longest meetings together, and so should have had – and appeared to have – optimal rapport and opportunity. The fundamental problem is that men from lower socio-economic groups do not have the knowledge about the health system and its management that is needed to contribute original solutions. (This difficulty is discussed next, as a limitation of PAR method.) Constructing larger groups also would likely have deterred some potential participants because distance travel would have been required of some men and this would have created practical difficulties associated with their age and state of general health. Another possibility would have been to engage men with higher socio-economic characteristics in these discussions. However, even the two men with these

characteristics that I did talk to (individually) had very little to contribute. Significantly involving such men in the development of intervention ideas would also risk diverting privilege from the needs and preferences voiced by men from lower socio-economic groups – indeed, such needs and preferences might not be voiced at all if poorly educated men felt intimidated in the presence of men perceived to be more competent. For both practical and philosophical reasons, therefore, format options for phase two discussions were limited, and I feel that the format used was the most optimal within the constraints of this project.

The matters I raise concerning PAR really reflect on the limits of the method rather than the limits of this study. As explained in the Methodology chapter, PAR is grounded in 'democratic' values and is designed to give voice to people who live or work with the problem or issue being researched, but who usually have little if any say in how it is managed (Genat, 2009; Lewin, 1946). The philosophy of the methodology asserts that those people, the CRG, have expertise both in describing the problem, and in formulating solutions, and PAR is a means of drawing those understandings from them (McNiff & Whitehead, 2006). Although it is well known that in application of PAR, facilitating the CRG to contribute its expertise can pose significant practical and financial challenges, the present study has revealed grounds to challenge both aspects of the assertion regarding the CRG's expertise.

It sounds like a truism to assert that a person who is suffering knows best the nature of their experience and how they cope with it, and therefore has greatest expertise on the subject. However, whether due to 'normative masculine alexithymia' or to masculine socialisation (Levant, 1992) or to masculine cultural pressure in the moment (Addis, Mansfield, & Syzdek, 2010), men are well known for underreporting their experience of psychological distress (Cochran & Rabinowitz, 2000). If the cause is alexithymia then they are not in fact fully aware of their emotional experience, and/or are not able to express it, and someone else who cares for them and knows them well, such as their wife/intimate partner, may be in a better position to describe some aspects of their experience. If the cause is pressure from socialisation or contemporary social context, then, again, a wife/intimate partner may have the freedom to express experiences that a man does not. There were signs of these possibilities while I was collecting interview data. Twice, after the interview was complete, I was having a coffee with the

participant and his wife and, contrary to what the men had said during their interviews, the wife told me how very anxious or depressed her husband had been. In one case the man then sounded a little embarrassed, both by the strength of term his wife used to describe his feelings and by the fact that the truth of his earlier reporting had now been brought into question. In the other case the man looked surprised and blank, as if he had no idea what his wife was talking about. The latter incident is consistent with alexithymia, and the former with pressures to underreport deriving from masculine culture.

I was aware of the possibility that men would underreport their distress before I began the interviews. However, PAR insists on respecting the expertise of the CRG, and it could seem condescending to require men's reporting to be verified by their wives. Who is to say, in any case, which version is more accurate? I took the view that it was better to hear men's experiences in the way they wished to tell them, and if there was any inaccuracy in their reporting, to let that be evidenced by their own interview rather than someone else's. In the event, the reporting of 'no distress' and ambiguous reporting became quite fascinating subjects of analysis in themselves.

Thus the present study illustrated an instance where the 'expertise' of the CRG to describe the problem which is the subject of the research is questionable. Had it not been that a large proportion of participants in the present study were willing and able to fully express their experience, the study could have foundered. There must be many other populations who are, for some reason, either incapable of, or uncomfortable with, fully expressing their experience. Yet respect for members of the CRG is absolutely central to PAR theory, and essential to winning the cooperation of participants with the further work required after initial data collection. It may be that the method is not the appropriate one to use for some populations.

The second PAR assumption that is challenged in the context of the present study is that members of the CRG have the expertise necessary to formulate solutions. In the present case, the nub of the research problem was identified as the CRG's lack of knowledge, including their lack of knowledge of the disease, of the health system and of support services. By definition then, participants were able to offer little by way of suggestion as to how services could be improved to better meet their needs. The very problem

causing/exacerbating their distressing experience was their *lack* of this aspect of expertise. It was necessary for solutions to be offered by someone who had some knowledge of what the health system could offer. Participants were in a position to then comment on the acceptability and workability of such suggestions from the point of view of potential service users – a topic on which they did have expertise.

This dilemma can be seen as merely requiring facilitation, but it is more fundamental than that. It is about power. If the researcher is obliged to offer possible solutions to the CRG's problems because the representatives of the CRG are not able to do so, this challenges PAR's democratic assumption 'that all men are created equal' and experts in their own cause. Of course, the reality is that they are not – some stakeholders in a social arena have a great deal more power than others, and those others suffer a great deal more accordingly, and are not in a position to alleviate their own suffering. Indeed, where there is a problem of suffering that continues unremediated, I would think it safe to assume that power inequalities are at play. There will be times when PAR's democratic philosophy should therefore be applied as an aspirational goal for the future of the CRG, rather than as a description of its capabilities when research begins.

Future research

The limitations affecting the sample of the present research indicate obvious areas for future research exploring the distress and coping of men: men who are from the young and middle age groups, men from New Zealand Chinese and immigrant Asian/Eastern and Pasifika ethnicities, gay men, married/partnered Māori men, and men whose wives/intimate partners were unsupportive or rejecting in the face of cancer. Another obvious area is quantitative research to specify the degree and incidence of identified features of distress or coping. Indeed, this type of research is part of what I have planned next: an attempt to quantify the distress of prostate patients stemming from their sexual dysfunction. Outcome research in relation to some of the specific interventions suggested would also be useful. For example, if a set of orienting DVDs are integrated into standard treatment pathways as suggested, how much difference would they make to men's cancer-related distress? But the areas of research that excite me most for their potential to affect beneficial change are those that have potential to build a new paradigm regarding the place and nature of information provided as part of

standard medical treatment pathways. Something of this ilk is the aim of the second part of the next project I have planned: focus groups with clinical staff exploring their views on what information regarding sexual rehabilitation can be integrated into treatment pathways for men with prostate cancer. It is at this systems level that psycho-oncology has the greatest potential to effect change that will benefit men, given their gender-related disadvantages regarding health information. Traditionally, clinical psychology has focussed on treating distress within a model that may be perceived as better suited to women. To help men, the most effective way may be to focus on preventing distress by tailoring medical systems to better meet their needs.

Closing thoughts

In drawing this thesis to a close I step back to my opening discussion and reflect further on how 'cultural blindness' has disadvantaged men's health, and the response it calls for.

In that opening I posited that men are at a similar cultural disadvantage in relation to health as Māori are in relation to many prosperity indicators (such as education), but with the irony and complexity that in other respects men are often culturally advantaged. In their study of urban Auckland GP's attitudes towards Māori, McCreanor and Nairn (2002) found that the rhetoric used by GPs had the effect of shedding responsibility for the impact of colonialism on Māori health, and the need to meet Māori health needs, by locating the cause of Māori health problems in the constitution (biology) and behaviour of Māori people. This meant that the cause of Māori ill-health was beyond the responsibility of the health system to correct. The root cause of such attribution may be ignorance of Māori culture and colonial history, and consequent subtle personal and/or institutional racism. Māori have therefore increasingly sought that responsibility and provision for health (and other social) services be handed over to them so that they can address their needs in their own way. Similarly, the poor health of men is commonly attributed to their own attitudes and behaviours, such that the health system is excused from acting to correct the manifest inequity in longevity statistics. But the complication for men is that the root cause of their disadvantage may be the cause of advantage to them in other domains, i.e. hegemonic masculine norms and the patriarchy that accompany them. Any claim of 'weakness' is counter both to those norms and to the justifying rationale of patriarchy (Courtenay, 2000).

It is an intriguing conundrum that patriarchy both privileges men and produces ill health in them, cutting short their lives, and causing them to suffer distress for which women would much more commonly receive peer support or professional treatment. New (2001) argues that men are 'oppressed' by Western norms of masculinity, to the extent that their emotional development – and therefore capacity to enjoy rich relationship – is restricted, their nature is misrepresented as inherently aggressive, and they are treated as 'hands', 'guns', or 'disposable bodies' (p.740). She points to their suffering displayed in their higher rates of substance abuse and suicide, and in their shorter life spans, and asserts that the fact that men are agents in creating this oppression does not take from the reality that they are systematically mistreated, nor from the responsibility that we all have to help dismantle this regime of oppression.

But the question is, 'How?' Social change is a slow process that must happen on multiple levels, little by little, over much time. For now, it is necessary to reach men on terms that are acceptable to them (and the women in their lives) within the cultural beliefs that they hold. Neither blaming men for 'not caring' about their health, nor valorising them for their stoicism, is going to help them with their cancer or cancer-related distress. Nor is requiring them to 'admit weakness' or acknowledge ignorance before help is made available. As with any other cultural group, it is incumbent upon service providers to learn how to serve their clientele within their clientele's norms and worldview. This means learning to 'speak their language' and identify needs and solutions compatible with how the clientele sees them.

In the present research, I have attempted to do this. With the assistance of 27 men who had cancer, I have produced a metaphor that 'speaks the language of men', and descriptions that explore the men's experience of distress and present their coping strengths. With their further help, I have also translated these theoretical findings into practical suggestions for how services might change to better serve men. At time of writing, I am engaging in a series of opportunities to disseminate these findings and suggestions to relevant service providers. My deep hope is that the investment made in this effort by my funders, supervisors and other supporters, and, most of all, by the participating men, will bear fruit as service providers have the opportunity to convert this offering into action.

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