

The Cancer Stories Project: narratives of encounters with cancer in Aotearoa, New Zealand

Richard Egan^{1*}, Rebecca Llewellyn¹, Sarah Wood¹, Joanne Doherty², Tira Albert³, Chris Walsh⁴, Kelly Atkinson⁵ and Phil Kerslake⁶

¹University of Otago, Cancer Society Social and Behavioural Research Unit, Department of Preventive and Social Medicine, New Zealand

²Doherty & Associates, New Zealand

³Mana Wahine, Kokiri Marae Health and Social Services, Wellington, New Zealand

⁴Health Quality and Safety Commission, New Zealand

⁵Cancer Society of New Zealand, Relay For Life and Community Development, New Zealand

⁶Life Paths Limited, New Zealand

*Correspondence to:

Cancer Society Social and Behavioural Research Unit, Te Hunga Rangahau Ārai Mate Pukupuku, Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago, PO Box 913, Dunedin 9054, New Zealand. E-mail: richard.egan@otago.ac.nz

Abstract

Objective: The Cancer Stories Study aimed to identify the factors that empower people who have experienced cancer. More specifically the project sought to explore the coping and support mechanisms people adopted to help understand and manage their cancer experience.

Methods: A participatory research approach involved researchers and consumers working in partnership on the project. This research team agreed on a qualitative method that focused on cancer survivors' personal stories. Semi-structured interviews were conducted with 38 cancer survivors in the lower half of the North Island, New Zealand (NZ). Generic qualitative analysis methods were employed including the recording, transcribing and thematic coding of interview narratives.

Results: Seven distinct themes were classified under the overarching theme of empowerment: attitude, change, family/whānau and friends, healthcare professionals and services, sources of support, employment and tangata whenua (NZ's indigenous peoples). The unique needs of each individual were strongly emphasised throughout all the themes indicating a 'one-size-fits-all' approach has its limitations. The need for improvements in communication, cultural and spiritual care was highlighted by many participants.

Conclusions: It is anticipated that this project will contribute to a greater understanding of the factors that might empower people in their cancer journey. An empowerment lens, that asks how those affected by cancer may be further enabled at an individual, family/whānau, employer and healthcare professional level may be useful in assisting people navigate and manage their cancer.

Copyright © 2015 John Wiley & Sons, Ltd.

Received: 27 October 2014

Revised: 15 June 2015

Accepted: 18 June 2015

Background

Despite the recent growth in cancer survivorship research [1], including that examining supportive care needs [2–5], there has been a notable lack of large qualitative studies conducted in New Zealand. Only two such large-scale studies exist: McGrath and Holewa [6] and Signal *et al.* current study, 'Cancer care journeys and clinical decision making'; however, neither of these explores the psychosocial-spiritual (PSS) aspects of the cancer experience. This despite the New Zealand Ministry of Health's [7] recent emphasis on addressing the PSS needs of cancer survivors and recommendations for holistic approaches to cancer care [8], in alignment with current international trends and research [9,10].

The recent shift from a 'compliance oriented' [11] approach in cancer care to one where the PSS needs of patients are acknowledged recognises that empowering cancer survivors to take control of their cancer journey is

beneficial for all involved. While there are diverse definitions of empowerment, it is commonly related to concepts of self-efficacy, patient-centeredness, self-management, shared decision-making and shared responsibility [11,12] and might be described as a 'participatory process that enables individuals to achieve a sense of control over their lives' [13]. Health related empowerment specifically focuses on enabling patients to share responsibility for their healthcare by improving their understanding and coping capacity [14,15]. Communication and information giving are at the core of such an approach [16,17] with literacy levels playing a 'central role' in determining health inequities [18].

The New Zealand context for cancer care comes from the Public Health and Disability Act 2000 which sets the strategic direction for the country's publicly funded health system and legislates for improved health outcomes, a reduction in disparities across populations and the facilitation of access to, and dissemination of information [19].

The Treaty of Waitangi with its principles of partnership, protection and participation underpins this Act and calls for the Government to work with Māori in decision making, planning, development and delivery of health services, to achieve equitable health outcomes while preserving Māori cultural values and practices [20]. Despite the aspirations these two foundation documents expound, Māori continue to be over represented in both cancer morbidity and mortality [21].

While this study focused on individual accounts of cancer care and support, addressing the factors that empower patients to exert some control over their illness must acknowledge that access to health care is inequitable and is shaped by health literacy and organisational practices, as well as wider social, cultural, economic and political factors [18,22]. The research aimed to explore what factors impact positively on people's understanding and learning during their cancer experience.

Methods

A participatory-based research [23] approach was used, and consumer networks were employed to recruit 10 people as co-researchers, including Māori and Pacific, who had experienced cancer first-hand or whose family members had experienced cancer. This research team worked alongside the primary investigator (PI) for the duration of the project. In addition, a kaumatua/kuia (Māori elders) advisory group were involved in discussions around cultural issues and two external academics were consulted on the project. The University of Otago's Human Ethics Committee approved the study (reference number 12/287).

The research team agreed on both the research topic and a qualitative approach, focusing on the factors that helped people understand, manage and cope with their cancer. Semi-structured interviews, designed to engage participants in a conversation rather than a straightforward question and answer format, were conducted by four members of the research team and the PI.

Participants were purposefully recruited via a snowball approach, through national and personal networks, emails and posters. Not all those who applied were interviewed to allow for both variation and inclusion of Māori and Pacific participants. The inclusion criteria were people over 18 years old who had finished their main treatment, and whose cancer was of any tumour type. While acknowledging the unique needs of discrete cancer types, the research team decided that recruitment would occur across cancer types believing that there would be commonalities regarding 'what got people through' their cancer experience. The project explicitly aimed to include Māori as a reasonable proportion of the participants, reflecting the unequal impact of cancer for Māori.

An information sheet provided participants with suggested topics for discussion to allow consideration prior to the interview. Topic areas and key questions were:

- i. What helped you to get through your cancer experience?
- ii. What were the strategies that you used?
- iii. What has been your experience of the language associated with cancer?
- iv. What helped you understand your cancer experience?
- v. What would you recommend people in your situation do to make it more manageable?

Philosophically, the research group largely came from a pragmatic position which affirms the use of individual stories and generic qualitative methods. The PI comes from a pluralist, epistemologically pragmatic position [24,25].

Generic qualitative analysis methods were employed, including the recording, transcribing and thematic coding of interview narratives [26]. Early transcripts were analysed by two researchers (EG and JD) and a coding scheme agreed upon. In an inductive and deductive process, analysis engaged with themes that emerged from both the literature and participants' own experiences. The PI worked collaboratively with the co-researchers throughout the research process, from the development of the study design, interview schedule and coding scheme through to data collection, analysis of results and review of the final report.

Results

Of the 45 people who registered interest in the project 38 people were interviewed: 15 Māori, 18 European/Pākehā, 4 Pacific and 1 Asian (Korean); the ages ranged from 18 to 88: 27 women, 11 men and 13 main cancer types. Those not interviewed did not fit the criteria or decided not to participate (Table 1).

Seven distinct themes were classified under the overarching central theme of empowerment: attitude, change, family/whānau and friends, healthcare professionals (HCPs) and services, sources of support, employment and tangata whenua.

Attitude

The power of a person's attitude and that of others to positively affect the experience of cancer was reiterated by many participants.

Some participants found it helpful to approach their cancer with a good humoured attitude:

"We could even joke about it and make light of it. As Māori that's what we do aye, like at a tangi [funeral]. We're grieving but within the next minute we can also be laughing and joking and that's what it was. You know like someone will get cheeky you know, and if I got cheeky back to her she'd say 'at least I've got two tits and we'd crack up laughing...'" (Jamie, male).

Table 1. Participant demographics

Demographic	Quality	Number
Gender	Male	11
	Female	27
Age range	18–19	1
	20–29	3
	30–39	5
	40–49	8
	50–59	6
	60–69	9
	70–79	2
Ethnicity	80–89	2
	Māori	15
	European/pakeha	18
	Pacific	4
	Asian	1
Cancer diagnosis	Breast	13
	Head and neck	6
	Prostate	4
	Leukaemia	2
	Thyroid	2
	Brain	2
	Cervical	2
	Ovarian	1
	Melanoma	1
	Bowel	1
	Renal	1
	Lymphoma	1
	Hodgkins	1

The ‘power of positivity’ was a recurring theme in the interviews, though participants commented that this did not necessarily mean being positive all the time:

“There is always the other side where you think it is doom and gloom but you can come out quite sunny on the other side of it but you have just got to keep an eye on things” (Bill).

Some participants considered it important to be surrounded by others with positive attitudes:

“And the positivity, surround yourself in, with positive people and disassociate with the negatives ‘cause we can all do that to ourselves. We don’t need other people doing it” (Jamie).

Many participants recognised the power of forward-thinking to get them through the challenges of cancer and to help preserve a positive outlook on the whole:

“Having a clear goal at the end helped me and kept me positive” (Lily).

Others found living in the present moment a means of remaining centred and in control:

“One piece of advice that I always remember someone gave me or I could’ve even given it to myself was about one day at a time because you kind of get in this cycle of things getting out of control with your thinking about the what ifs and the what ifs” (Bill).

Change

The re-evaluation of one’s personal outlook as a result of cancer was commonly referred to as a life-enriching transformation, despite the physical and psychological trauma of diagnosis and treatment:

“I’ve always spoken from a positive place about it. It was a rough time going through it, but ultimately it was a blessing. It slowed my life down a bit. Taught me what was important and you know brought my whānau closer together” (John).

“It’s that glass half full now—more positive and thankful for what you have” (Maggie).

Some participants were prompted to become an advocate for cancer awareness and prevention:

“I say ‘Oh well go for your mammogram’. And they go ‘Oh no I don’t want to get my tit squeezed, it’s gonna hurt you know’. I said, ‘OK die then. You know prevention. Do you want to see your moko’s [grandchildren]? Do you want to see your family, you know?’ You know? So a bit of a bully, being really harsh and to the point. Just go and do it. That’s a conversation killer but if we can save a Māori life then do it—you know too many of our people are dying” (Rosemary).

Family/whānau and friends

Many participants recognised the solid foundation family/whānau and friends provided during their cancer experience:

“There’s nothing quite like those who love you being there for you—nothing, nothing” (Frances).

Support people assisted survivors with the acquisition of knowledge and a greater understanding of their cancer:

“Good to have Mum and Dad there to listen—they did try and explain it all in laymen’s terms—they could ask questions I couldn’t even think of” (John).

The degree to which participants informed their friends and family of their diagnosis differed. While some participants wanted their entire community to be made aware, others did not wish the news to go beyond a small circle of family and friends:

“For me I am a very open book and I went straight home and rang everybody I knew and told them” (Rebecca).

“My close friends and family all knew—no one else needed to” (Lily).

Assistance with the provision of care and support for the children of survivors was cited as a pre-requisite for being able to cope with the various obstacles of the cancer journey:

“Ah what got me through? Um, knowing that my children were all good. Knowing that they understood” (Rosemary).

This participant captured the varying reactions of family/whānau and friends to the cancer journey:

“My husband talks with me matter of factly, my brother who is my only sibling has talked with me cautiously, good friends have talked with me openly and compassionately and there is a continuum that goes from at length to briefly, depending on the day and the person” (Frances).

In the absence of outside support, participants showed resilience by looking to themselves for strength and stability:

“I was strong all the way through because my mum was very emotional and my husband stuck his head in the sand—he wasn’t there at all emotionally or physically” (Rebecca).

Healthcare professionals (HCPs)

Many participants affirmed an appreciation of simple and plain language used by HCPs to convey information, including the use of language tools such as metaphors:

“Grade 3 cells—the surgeon said they were more lion than pussy cat—I found this useful language to explain to friends” (Patsy).

“They didn’t really use a lot of strange words around me—basically ‘you’ve got a tumour—it needs to come out’ nice and simple plain English” (Martin).

Some participants commented on the need to draw on support when treatment plans were being discussed and allow time to make measured decisions about such plans:

“You need a lot of support and advice to make these decisions—time to reflect on options—have another person there to listen” (John).

Participants expressed gratitude for HCPs who showed an awareness of the overwhelming nature of the cancer journey and were prepared to make themselves available beyond their usual job description:

“My oncologist always made herself available when I needed her—gave me her number so I could text her” (Aroha).

Some people interviewed commented on the important role their general practitioner (GP) played as a health care provider:

“He wasn’t happy with the results of the mammogram so he sent me to have it biopsied so I’ve always given credit to my wonderful GP for that because it was from the biopsy that it came back as a grade three cancer, yeah, yeah” (Rose).

Sources of support

Participants sought various forms of support and self-care during their cancer journey:

“It was, ah, soul sucking... It really did sink me into a, deep depression and if anything I can learn from that is that that’s probably what I could [have] paid a lot more, ah attention to in terms of seeking a lot more help around that” (John).

“I didn’t want to be labelled as a cancer patient—but after 4–5 panic attacks I thought it might be good to talk to someone so I rang the Cancer Society” (Teresa).

The individuality of self-care became evident. For one participant, self-care involved creative expression through body art:

“When it came back clear I ended up getting a tattoo just above my scar—it is a daffodil and it says, never give up. And now I have 6 daffodils going around it for every year of survival—it is just an incentive, a little goal really, a positive reminder” (Bill).

Overall, self-help did not preclude the need to ask for outside help:

“Take ownership of the situation—learning to be my own advocate and my own best friend, trying to keep an open mind about things I am told and what I hear... Or ask someone else to be your advocate, someone you trust who would be prepared to hold your hand” (Frances).

Spirituality and active prayer were common forms of support sought by participants; often as a means to promote positivity, determination and self-discovery:

“I remember praying for courage to deal with it so my children would be proud of me. I started praying to the Lord—that’s where my strength comes from, through praying” (Jasmine).

“Becomes a really spiritual journey and you learn about who you are as a person and know who you are...” (Maree).

The informational needs of participants varied widely:

"I read everything I could [lay] my hands on which is how I coped with things" (Lily).

"I looked up renal cancer, read one sentence and looked at one picture—turned the computer off and never went there again—I'm a bit of an ostrich, I just get on with it, don't need to know all the ins and outs" (Teresa).

Employment

A positive theme that came out of the interviews was the source of support that employers, colleagues and in general the workplace environment could provide:

"Work said 'take all the time you need, we'll help you out and there'll be a job for you when you come back...I'm extremely grateful to them'" (John).

Employers could often understand their employee's situation because of their own first or second-hand experience with cancer:

"Work were very supportive because a couple of the directors had family members involved with cancer—if I needed anything I just had to ask—the director said as soon as you know the findings I want to know and he made a point of coming to see me" (Bill).

Employment could provide a form of support because of the grounding sense of 'normalcy' it provided:

"I had said, if I ever got cancer the first thing I would do will be to give up work, and then when it happened the last thing I wanted to do was give up work because work was this pocket of my life where I could do normal things" (Frances).

For some, the sense of 'normalcy' provided by employment in terms of contributing to the household income was positive affirmation of a future without cancer:

"Good to still contribute to household and a reminder I had a life after this" (Stella).

Tangata whenua

Māori participants noted the significant influence their culture had on the perspective they brought to the cancer experience and their treatment:

"You know the breast is a part of you. You can't just disrespect and leave it out there and when I was better we went to Tolaga Bay and buried it at urupa [Māori burial site] by my Grandparents" (Jamie).

"Chemo is not for me—I'm going on rongoa Māori (traditional medicine) from the bush" (Jasmine).

Being able to express common cultural practices (such as prayer/karakia) was a source of strength and was self-affirming:

"We went home straight away and had karakia [prayer] with my mum and aunty, another elderly kuia that you know is well respected and kind of put it back into perspective because I was yeah a mess and we just went back into her lounge and just sat down and yeah we had karakia and once that had happened I you know I settled down" (Maggie).

The importance of spirituality or spiritual health/wairua was emphasised by participants, who saw it as an essential and sometimes underestimated part of a holistic model of health:

"When people get sick they become very spiritual—there's a lot of time for reflection, even if you don't believe in God—You say all those karakia—they are always there—but you become more intoned to those spiritual people" (Rosemary).

Barriers to empowerment

While this study predominately investigated mechanisms and supports people used to cope with their cancer, some participants invariably raised issues that could be considered potential barriers to empowerment. Here we highlight two of these issues:

Language and communication

Health literacy can serve to support empowerment in decision making. Equally, poor health literacy and communication has the potential to disempower and confound, particularly at critical and distressing junctures in the cancer journey such as diagnosis and decision making around treatment options.

One participant signalled the importance of HCPs using appropriate language and exhibiting sensitivity and professionalism when delivering a diagnosis/prognosis:

"He basically said, 'Well, you've got a 65% chance of it coming back and if it comes back on your left side, you're stuffed.' Not good." (Stella).

Other comments reinforced the need for HCPs to recognise patients' varying levels of health literacy or comprehension:

One participant when asked by the interviewer if they understood what "aggressive" meant responded: *"Not really. I had to go and study about it myself..."* (Tom).

“When the doctor told me it was grade 3—I said oh that’s good, does it go up to ten and he said no grade 4 is terminal...[I] sat there like a stunned mullet then cried and cried...” (Rose).

This from an individual for whom English was a second language:

“We just heard the word cancer and prayed very hard—we couldn’t understand anything else, then we got a pamphlet in Samoan language and I read it all the time—it is about cancer” (Politi, female).

A number of participants held mixed feelings regarding the use of survivorship language such as ‘fighting’ or ‘battling’ cancer:

“I struggle with the notion of a fight or battle with cancer—it is my metabolism that is being ineffective so to fight it is to fight yourself” (Frances).

One participant commented on a lack of timeliness when seeking clarification and support from their HCP about treatment options:

“When I get an answer to a question I go away and end up with another 10 questions—health professionals’ are very busy, overloaded, not enough time” (Frances).

Finally some participants commented on the challenge of asserting and questioning treatment options:

“We did measure and challenge the doctors on what they were telling us... we did a bit of homework on it ’cos I was really against the radiation. I didn’t want to do it because I had the clear margins.... but they were really pushing in terms of added precaution. I challenged them on the clear margins, and no evidence to suggest that it’s going any further” (John).

Lack of cultural support

Crucially, many of the Māori interviewees experienced a cultural and spiritual disconnect within the medical system:

“I can’t say that I got any cultural support. Na there was no cultural considerations, there was no um, even suggestion of you know cultural support. Um, I m, they recognised that I had strong cultural support within my whānau but you know.....it doesn’t, doesn’t stop them from asking the question. No I can’t remember once” (John).

A focus on information-giving and the physical aspects of health instead of a culturally relevant holistic focus was seen as problematic:

“Good resources and information but no cultural context—no offer for you know mental health or anything. And um, a consideration of wairua [spirituality], hinengaro[mental health], the rest of me as opposed to just that physical state. And that’s probably the downfall of it really” (John)

One participant described her experience of the health care system as alienating, inappropriate and lacking in cultural competence:

“I found my voice since I’ve had my journey and I’ve become involved in the Cancer Society. Resources aren’t always given to whānau and there’s a lot of gate keeping that goes on in there—I wasn’t happy because it’s quite racist to be quite blatant. It was quite lonely, because I was young, Māori and trying to make a difference” (Rose).

Discussion

The interviews highlighted various factors that influence the capacity of people with cancer for empowerment. While the concept of ‘resilience’ was not overtly discussed during the interviews it might be considered an undercurrent to many of the themes. Wise & Marchand’s interviews of ‘resilient people’ with advanced cancer found personal assets, ‘including positive relationships, purpose in life, faith and mastery’ added to quality of life (p.76) [27]. The benefits of a positive attitude on the cancer journey are supported by the literature [28,29], specifically in relation to positive attitudes facilitating or being related to the phenomena of post-traumatic growth [30]. However, some participants noted this did not necessitate being positive all the time, which could in itself become burdensome. Wilkinson and Kitzinger [31] heed caution regarding the emphasis and societal expectation placed on patients to be ‘positive,’ pointing to the recent trend where cancer patients are labelled as responsible for the onset or progression of their disease, with a failure to ‘think positive’ a common accusation.

Participants in this study showed an appreciation for a patient-centred approach in which HCPs are cognisant of patients’ needs, values and views [16] and expressed a desire for HCPs to communicate with clarity, balance and sensitivity [16,32]. However, this was not the case for a number of participants in our study. It is argued that ‘by improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment’ (p. 2075) and overall health status [18]. The Kōrero Mārama report [33] found overall the majority of New Zealanders have health literacy issues, with Māori having poorer health literacy skills compared to non-Māori. The report contends improving population health literacy levels constitutes a shift from individual

responsibility to include a multi-sectoral effort from schools, government agencies and the health care system [33].

The promotion of spirituality as a form of self-care appears supported by both participants' observations and the existing literature. Mytko and Knight's [34] found that 'religious, spiritual and quality of life concerns are paramount' (p.439) for many cancer patients. Notably, Māori participants more frequently expressed cancer as a spiritual journey, and reported taking more measures to attend to spiritual needs. This supports existing accounts of spirituality as 'a practice and belief that... pervades all of Maori culture (Tikanga) and ways of life' [35]. Cultural differences in psycho-spiritual needs in cancer care have similarly been documented in other countries [36]. Taylor *et al.* [36] conclude that HCPs need to increase their awareness of patients' psycho-spiritual beliefs, facilitate optimal care and better assist patients to follow appropriate forms of self-care.

The importance of drawing on traditional culture and practices throughout the cancer journey was strongly emphasised by Māori participants. Despite the explicit objective of health care services to provide 'emotional, spiritual, cultural and social support for those with cancer and their family and whānau' (p. 80) [37] participants reported having to rely on family/whānau to initiate such care. In another recent qualitative study Māori patients perceived palliative care services lacked environments and practices conducive to a Māori worldview, further there were questions around appropriateness and cultural competence of the care offered [38]. It may be that spiritual and cultural care is lacking or being initiated too late, and this may in some way be contributing to the disparities in Māori cancer incidence

and mortality in New Zealand [39]. Of note, limitations of this study included: not all tumour types or ethnicities were included, the analysis was primarily pragmatic thus did not include theoretical perspectives and the findings are not generalizable in a quantitative sense.

It was not the intention of this project to develop prescriptive recommendations but rather to address the lack of qualitative cancer survivorship research in New Zealand. Furthermore, the valuable experiential insights into the cancer journey provide indications of where future research is needed, particularly in the areas of post-traumatic growth, health literacy, employment and spirituality, to ensure optimal conditions for PSS care and overall empowerment. An empowerment lens, which asks how those affected by cancer might be empowered at an individual, family/whānau, employer and HCP level, may assist people in their cancer experience. Overall this study affirms the unique nature of the cancer survivorship experience and the need to support the aforementioned individuals and groups whose influence on the cancer journey is undeniable.

Acknowledgements

We would like to thank the research participants and the following research team members: Teresea Olsen, Christine Pihema, John Kramer, Al Frost, Marie Retimanu-Pule, Pam McGrath, Chris Atkinson and the kaumatua/kuia group; and Susan Sutcliff, Marie Daly and Sarah Stacy-Baynes.

Conflict of interest

The authors declare that there is no conflict of interest.

References

1. Avis NE, Deimling GT. Cancer survivorship and aging. *Cancer* 2008;**113**(S12):3519–3529.
2. Cancer Control Council of New Zealand. *The Voice of Experience. National Report: Preliminary Results from the 2009 Cancer Care Survey*. Cancer Control Council of New Zealand: Wellington, 2009.
3. Harrison D, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care Cancer* 2009;**17**:1117–1128.
4. Armes J, Crowe M, Colbourne L *et al.* Patients' supportive care needs beyond the end of cancer treatment: A prospective longitudinal survey. *Journal of Clinical Oncology* 2009;**27**(36):6172–6179.
5. Hodgkinson K, Butow P, Hobbs KM, Hunt GE, Lo SK, Wain G. Assessing unmet supportive care needs in partners of cancer survivors: the development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psycho-Oncology* 2007;**16**(9):805–813.
6. McGrath P, Holewa H. Reconceptualising relocation for specialist treatment: insights from New Zealand. *Supportive Care in Cancer* 2012;**20**(3):499–505.
7. Ministry of Health. *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Ministry of Health: Wellington, 2010.
8. Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. The National Academies Press: Washington, DC, 2008.
9. Holland J. ed. *Psycho-oncology*. 2nd Edition ed. Holland JC. Oxford University Press: New York, 2010.
10. National Institute for Clinical Excellence. *Guidance on cancer services improving supportive and palliative care for adults with cancer the manual*. Department of Health UK, Editor. National Institute for Clinical Excellence: London, 2004.
11. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: polysemy or cacophony? *Patient Education and Counseling* 2007;**66**(1):13–20.
12. Tengland PA. Behavior change or empowerment: on the ethics of health-promotion strategies. *Public Health Ethics* 2012;**5**(2):140–153.
13. Herbert RJ, Gagnon AJ, Rennick JE, O'Loughlin JL. A systematic review of questionnaires measuring health-related empowerment. *Research and theory for nursing practice* 2009;**23**(2):107–132.
14. Arora NK, Weaver KE, Clayman ML, Oakley-Girvan I, Potosky AL. Physicians' decision-making style and psychosocial outcomes among cancer survivors. *Patient education and counseling* 2009;**77**(3):404–412.
15. Bulsara C, Styles I, Ward AM, Bulsara M. The psychometrics of developing the Patient Empowerment Scale. *Journal of Psychosocial Oncology* 2006;**24**(2):1–16.
16. Epstein R, Street RJ. *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. National Cancer Institute, NIH Publication No. 07-6225: Bethesda, MD, 2007.

17. Holmström I, Röing M. The relation between patient-centeredness and patient empowerment: a discussion on concepts. *Patient Education and Counseling*, 2010;**79**(2):167–172.
18. Nutbeam D. The evolving concept of health literacy. *Social Science & Medicine* 2008; **67**(12):2072–2078.
19. NZP Health and D Act. 2000. Available from: <http://www.legislation.govt.nz/act/public/2000/0091/latest/DLM80051.html>
20. New Zealand Ministry of Health. He korowai oranga. *Te Whang-nui-a-Tara*, Aotearoa: Manatū Hauora, 2002.
21. New Zealand Ministry of Health. *Cancer: New Registrations and Deaths 2011*. Ministry of Health: Wellington, 2014.
22. Ellison-Loschmann L, Pearce N. Improving access to health care among New Zealand's Maori population. *American Journal of Public Health* 2006;**96**(4):612.
23. Makhoul J, Nakkash R, Harpham T, Qutteina Y. Community-based participatory research in complex settings: clean mind–dirty hands. *Health Promotion International* 2014;**29**(3): 510–517.
24. Avis M. Do we need methodological theory to do qualitative research? *Qualitative Health Research* 2003;**13**(7):995–1004.
25. Creswell JW, Plano Clark VL. *Designing and Conducting Mixed Methods Research*. Sage Publications, Inc.: Thousand Oaks, 2007.
26. Patton MQ. *Qualitative Research and Evaluation Methods*. 3rd ed. Sage: Thousand Oaks, 2002.
27. Wise M, Marchand L. Living fully in the shadow of mortal time: psychosocial assets in advanced cancer. *Journal of Palliative Care* 2013;**29**(2):76–82.
28. Stewart D, Cheung AM, Duff S *et al*. Attributions of cause and recurrence in long-term breast cancer survivors. *Psycho-Oncology* 2001;**10**(2):179–183.
29. Ho SM, CL Chan, Ho RT. Posttraumatic growth in Chinese cancer survivors. *Psycho-Oncology* 2004;**13**(6):377–389.
30. Connerty TJ, Knott V. Promoting positive change in the face of adversity: experiences of cancer and post-traumatic growth. *European journal of cancer care* 2013;**22**(3):334–344.
31. Wilkinson S, Kitzinger C. Thinking differently about thinking positive: a discursive approach to cancer patients' talk. *Social Science & Medicine* 2000;**50**(6):797–811.
32. Ouschan R, Sweeney J, Johnson L. Customer empowerment and relationship outcomes in healthcare consultations. *European Journal of Marketing* 2006; **40**(9/10):1068–1086.
33. Priston M. *Kōrero Mārama: Health Literacy and Māori: Results from the 2006 Adult Literacy and Life Skills Survey*. Ministry of Health: Wellington, N.Z., 2006.
34. Mytko JJ, Knight SJ. Body, mind and spirit: towards the integration of religiosity and spirituality in cancer quality of life research. *Psycho-Oncology* 1999; **8**(5):439–450.
35. Phillip C. *Seeds of the Word: Nga Kakano o te Kupa*. Steele Roberts:Wellington, 2004.
36. Taylor EJ. Spirituality, culture, and cancer care. *Semin Oncol Nurs* 2001;**17**(3):197–205.
37. Taskforce CC. *The New Zealand Cancer Control Strategy: ACTION PLAN 2005–2010*. Ministry of Health and New Zealand Cancer Control Trust: Wellington, 2005.
38. Kidd J, Reid S, Collins N *et al*. *Kia Mau te Kahu whakamauru: Health Literacy in Palliative Care*. University of Auckland. Available from: <https://cdn.auckland.ac.nz/assets/fmhs/faculty/ABOUT/newsandevents/docs/Health-literacy-in%20palliative-care-report.pdf>. June 2014.
39. Ministry of Health. *Cancer: New Registrations and Deaths 2009*. Wellington: Ministry of Health, 2012.