

Patients' and clinicians' views on shared decision making in cancer care: a qualitative study of Aotearoa New Zealand patients' and clinicians' perspectives

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ABSTRACT

AIMS: Oncology stakeholders' view on shared decision making (SDM) in Aotearoa New Zealand is not well described in the literature. This study aimed to explore the perspectives of patients, clinicians and other cancer care stakeholders on shared decision making, and how and why shared decision making in cancer care can be viable and appropriate for patients and healthcare providers.

METHODS: Non-random, purposive sampling, combined with advertisement and snowball recruitment identified patient, whānau and healthcare provider participants for qualitative interviews. One-hour, semi-structured interviews were conducted to elicit perspectives on SDM. Data was analysed using Directed Content Analysis.

RESULTS: Thirty-one participants were interviewed. SDM conceptualisations primarily concerned the sharing of information. Participants' stories highlighted patients' and whānau willingness to participate in making decisions about their care, to hold authority in this process, and to have their needs and preferences considered beyond the biomedical model. Patients and clinicians identified a range of factors moderating the extent of SDM, creating a gap between SDM expectations and practice.

CONCLUSIONS: These data highlight the complexity of information needs in cancer care, and the discrepancy between patients' and their whānau and clinicians' views. This study increases our understanding of cancer stakeholders' expectations of SDM by highlighting various views on the meaning of SDM, informational needs and decision making engagement level. These findings can aid clinicians in creating space for patients to exercise their right to self-determination/rangatiratanga of health and wellbeing. Future work should explore approaches and implementations of SDM to facilitate an equitable experience of cancer care.

Shared decision making (SDM) is the collaboration between patients and healthcare providers to make care decisions based on the available medical evidence in accordance with patients' values and preferences.¹⁻³ Critical to patient-centred care, SDM can be used across all healthcare settings and patient populations, and allows patients and their support network to actively participate in making decisions about the care they receive.⁴⁻⁶ SDM is also considered an indicator of care quality, and may contribute to improved equity of health outcomes in Aotearoa New Zealand.^{3,7,8} The positive impacts SDM offers include whole of system benefits, such as improved healthcare utilisation and cost savings.⁹ However, despite these benefits and patients' overall preference for SDM, the integration of SDM into clinical practice has not improved much over time.¹⁰

Cancer is the second leading cause of death worldwide, with an estimated ten million deaths in 2020 globally.¹¹ This number includes 9,500 deaths in Aotearoa New Zealand,¹² with new cancer registration rates much higher for Māori patients than for non-Māori (411.5 versus 328.8 per 100,000, respectively). Medical decision making in cancer care is a multi-stage process involving complex concepts, often without clear optimal choices. Cancer care is often comprised of surgery, radiation and chemotherapy, with each therapeutic modality presenting uncertainty around risks, side effects, benefits and long-term consequences.^{10,13} In spite of this complexity, studies show that patients with cancer expect to be actively involved in their treatment decision-making and enabled to make informed decisions, with subsequent benefits including increases in patient engagement without significant increases

in consultation time, and reductions in decisional conflict and decisional regret.^{4,13,14} However, a recent study of decision making in cancer care in Aotearoa New Zealand observed clinicians often made direct and preferred recommendations during clinical consults, limiting patients' ability to exercise their self-determination rights.¹⁵ This highlights the continuing discrepancy between recognition of the benefits of SDM versus implementation in clinical practice.¹⁰

Providing patients with informative and relevant contextual information to support decision making is essential to SDM.¹ Patient-facing decision aids (PDAs) enable these essential aspects of SDM. PDAs are designed to help patients make deliberate decisions that are congruent with their personal values and preferences.^{10,16} A PDA can be developed as a booklet, app, video/audio recording, or static/interactive information dashboard to present complex medical information, including treatment options, risks, and benefits.¹⁶ Examples include: a booklet for prevention of breast cancer for women with BRCA1 or BRCA2 mutations containing information about breast cancer risks, preventive options, guidelines, studies, and comparisons;¹⁷ a web-based breast cancer application with the following content tailored to individual patients: breast anatomy, breast cancer definition and types, tumour grader and markers, types of treatments and associated risks, benefits and recovery timelines.¹⁸ PDAs can help patients make high-quality decisions within their cancer journey.¹⁹

Recent reports published by Health Informatics New Zealand and Manatū Hauora – Ministry of Health call for increased focus on digital solutions to enable better consumer choice, flexibility and decision-making in aid of reducing healthcare access and outcome inequities.^{20,21} Addressing these needs in Aotearoa New Zealand presents several unique challenges: the disproportionate cancer burden experienced by Māori patients, which is in breach of Te Tiriti o Waitangi provisions; the large disparity in treatment options via public versus private funding; continuing poor health system integration; and significant resource constraints with limited time for decision making.²² Importantly, an increased understanding of patients' SDM expectations is necessary to aid clinicians in creating space for patients to exercise their right to self-determination/rangatiratanga of health and wellbeing.²³ As part of the development of a PDA to facilitate SDM in cancer care in Aotearoa New Zealand, we conducted a study exploring cancer care stakeholders'

perspectives on the use of SDM, when decisions are made in cancer care, and key considerations when making these decisions.

Methods

Study design and location

In this Qualitative Description study,²⁴ we explored the perspectives of oncology patients, clinicians, and other stakeholders. The study was conducted in Aotearoa New Zealand between June and September 2022. Ethical approval for the study was received from the Health and Disability Ethics Committees of Aotearoa NZ 2022 EXP 12168.

Participant selection

Participants were oncology stakeholders, defined as: patients and their whānau, clinicians and other (e.g., patient advocates, digital health solutions developers, etc.). They were recruited using non-random, purposive sampling,²⁵ combining advertisement and snowball recruitment at cancer support organisations across Aotearoa New Zealand. Those who responded to the initial invitation were emailed the participant information sheet, which described the study purpose and expectations for participation. We prioritised equitable participation of Māori in this study by contracting a Māori researcher who developed a culturally appropriate flyer, and offered a "by Māori, for Māori" approach to recruiting and interviewing Māori participants. To reflect the totality of the treatment population, we recruited participants from a range of socio-demographic backgrounds, specifically seeking diversity of ethnicity, age and variation in place of residence (city, town, or rural). All participants received a \$50 grocery voucher as an acknowledgement of their contribution to this study.

Participants were eligible for inclusion if aged 18 years old or older, displayed capacity for informed consent, lived in Aotearoa New Zealand, and were in one of the following groups: diagnosed with breast or prostate cancer in the last 5 years, or whānau of a breast or prostate cancer patient; clinicians working with patients who have cancer; currently involved in work related to provision of oncology services, for example: patient advocates, researchers, staff at organisations such as the Cancer Society, health-care software developers. Participants had to have sufficient capacity to complete the interview in English or Te Reo Māori. Breast and prostate cancer were specifically pursued as these are

among the most prevalent cancers in Aotearoa New Zealand, with several possible treatment pathways leading to complex decision pathways and relatively high five-year survival rates.²⁶

To achieve adequate information power²⁷ we aimed to recruit approximately 20–30 participants, including: 5–10 patients with breast cancer, 5–10 patients with prostate cancer, and 5–10 oncology clinicians/researchers/patient advocates. Our sample size expectation was based on Malterud et al. guidelines²⁷: 1) broad aim (the overall experience of SDM in cancer care), 2) high quality of dialogue (semi-structured, in-depth interviews), 3) well-defined analytical focus (prespecified categories for data analysis), 4) cross-case analysis (exploring the range of experiences), and 5) specific sample (patients with breast or prostate cancer, cancer clinicians).

Data collection

Participants took part in one-off, semi-structured, face-to-face interviews (primarily via Zoom, with two interviews conducted in person at the participants' request). We used two interview guides (a patient and whānau, and a clinician and other stakeholder version; Appendices 1 and 2) to explore participants' perspectives on several pre-specified categories: the meaning and experience of SDM, factors moderating SDM, when decisions were made in cancer care, and decisional considerations. The interviews lasted between 30 and 90 minutes. They were audio recorded and transcribed semi-verbatim. Participants were invited to have their whānau/family/support people present at the interview and were also given the option to review their transcripts for accuracy before analysis. There were three interviewers: Te Hao Apaapa-Timu (female; speaking English and Te Reo Māori; Master of Public Health; experienced in qualitative research), Karol Czuba (male; English; PhD; experienced in qualitative research), and Rachel Owens (female; English; Master of Data Science; experienced in qualitative interviewing). Participants were able to indicate with whom they wanted to be interviewed. Participants and interviewers involved in the study did not have any prior personal or professional familiarity.

We also collected standard demographic information (sex, age, ethnicity) for all participants. We asked them about their location (rural vs urban), cancer type, stage, and time since diagnosis (patients), and their role in relation to provision of oncology service (non-patient participants).

Data analysis

Participants' demographic data were summarised descriptively. Interviews were analysed using Directed Content Analysis,²⁸ employing primarily a deductive approach and focusing on the prespecified categories. Coding of all transcripts in QSR NVivo was conducted by KC, who read the transcripts multiple times to become immersed in the data. Initially ten transcripts were coded inductively, and the resulting codes were then linked to the prespecified categories, providing a refined coding framework. This framework was then used to code all 31 transcripts. The resulting codes, subcategories, and categories were reviewed at the project team's fortnightly progress meetings. KC, RO, PB, and RR discussed the emerging findings and the two coders' interpretations of the participants' reports.

Deidentified quotes (*in italics*) from participants' transcripts are presented to support our interpretations of the data. Each study participant was allocated an alphanumeric identifier (e.g., PB1) representing their background: 1) PB—patient with breast cancer, 2) PP—patient with prostate cancer, 3) C—clinician, and 4) O—other stakeholder.

Results

Forty-nine potential candidates responded to the study invitation. Four were not eligible to take part (not breast/prostate cancer [$n=3$] and diagnosed over 20 years earlier [$n=1$]). Nine people who enquired about the study did not respond to our follow-up emails. Five people were eligible, but enquired late in the recruitment at which time we were seeking participants of non-European ethnicity to ensure diversity of participants.

Thirty-one participants were interviewed. No whānau/family/support persons were formally interviewed; however, in several instances they were present in the same space as the participant (e.g., in the background when participants were being interviewed via Zoom). Initial recruitment was halted after 28 participants were interviewed, followed by recruitment of three additional stakeholders to balance the research cohort. Following these last three interviews, the study sample was deemed to hold adequate information power.²⁷ Nineteen participants took part as patients who had cancer, seven as clinicians (of whom three had a current cancer diagnosis), and five as "other" (of whom three had a current cancer diagnosis). Table 1 presents a summary of the participants' demographic characteristics.

Overall, participants expressed definitions of SDM ranging from informed acceptance of clinicians' recommendations to desire for detailed in-depth discussion related to cancer treatment. Most patients wanted to be involved in decision-making; however, there were some who wanted to only "do what they are told". Clinicians expressed support for SDM but noted significant variation in practice. They also expressed an element of hesitancy to utilise SDM, concerned the process may introduce further uncertainty into decision making. Several factors appearing to moderate the practice of SDM were identified: patient and clinician characteristics, patient-clinician relationship, time and space to make decisions, healthcare system constraints and the uncertainty surrounding cancer care. In the following sections, we report the findings for each of the prespecified categories, along with tables presenting the subcategories and participant quotes.

Meaning of SDM: from accepting care recommendations to deliberating every nuance

Participants shared their perspectives on what SDM meant to them and what it looked like in practice. Overall, both patients' and clinicians' definitions of SDM revolved around provision and sharing of information about the available cancer care options. The extent of SDM depended on a range of moderating factors.

Patients' views on SDM: "I want to have a say and contribute to the decision making process"

The minimum expectation regarding SDM was that anything to do with cancer care had to "be agreed", or accepted, by the patient. In some cases, as explained by PP8, it may mean agreeing to do "what he was told, as he was trying to be a good person", especially when patients were primarily focused on facilitating expediency in making care-related decisions. Other patients, like PB10, wanted to know about all possible treatment options, all potential side effects and "all the facts and figures", and be able to ask questions about anything that broadly related to their cancer care. Table 2 outlines the subcategories and representative quotes for "patients' views on the meaning of SDM".

Although for a few patients the relationship with their treating clinician seemed mostly unidirectional with no room for deliberation, most patients expected a much more "consultative"

SDM process. Furthermore, with cancer impacts extending beyond the diagnosed patient, some participants highlighted the importance of including their whānau and family in SDM. This appeared particularly important to Māori patients, for whom collective decision making is often more acceptable than individual decision practices.²⁹

The above-mentioned expectations around SDM were also reflected in patients' care experiences. Some patients reported that not much consultation was needed between them and their clinician. Others, for example PB1, were involved in deliberating "every single nuance of every treatment". However, patients' satisfaction with how much SDM occurred appeared to depend less on the extent of SDM itself, and more on their preferences and expectations.

When asked about the most important aspects of SDM, patients talked specifically about provision of information, and wanting to know as much as possible about their condition and options. Some postulated that "information is power", and given the uncertainty accompanying cancer, having sufficient information provided a sense of control. This sense of control, in turn, contributed to maximising patients' autonomy, and empowered them to make decisions about their care.

"I think the biggest thing around cancer is that you need to give patients the feeling they may have some control over something that seems so uncontrollable. Even if that control is only that my oncologist and I are going to do the best that we can to monitor me, and give me the best drugs, and help me on my journey—then I've got control of that." (O2)

Clinicians' views on SDM: SDM can be beneficial, but challenging in practice

Clinicians had a similar understanding of SDM, proposing that SDM involved sharing information about treatment options and outcomes to help patients understand their situation and make informed decisions regarding their cancer care. However, clinicians tended to focus more than patients on the realities of SDM, specifically, on the difference between the ideal SDM and implementation in clinical practice. Table 3 outlines the subcategories and representative quotes related to this category.

As C2 reflected, the nature of clinician-patient

Table 1: Demographic characteristics of the participants.

	Patients with breast cancer (n=11)	Patients with prostate cancer (n=8)	Clinicians (n=7)	Other (n=5)
Age (years); median (range)	51 (38–74)	70.5 (55–74)	37 (28–72)	63 (39–85)
Gender (F:M)	11:0	0:8	5:2	4:1
Ethnicity				
European	7	6	5	5
Māori	4	2		
Asian			2	
Place of residence¹				
City	4	5	7	4
Town	6	2		1
Rural	1	1		
Cancer diagnosis type²				
Breast	11			2
Prostate		8	1	
Bowel			2	
Brain				1
None			4	2
Cancer stage²				
Stage 1	2	1	NA	NA
Stage 2	3	2		
Stage 3	4	3		
Stage 4	1			
Not reported	1	2		
Time since diagnosis ² (median [range])	7 months (3–24)	36 months (7–60)	NA	NA

Table 1 (continued): Demographic characteristics of the participants.

	Patients with breast cancer (n=11)	Patients with prostate cancer (n=8)	Clinicians (n=7)	Other (n=5)
Role	NA	NA	Anaesthetist – 1 GP – 1 Haematologist – 1 Medical oncologist – 2 Pathologist – 1 Radiation oncologist – 1	Patient advocate – 2 Digital solutions developer – 2 Cancer support volunteer – 1
¹ City—any urban area with a population of at least 100K; town—any other urban area; rural—any area not included under city or town. ² Patient-reported data				

Table 2: Subcategories and quotes for: patients' views on SDM.

Do what the doctor suggests
<p><i>"I don't like messing around—the clinician explained things really well, made me feel comfortable about it and I wanted this thing (cancer) zapped out of me."</i> (PP6)</p> <p><i>"They came at it in a fairly professional way, you know, just the hard, cold, facts. There wasn't any ... any warmth or any sort of feelings. Either 'this' or 'that', 'take it or leave it—what do you want to do?' sort of thing. They didn't discuss it through much, they just said 'you can either cut it out or you can have the other treatment. Here's some books for you to decide, let us know'."</i> (PP4)</p>
Be involved in every single decision
<p><i>"It never occurred to me that it could be any other way until I spoke to this other person, and she was like: 'what? You are doing this?' And it seemed like their oncologist had made some decisions without consulting her. It was only then that I realised that I actually had been privy to every single nuance of every treatment, and it all has been run by me."</i> (PB1)</p> <p><i>"What it should look like is that the healthcare professional describes the options and the pluses and minuses of all of the options. I can then question for more details, for example, statistics around appropriateness of the treatment for my situation, or survival statistics for a particular treatment plan. From there, I get to choose what treatment I would like to have."</i> (PB3)</p>
Provide information to foster empowerment
<p><i>"I think the biggest thing around cancer is that you need to give patients the feeling they may have some control over something that seems so uncontrollable. Even if that control is only that my oncologist and I are going to do the best that we can to monitor me, and give me the best drugs, and help me on my journey—then I've got control of that."</i> (O2)</p>

Table 3: Subcategories and quotes for: clinicians' views on SDM.

SDM is about being on the same page with patients
<i>"Shared decision making is about sitting down with the patient and having all the same information, having a talk about their diagnosis and various options for testing and treatment, and then talking about their goals and what they wish as well, and what their priorities are for their health. Then talk about the options of what we've got and using their wishes to guide or inform which ultimate choice we end up going for in terms of treatment and further testing or investigations. It's about me presenting them with some information, them asking questions, and making sure that it's all understood, that whatever we choose is with their input and wishes in mind." (C7)</i>
SDM in practice varies widely
<i>"Traditionally it's very hierarchical, so, it was the doctor, the lead consultant saying, 'this is what we're going to do' and everyone went with it. Nowadays, we take a lot of people's opinion into account and it's a shared decision. So, most importantly the patient, the multidisciplinary team members, nursing staff, junior doctors. The outcome for the patient is much more autonomous and it's more fair as well because a lot of people have input in it." (C2)</i>
<i>"I think my role is to interpret the information/knowledge/experience I have in a way for patients to understand that allows them to make the best decision for them." (C3)</i>
Too many options can increase feelings of uncertainty
<i>"It's obviously a good thing and the patients feel happy if they can be involved rather than, I think, years ago, doctors were like 'God' in what they said, and patients went along. Things have changed a lot. I think people expect more collegial decision making ... you give them all the options, but don't give them too many options; otherwise, they tend to get confused." (C1)</i>

Table 4: Subcategories and quotes related to: factors moderating SDM.

Patient characteristics
<i>"Just from my experience with this exercise so far, if you're not tenacious, there's a good chance you won't get the care that you'd get if you are tenacious. Which is a very sad thing." (PB3)</i>
<i>"I asked 'where is your model of Te Whare Tapa Whā?'—'What's that?'—I said, 'Oh my goodness. You disappoint me! That's where it lacks a lot, that's where a consumer misses out. We fall through the cracks. You get so exhausted in trying to teach them. You give up.'" (PB10)</i>
Clinician characteristics
<i>"What was perhaps useful, was my clinician's complete understanding of the situation, because her husband had been through something similar and was just coming through the other end. So, she'd been through that, she could understand the heartbreak, the worry, the stresses that we were going through." (PB1)</i>
<i>"You put your trust in the medical profession. And if there are other things available, whether they think that you can afford it or not, they can't judge anybody by just walking into the office and saying they can afford this drug or not." (PB2)</i>
Patient-clinician relationship
<i>"I think my clinician is very personable. Easy for me to relate to. Similar age. Similar stage of life. She understood where I was coming from. And what the things were that were important to me." (PB1)</i>
<i>"Traditionally medicine has been a very hierarchical profession, even among its members. So, how we were taught at medical school was definitely very different to how older doctors were taught and what they were exposed to. The way we practise is quite different." (C2)</i>

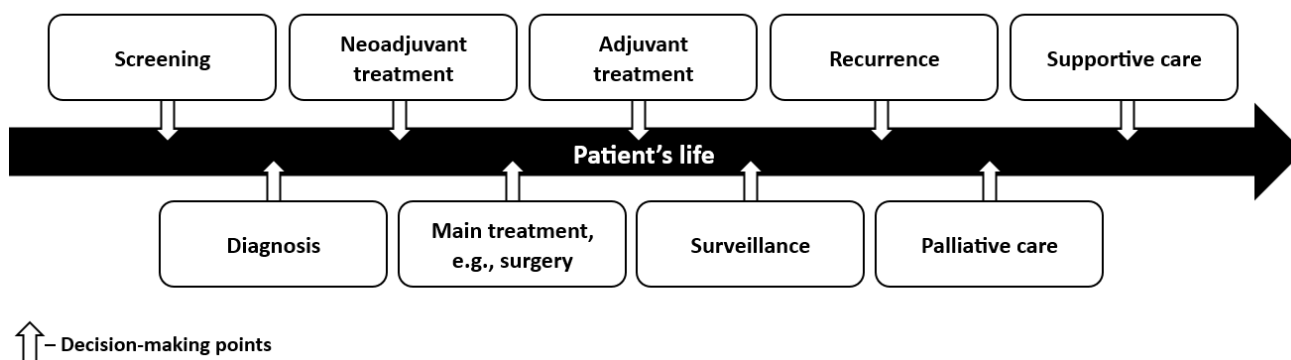
Table 4 (continued): Subcategories and quotes related to: factors moderating SDM.

Time and space to make decisions
<p><i>“Me and my daughter listened to it in the comfort of our own home, our own surroundings and took in the information and made decisions that we felt, that I felt good with because I was in my own surroundings. Not in a clinical setting.” (PB10)</i></p> <p><i>“What really helped was we had a whole family meeting, with about five of her children and their partners came and we also got the kaumatua, or the Māori liaison support worker to come and help us. That was the most successful interaction she’d had about talking about her cancer and making her wishes expressed at that point so we could actually move forward. Prior to this, she’d had a number of consultations where we weren’t able to achieve very much or make any leeway.” (C2)</i></p>
Healthcare system constraints
<p><i>“The standard port of call for the oncologist is to go through the standard protocol and you never get fired for that. And so initially they’re a little bit reticent to do statins, metformin, stuff like that. But after a while, they realise that, you know, this is a patient who will give it a go. And so, they get more experimental.” (O5)</i></p> <p><i>“I had my first appointment in the public sector before I decided I was definitely going private. Man, that waiting room was chocka-block full of people, they were half an hour behind schedule by the time I had my appointment. I just don’t think they have time to have these really open-ended, challenge-everything discussions.” (O4)</i></p>
Uncertainty surrounding cancer care
<p><i>“Sometimes a little knowledge is better than too much because you really don’t know what you’re in for. You don’t understand, no matter how much you read and how much you hear from people, you don’t really appreciate what you’re up for.” (PP6)</i></p> <p><i>“You don’t know whether chemotherapy is needed until after they’ve had surgery and then they’ll see me and I’ll go ‘yeah, you need chemo and you need radiation’ but I’ve got no idea whether it’s four weeks or three weeks or five weeks.” (C7)</i></p>

Table 5: Subcategories and quotes related to: decisional considerations.

Complexity of cancer care
<p><i>“My typical presentation for a decision, for when we’re discussing a treatment with a patient and requiring a decision regarding treatment would be a broad outline of the cancer in general, tying that back to their specific situation. So, what are the expected outcomes; outcomes from treatment; if this is a life-shortening illness, what a typical life expectancy might be, because decisions about treatment that may have high-ish toxicity and relatively low efficacy, I don’t think can be readily made in the absence of that context. There’s some discussion about baseline prognosis. Then, some estimate of what the likely benefit of treatment might be, you know, on average, based on clinical studies to the degree that they apply to you and your individual situation, what’s the likely lifespan extension? Then, secondarily, what are the toxicities of treatment, what’s the cost in terms of ... well, fiscal financial cost, if there is one, but more generally speaking, just cost in terms of time. Then, an exploration with the patient about how they perceive that, how they perceive those things to be ... to measure up against one another.” (C5)</i></p>
Diagnosis-related considerations
<p><i>“Their underlying comorbidities or past medical history is really important, because there are certain things that we can’t treat if they’ve already had certain conditions. But their functional status is very important; I need to know that at the moment they are able to mobilise by themselves, they’re able to shower, dress and toilet themselves—so we know, at baseline, that they’ll be able to tolerate the treatments and we can yield the good improvement with the treatments too.” (C2)</i></p> <p><i>“My surgeon that I’ve got now, she said ‘Oh, there’s no harm in getting a second opinion’. Everybody should have a second opinion. But there’s still oncologists and surgeons out there that don’t think like that. So, I think it’s allowing people an opportunity to do that. And encouraging them to do so, to be your self-advocate. Knowledge is power and that’s what you need at that point.” (PB2)</i></p> <p><i>“For example, there are these skull caps which send electric waves through your head and could give you another two months. But do you want the quality of life walking around looking like a robot? No...” (O5)</i></p>
Treatment-related considerations
<p><i>“Because some of these treatments have some big down sides. I thought, I’m not going to put up with all that crap just to get another three months.” (PP6)</i></p> <p><i>“Quality of life does not really come into that. You’re just trying to take, do whatever you can, the best possible you know ... to kill the cancer is what you’re trying to.” (O5)</i></p> <p><i>“There’s definitely the odd thing, like sometimes some reactions to the radiation treatment, the lymphedema. One that my own GP has to manage for me having no bowel is diarrhoea, and that’s just life now.” (C6)</i></p> <p><i>“I reckon that should be an option, having tohunga, having the option of mirimiri. Not everyone wants mirimiri, not everyone likes honohono, but having those options ... and romiromi, and rongoā—the Māori medicine from the plants.” (PB10)</i></p>
Psychosocial-related considerations
<p><i>“Having a cancer diagnosis is utterly terrifying and life changing. Facing this sort of existential crisis is no small thing. And generally, even if you are the most confident and worldly person, you’re brought to your knees.” (PB7)</i></p> <p><i>“Unfortunately, the best way to do that was to give my breast. And that was, you know, I’ve got three children and I breast fed all of them. And thankfully I’ve finished with that stage, my kids are old enough and I don’t want to have any more kids. So, in that respect my breasts have done their purpose and are not needed for this important job of feeding my children anymore.” (PB4)</i></p> <p><i>“Most people want to be heard, and I think when you open up the conversation like that, most people are happy to be able to have a say and contribute to those decision making processes.” (C2)</i></p>

Figure 1: Potential decision making points in cancer care.



relationship often dictates how much SDM occurs. She noted that the more “*traditional clinicians*” tended to be quite authoritarian with their patients, while many others focused more on maximising their patients’ autonomy in making decisions. C6 argued that patients often want to be told what to do, rather than being presented with all their possible choices as it can be “*too hard, too overwhelming*”. Additionally, as noted by C5, some patients may have “*unrealistic*” expectations of treatment efficacy, potentially limiting patients’ ability to engage in “*fully informed decision making*”.

Regardless of the extent of information sharing, it appeared that an effective SDM process may offer benefits to both the patient and their clinician. As C7 reflected, SDM supports patients in deliberating their options and selecting the most appropriate treatment: “*I think the sharing of information is really important, both for patients and me, to get the right decision for them at the end of the day*”.

Factors moderating SDM: the gap between expectations and clinical practice

Several factors moderating the extent of SDM were identified. Table 4 presents a summary of the moderating factors and examples of quotes supporting them.

Patient and clinician characteristics were highlighted as having a major impact on the alignment between their expectations of SDM and the actual experience. Patient characteristics included personality traits (e.g., assertive, agreeable), level of empowerment and engagement, coping skills, educational attainment, overall health status,

values and beliefs, cancer diagnosis and prognosis, treatment expectations, and individual preferences. Clinician characteristics included clinicians’ attitudes towards and training in SDM, their ability to tailor information for patients, and their degree of empathy. Importantly, participants noted the many biases held by clinicians and patients, including prior experiences with the healthcare system, not offering treatments to patients who do not seem able to afford them, and making decisions based on incomplete information. These biases can affect the extent of SDM that occurs in practice.

“It actually never occurred to me that it could be any other way. Until I spoke to this other person, and she was like, what? You are doing this? And it seemed like their oncologist had made some decisions without consulting her. It was only then that I realised that I actually had been privy to every single nuance of every treatment, and it all has been run by me.” (PB1)

The patient–clinician dyad was also noted as an important SDM moderator. Some clinicians were described by participants as “*quite authoritarian*”, noting this was preferred particularly by those patients who wanted to be told what to do next. Other patients preferred a more collaborative relationship, as they found the ability to ask questions reassuring. One clinician argued the authoritarian style was more prevalent among clinicians who were trained in the previous century, while more recently trained oncologists tended to foster more collegial relationships with their patients. In this context, it

appeared that a “good match” personality-wise can facilitate patients’ satisfaction with SDM. Participants also noted effective communication was key to building trust and understanding, which are essential for successful SDM. However, some clinicians commented that it is challenging to communicate to patients the uncertainty surrounding cancer treatments, with no clear “best” choice based on available evidence. In this context, as C6 argued, some patients want the clinician to tell them exactly what to do, rather than practise SDM.

Participants also deliberated on several moderating factors related to the broader healthcare system in Aotearoa New Zealand. A range of inequities, for example, inequitable access to information, were noted as impeding patients’ ability to make shared decisions. PB10, who is Māori, noted the lack of recognition of her cultural background negatively impacted her care experience, where she struggled to engage with clinical staff and was left feeling poorly informed about her care options. She recalled multiple encounters when she felt disrespected and disempowered, and it furthered her mistrust towards the healthcare system. Additionally, C2 argued the limited choice of publicly funded cancer treatments in Aotearoa New Zealand may be further deepening the health outcome inequities. Some participants even noted the lack of choice may render SDM unnecessary. Furthermore, staff shortages, resource-related constraints and system fragmentation were named as barriers to SDM. These constraints, as noted by C5, can contribute to clinicians only presenting the information that they consider most critical. Finally, many patients noted the importance of having sufficient time and being in an appropriate space to deliberate treatment options. Some argued being able to discuss these options with their family and whānau would help them make decisions truly reflecting their preferences and needs, and as noted by PB10, it could also help their whānau understand the specific implications of their relatives’ cancer diagnosis on themselves.

Cancer care decisions and considerations: arriving at “a clear decision that the patient is comfortable with”

Participants reflected on a broad range of decisions patients may have to make throughout their cancer journeys. Figure 1 presents an example of the potential decision making points in cancer

care identified by participants; the specific stages and sequence in which they occur can vary.

They included decisions related to screening, diagnosis, care team selection and changes, treatments (including types, order, funding, changing goals) and post-treatment procedures. These decisions were emotional and complex, involving elements of uncertainty, risk, and compromise, often in the context of urgency and varying patient preferences. Participants also identified a number of important considerations for making the above-mentioned decisions. We grouped these considerations into three subcategories: 1) diagnosis-related, 2) treatment-related, and 3) psychosocial-related considerations. Table 5 presents the subcategories and representative quotes related to this category.

First, a good understanding of cancer diagnosis is crucial in helping patients to choose the most appropriate treatment plan and develop realistic expectations about their care and outcomes. C2 noted underlying comorbidities, medication, past medical history and functional status play a critical role in determining the best course of treatment, with the evolving nature of cancer adding further complexity. Some comorbidities, for example diabetes or heart disease, may make certain treatments more risky or unsafe for patients. Additionally, as reported by PB2, the option of seeking a second opinion may play an important role in building trust and enabling effective SDM; however, not all clinicians support this practice. Indeed, as argued by O1, disagreeing with the initial diagnosis and seeking a second opinion is part of the cancer journey for some patients, who “*stay with the original person*” but become better informed.

Second, participants reflected on several aspects of the treatment decision making, including treatment options, goals and aims, effectiveness, costs, side effects, timelines and alternative treatments. In many participants’ stories, eliminating cancer appeared to be the primary driver for treatment decisions. PP7 simply wanted “a peace of mind” and to know the cancer is gone. However, some participants with the more advanced stages of cancer postulated the treatment’s impact on their quality of life and functional independence were key determinants. Some participants also expressed interest in non-standard treatments. PB10 argued for more recognition and consideration of traditional approaches, like rongoā Māori. PB2 was interested in combining radiation with evidence-based, non-standard treatments like sauna, but her clinician “*was like: Pfffft!*”. At

the other end of the spectrum, O5, whose cancer was diagnosed as terminal and was treated via the private sector, appreciated his ability to discuss standard and non-standard treatment with his clinician. Significant consideration was also given to side effects such as incontinence, erectile dysfunction, diarrhoea and lymphedema. Side effects were alternatively seen as necessary trade-offs and treatment deterrents. In this context, as PP6 described, *“seeing other people’s stories and information as best as you can was highly valuable”*.

Finally, some participants felt considerations relating to the psychosocial domain do not get acknowledged enough in the clinical context. The emotional impact of receiving a cancer diagnosis, which is often unexpected, was reported by most as significant and impacting a patient’s ability to engage in SDM. For example, PB7 described her diagnosis as *“utterly terrifying and life-changing,”* and emphasised the need to cope with emotions before making treatment decisions. For PB4, the diagnosis was isolating and she *“did not know what to do with her emotions”*. She sought a community of similar people and found knowing how patients felt in similar situations helped her cope with emotions. Participants’ stories also highlighted the need for consideration of whānau and family: their preferences and how cancer diagnosis and treatment may affect these groups. For some participants, treatment decisions were dictated by the extent of support they might require from relatives. Their roles within their family and whānau, and also more broadly, were also considered. For PB4, losing her breast in mastectomy did not concern her as much as it would have, had she wanted to breastfeed her, now older, children. However, knowing her sexuality and self-image were affected by the procedure made her wonder if opting for a more conservative treatment would have fit her preferences better.

“How do you see the pros and cons or the benefits and all that? How does one weigh up against the other? How does it affect your urinary function? How does it affect your sex life? What bits do they take out? How do they take it out? How do I manoeuvre my way through this thing and actually come out the other end with a clear decision that I’m comfortable with?” (PP5)

Discussion

Participants’ reflections of SDM in cancer care revolved around the sharing of information and collaboration between patients and clinicians. The context within which care decisions are made is characterised by significant complexity, compounded by the volume of potential decisions and limited foresight, and cancer being an evolving disease. Participants’ stories suggest perceptions about the right level of information varies between patients, and also between clinicians. In light of the complexity of cancer care, wide range of SDM expectations’ and variability of informational needs, it is clear a “one size fits all” approach is unlikely to succeed in providing optimal health-care to cancer patients. Furthermore, it appears that the current processes for supporting SDM may be insufficient, with patients often wanting more time and space to deliberate options with their whānau, express preferences and have their concerns addressed. Participants recounted several areas patients consider during their cancer care experience, focusing on diagnosis, treatment and specific psychosocial aspects.

Our findings suggest practising SDM may be particularly beneficial in the Aotearoa New Zealand context, with the increased focus on upholding Te Tiriti o Waitangi and the implementation of the Pae Ora (Healthy Futures) Act 2022. The Act involves explicit attention to the ongoing effects of colonisation on Māori, including a range of social and health inequities.³⁰ Fortifying responsiveness to Māori in designing SDM platforms also honours the other two articles of Te Tiriti, as it facilitates Māori to exercise Tino Rangatiratanga (Article 2, Authority) and forms pathways towards achieving Ōritetanga for Māori (Article 3, Equity). In the current study, Māori participants’ stories highlighted patients’ willingness to participate in making decisions about their care and to feel empowered to hold authority in this process and have their needs and preferences considered beyond the biomedical model. Importantly, most non-Māori patients also shared this view. These findings can contribute to building Te Tiriti responsiveness across the cancer care and other healthcare settings, for example, by recognising patients’ preferences for treatments such as rongoā (traditional Māori healing) and that Māori approaches to health and wellbeing are holistic and encompass concepts of collectivism rather than individualism.³⁰ Indeed, both Māori and non-Māori participants in this study recommended more focus on including

whānau/family/support persons in SDM. These notions, as well as cultural dynamics, should be incorporated into health technologies,³¹ such as PDAs, to foster patients' agency in decision-making. Input from Māori stakeholders to this process will be imperative for responsiveness to a range of cultural nuances, such as whakamā or shyness, and to ensure high usability of these new technologies.³¹

While participants appeared to generally agree on what SDM involves, some discrepancies were noted regarding how it should be enacted in practice. Specifically, there appears to be a gap between how much patients want to know and what clinicians deemed to be feasible or beneficial for the patient. This observation is consistent with prior publications of SDM in cancer settings: e.g., in cancer care in Aotearoa New Zealand,¹⁵ in surveillance imaging for lung cancer,³² surgical options for breast cancer,³³ or surgery or chemotherapy in breast cancer.³⁴ The existence of this gap may be driven by a common underlying assumption that provision of more information leads to better outcomes and more satisfaction with decisions.³⁵ As argued by Peters et al.,³⁵ for this assumption to be true, the provision of information should be accompanied by other forms of support or interventions providing a structure for using this information, for example goal setting or decision frameworks. Moreover, Peters et al.³⁵ also note that there exist between- and within-individual differences in desired levels of information across multiple domains. These differences were also evident in the current study, where the participants' SDM expectations appeared more important to their overall care experience than the level of SDM actually occurring. Thus, tailoring the information being given to patients, including its format, breadth and depth, appears critical to SDM, as it may prevent such unintended consequences in patients as increased anxiety or poorer decision making. Additionally, the differences in SDM expectations pose a challenge to building reliable clinical heuristics, which could be overcome by PDAs assisting clinicians to quickly decide the appropriate level of engagement and kind of information for each specific situation.¹⁰

Finally, our research identifies several factors moderating the level of SDM, some of which are fixed and some of which may be amenable to interventions. The fixed characteristics—e.g., personalities, education level, time constraints, available drugs—may be mitigated by interventions expediting information transmission,

maximise the available options in the clinical interaction while also supporting self-directed learning in other options, and offer a range of presentations to transmit complex concepts for better comprehension. Furthermore, some of the moderating factors are likely correctable. For example, a clinician bias in presenting information can be mitigated by standardised patient decision supports, giving all patients access to the same information and saving clinicians' time. This time could be potentially spent on exploring patient values, rather than on, e.g., prostate anatomy, which can be done more efficiently presented in a PDA. PDAs can play an important role in mitigating patient, provider and system constraints to achieving ideal SDM.

Limitations

Our findings present a spectrum of perspectives and experiences of cancer care stakeholders. Limitations include a lack of representation of key ethnic groups, particularly from Māori clinicians. As non-Māori are overrepresented within the clinical workforce, we aimed to balance this by recruiting more Māori patients and/or patient advocates. However, during the initial recruitment phase we were only able to interview one participant who identified as Māori. We then focused specifically on recruiting Māori patients (we engaged a Māori interviewer, developed a flyer and liaised with Māori cancer support organisations) and managed to recruit another five Māori patient participants. With Māori as Te Tiriti o Waitangi partners who experience excessive inequities in health outcomes, there is an urgency to develop strategies that support a responsive health system constructed to effectively engage Māori at all levels, in pursuit of attaining health equity for all. Prioritising a focus on whānau engagement in SDM in future research would be one way of honouring Te Tiriti in future strategies.

In this study we focused specifically on patients with breast or prostate cancer. There is at least some overlap between the two selected cancer types and the other cancer types in terms of how shared decision making is enacted in practice. In that regard, we believe that our findings are largely transferable to other populations of patients with cancer. However, further research is required to ascertain whether there are any specific differences between breast and prostate cancer and other cancer populations that may impact patients' and clinicians' attitudes to SDM.

Conclusion

This qualitative evaluation describes patients' and clinicians' accounts of SDM in cancer care in Aotearoa New Zealand. Participants described a broad range of experiences in relation to SDM, highlighting a gap between the SDM expectations and its practice. Several factors were identified appearing to contribute to this gap, making it more challenging to achieve optimal outcomes for

patients. These findings increase our understanding of cancer stakeholders' expectations of SDM to aid clinicians in creating space for patients to exercise their right to self-determination/rangatiratanga of health and wellbeing. Future work should focus on key content and design features of PDAs, supporting SDM processes, improving information transfer and comprehension and facilitating equitable experience and outcomes of cancer care for all patients.

COMPETING INTERESTS

Nil.

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Appendix 1: Patient and whānau interview guide.

Potential questions and prompts

- Where are you currently in your cancer journey?
- What does shared decision making mean to you?
- What has SDM looked like for you in your (your whānau member's) cancer journey so far? How did you and your clinician decide on your treatment? What information did you use (also through own research)? What aids/tools did you use? What visual aids? Did you discuss how your symptoms may develop over time? Care timeline/trajectory? Did you talk to anyone else?
- How important is shared decision making (SDM) to you? When do you feel that you are/are not included in the decision making?
- Were there many treatment options to choose from? How did you decide? What factors did you consider? How did you consider potential benefits vs harms? How was the risk around treatment communicated to you? How did it make you feel? Would you prefer it was done differently?
- What kinds of information are/would have been helpful to you when making decision about your (your whānau member's) cancer care?
- How were your choices/wishes/culture/values/needs/preferences/personal circumstances identified and considered by the clinician? What about the treatment's impact on your (your whānau member's) life/whānau? Your (your whānau member's) other responsibilities? On your (your whānau member's) quality of life?
- What would you (or did you) do if you and your clinician had differing opinions regarding your (your whānau member's) treatment?
- If your oncologist tells you that you (your whānau member) should get a treatment that is not included in the guidelines (not standard or usually recommended), how would you react? What questions would you ask?
- What are some key considerations when it comes to trusting/mistrusting your clinician's advice/recommendations?

Appendix 2: Clinician and other stakeholder interview guide.

Potential questions and prompts

- Could you please tell me a little bit about your role in relation to the topic of this research study?
- What does shared decision making mean to you? What is its role in your practice? What do you usually do to engage your patients in that process?
- Thinking about the decision making flows and key decision points—what is your usual approach to developing a care plan for your cancer patients? Can you talk me through that process step-by-step?
- What information do you use to discuss care/treatment decisions with your patients? What do your patients want to know when discussing care/treatment options? What tools/aids do you use and how? How do you know if they are available to your patient?
- When making a treatment decision, what are the most important factors to you when making treatment choices?
- How do you consider your patients' choices/wishes? Life/family situation? Logistics/costs of treatment? Cultural factors? Are there any particular cultures or groups who you would find these tools particularly helpful for?
- How do you explain to your patients what the important considerations are, what the different risks are? How did you discuss potential benefits vs harms? How do you help your patients decide?
- How do you incorporate clinical guidelines into your decision making process and discussions with your patients (thinking about 'recommended' treatment vs alternatives)? How do you know if the guidelines are appropriate for your patient? Which guidelines do you use (e.g., ASCO or ESMO; NCCN)?

- What about other/alternative treatment options, e.g., via clinical trials—how do you find out if your patient could take part in a trial?
- How do you approach discussing your patients' treatments options, prognosis, predicted survival/mortality rate?
- What do you do if there is a disagreement between you and your patient regarding next steps?